Penrose Inquiry

The following transcript is for Day 29 of the Oral Hearings of The Penrose Inquiry, held on 8th June 2011.

Please note that this session comprised two parts:

The first was a closed session during which a patient or relative gave evidence anonymously to protect their privacy.

Please note that supporting documents referred to by this anonymised witness during the course of evidence, such as medical records and witness statements, will *not* be hosted on the Inquiry website, in the interests of confidentiality. These supporting documents have been made available on the basis of specific undertakings of confidentiality to the legal representatives of Core Participants and have been considered by Lord Penrose and the Inquiry Team. Except to the extent that they are published by the Inquiry, the evidence given by these witnesses in closed sessions and documents relating to those witnesses are the subject of a Restriction Order made by Lord Penrose under sections 19 & 20 of the Inquiries Act 2005 preventing further disclosure or publication.

Consequently, unlike other transcripts on the Inquiry website, hyperlinking has been disabled for the closed part of the session.

The second was an open session, and the transcript is a verbatim account of the proceedings with all supporting documents referred to in the course of evidence available through hyperlinking.

1 Wednesday, 8 June 2011

2 (9.30 am)

3 AMY

4 Questions by MS PATRICK

5 THE CHAIRMAN: Good morning. Yes?

6 MS PATRICK: Good morning. The witness this morning is Amy.

7 Amy, before we start, I thought I would explain to

8 you who everybody is in the room, so you know who is

9 sitting here. You obviously know Margaret who is seated

10 next to you and Lord Penrose is in the chair with Oliver

11 James, his medical adviser, sitting next to him. Then

12 coming along this front row, the two people nearest to

13 you are the stenographers, who are noting what is said

14 this morning and that will go into the transcript of the

15 hearing, which I think you have heard about. You know

16 that you will get a chance to look at that and take out

17 any details that cause you concern about your identity

18 being disclosed.

19 Seated next to them is Maria McCann, who is the

20 secretary to the Inquiry and next to her is

21 Keith Fleming who is in charge of the documents. As we

22 go through this morning, I will refer you to some of

23 your son's medical records and Keith will be arranging

24 for them to appear on the screen in front of you.

25 Then there is myself, whom you have met and Laura,

1 who is the senior counsel for the Inquiry. Sitting
2 behind her is Yasmin Shepherd who works also at the
3 Inquiry and is a paralegal and is helping in relation to
4 this topic. Along this row here we have the lawyers for
5 each of the different parties involved in this Inquiry
6 and closest to me are the lawyers for patients,
7 relatives and Haemophilia Society.
8 In the middle we have the lawyers for the health
9 board and the Blood Transfusion Service and then nearest
10 to you we have the lawyers on behalf of the government.
11 Okay?
12 You helpfully provided, some time ago, the Inquiry
13 with a witness statement in respect of your eldest son
14 ████████ infection with HIV from a blood transfusion.
15 This is WIT0040001. I hope that you have a hard
16 copy of this in front of you?
17 A. Hm-mm.
18 Q. As we speak, parts of it that I'm referring you to will
19 also appear on the screen in front of you. Your
20 statement narrates in paragraph 1 that you are 48 years
21 old. Is that out of date or is that still right?
22 A. No, I'm a year older.
23 Q. Okay. You have two sons, the eldest being ██████?
24 A. Yes.
25 Q. You are separated from ██████'s father?

1 A. Yes.
2 Q. You live in the [redacted] area?
3 A. Yes.
4 Q. Do you work?
5 A. Yes.
6 Q. What do you work as?
7 A. I'm a [redacted].
8 Q. [redacted]?
9 A. I work for [redacted].
10 Q. How long have you worked at that for?
11 A. Since 2004.
12 Q. What does your work involve?
13 A. [redacted].
14 Q. Thank you. As you know, your son also provided
15 a statement to the Inquiry but he understandably finds
16 it very distressing to talk about what has happened to
17 him and so this morning it's with his approval that you
18 are coming today to tell the story on his behalf?
19 A. Yes.
20 Q. The Inquiry sent you and him copies of some of his
21 medical records, which it had recovered, so both you and
22 he have had a chance to go through these?
23 A. Yes.
24 Q. Yes. For the record, the excerpts of [redacted] medical
25 records are WIT0040146 to WIT0040239.

1 In paragraph 2 you tell us that [redacted] was born in
2 Ninewells Hospital, Dundee and this was in [redacted]?
3 A. Yes.
4 Q. I think you were some time over your due date. Is that
5 right?
6 A. Yes, two weeks.
7 Q. So were you induced?
8 A. Yes.
9 Q. Yes. Then in paragraph 3 you tell us that you were in
10 labour for some time and then you were told that the
11 baby was going into stress and so you needed an
12 emergency Cesarian section?
13 A. Yes.
14 Q. Was that done under general anaesthetic?
15 A. Yes, in the end.
16 Q. In the end it was. Was your husband with you at that
17 time?
18 A. Yes.
19 Q. In paragraph 4 you tell us that when you came round from
20 the anaesthetic, you were given a photo of [redacted] as he
21 wasn't with you at the time; he had been transferred to
22 the special care baby unit?
23 A. Yes.
24 Q. You were told that he had been given a blood
25 transfusion?

1 A. Yes.
2 Q. Can you remember who told you this?
3 A. It would have been the doctor that was involved.
4 Q. With the care?
5 A. Yes.
6 Q. I think you have said in paragraph 3 you can't remember
7 the name of the doctor who was in charge at that time.
8 A. No.
9 Q. I think I have a letter we can refer you to and a name
10 may ring a bell in that. Do you know if, before [redacted]
11 received the blood transfusion, there was any discussion
12 with your husband about the need for that?
13 A. I honestly can't remember because everything just
14 happened so quick --
15 Q. Of course.
16 A. -- because he was in distress and like that, everything
17 was like an emergency.
18 Q. Yes. So do you know if the risks of a blood transfusion
19 were discussed with your husband?
20 A. Probably. I can't remember.
21 Q. You obviously weren't there. So he hasn't mentioned it
22 to you since?
23 A. No.
24 Q. It was obviously a very difficult time then, after he
25 was born, and you say that this wasn't helped by the

1 fact that you were initially in a bay of six mothers who
2 presumably had their babies with them and you didn't
3 have [redacted]?
4 A. I did not have [redacted].
5 Q. But eventually you were put in a room on your own?
6 A. On my own, yes.
7 Q. I wonder if you could, please, look at a letter, which
8 is WIT0040150. Could you actually go to the second
9 page, which is the next number, 0151. You will see that
10 this is a letter from an "M Madlom", registrar to
11 Dr Cater. Does that name ring a bell at all?
12 A. No, it doesn't ring any bell.
13 Q. Could we go back to the first page, please? This is
14 a letter from M. Madlom at the hospital to your GP and
15 it's a discharge letter explaining what had happened at
16 [redacted]'s birth and about [redacted]'s time in the hospital
17 after he was born. As you will see, the problems -- if
18 we scroll up -- are described as being asphyxia, renal
19 failure, cerebral oedema, which I think is water on the
20 brain. Does that sound right?
21 A. Hm-mm.
22 Q. And also vomiting of blood, I think is the other problem
23 that is described there. It explains that [redacted] was
24 born at 42 weeks by an emergency Caesarian for foetal
25 distress. Further down in the first paragraph:

1 "The liquor was bloodstained which was suggestive of
2 possible abruption and at birth the baby was rather flat
3 with Apgar score of 1 at one minute."
4 He was ventilated and admitted to the special care
5 baby unit. Then it goes on to explain that there were
6 signs suggestive of cerebral irritation and convulsions
7 and an ultrasound was suggestive of cerebral oedema,
8 which is the fluid on the brain. Also, I think [redacted]
9 had low blood pressure and it describes there how all
10 this was managed, including a loading dose of
11 Phenobarbitone, which is an anti-convulsant. Is that
12 right?
13 A. Yes, he was given that in his milk for quite a while.
14 Q. Because there were obviously concerns that he was having
15 seizures.
16 A. Yes.
17 Q. It says that hypotension, the low blood pressure, was
18 corrected with plasma protein solution and fluids were
19 given intravenously. It then goes on to say that blood
20 was aspirated from the endotracheal tube and [redacted] was
21 given fresh-frozen plasma.
22 It then goes on to describe how, over the next few
23 days, he showed signs of renal failure and this was
24 settled. Then, if we go on to the next page, it states
25 that:

1 "After [REDACTED] was started on Phenobarbitone and
2 maintained on it, no abnormal movements were
3 noticed."
4 And he did well until [REDACTED]. What date was [REDACTED]
5 born?
6 A. [REDACTED].
7 Q. Okay. So that was about a week after, when there was
8 a slight deterioration and this was found to be due to
9 klebsiella, which is a bacterial infection. So [REDACTED]
10 was treated for this and things improved again.
11 You were able to take [REDACTED] home again on the 16th
12 day of life and he was still at that point on the
13 Phenobarbitone and the plan was that he would come back
14 for review at the outpatient clinic.
15 So how was [REDACTED] when you took him home?
16 A. He was fine but he had like a monitor to monitor the
17 heart as well.
18 Q. Right. Did the hospital provide that?
19 A. Yes.
20 Q. When did you use that?
21 A. It was mainly, like, when he was sleeping and that and
22 in his pram.
23 Q. So did that simply monitor his heart rate?
24 A. Yes, yes. It was just like -- it just kept a constant
25 beat. So it was just, I think, monitoring his heart.

1 Q. So did you use that all the time you went home until you
2 went to your review appointment?
3 A. Yes.
4 Q. If we turn to WIT0040152, I don't think this is the
5 next review appointment but I think it's one that
6 followed that. It shows that [redacted] has made good
7 progress and his treatment with Phenobarbitone was
8 stopped towards the end of [redacted], and when he
9 attended here on [redacted], he was making excellent
10 progress and his mother had no concern about him. He
11 was smiling and laughing, gurgling normally and was
12 alert and lively. So [redacted] had made a very good
13 recovery from his very difficult birth?
14 A. Yes.
15 Q. Going back to your statement, WIT004002 at
16 paragraph 6, you tell us there that about six months
17 after [redacted]'s birth, your GP called at your home
18 unexpectedly. He asked you to sit down and explained
19 that [redacted] had contracted HIV through contaminated
20 blood he had received at birth. This was obviously
21 a total shock for you and you couldn't believe what you
22 were hearing. You say that you believe your GP had been
23 informed by Ninewells Hospital through a look-back
24 exercise and you tell us that he did discuss some things
25 with you regarding HIV. You tell us that news headlines

1 and documentaries also made you aware.

2 So how did it come about that your GP came to your

3 house that day? Did he phone and ask to come and see

4 you?

5 A. All I remember was I was out with my mum with [redacted].

6 It was a lovely day and we had both gotten back and it

7 was, like, there was a knock at the door and it was the

8 GP.

9 Q. Right. So he came in and told you this. What did you

10 know about HIV at that time?

11 A. The biggest headlines I remember was Rock Hudson, and

12 that was during my pregnancy.

13 Q. So that was during your pregnancy?

14 A. Yes.

15 Q. That's about the Hollywood actor having AIDS?

16 A. Yes, that was the biggest, like, headlines at that time.

17 Q. Right. So when he told you that, what did you think

18 that meant for [redacted]?

19 A. I know -- like, when we were told -- it was bad enough

20 what he had gone through, and they said at the time when

21 he was born he was only living on a day-to-day, but

22 because his weight and everything -- that really helped

23 him pull through and then to be told this was really,

24 really devastating.

25 Q. Yes.

1 A. And, because, obviously, medications at that time
2 weren't as good as they are now, it was like we were
3 still living on a day-to-day basis with him.
4 Q. Yes. After he was born, you felt you were going to be
5 living on a day-to-day basis and then [redacted] improved
6 and you felt that that disappeared for a bit and then
7 this brought it back. Is that what you are saying?
8 A. Yes.
9 Q. Yes, thank you. Was your husband with you at the time
10 your GP came?
11 A. No, he was working. It was my mum.
12 Q. Your mum was there. Are you all right? (Pause)
13 Are you okay to continue?
14 A. Yes.
15 Q. You say that your GP did discuss some things with you
16 regarding HIV. I appreciate this must be very difficult
17 but can you remember what information he gave you at
18 that time?
19 A. It was -- I don't really remember that much. It was
20 really just to say that he had contracted this through
21 blood transfusion.
22 Q. Right. Did he tell you what would happen next, what the
23 plan was for looking after [redacted] in relation to this?
24 A. It would be like the hospital visits.
25 Q. Right. Did he offer you any support or counselling at

1 that point?

2 A. I honestly can't remember. I don't think a way back.

3 Q. So did your GP then leave you with this news and then

4 you had to tell your husband when he returned home?

5 A. Yes, when he came in later. Yes, it was just such

6 a shock because it was just so unexpected.

7 Q. Yes. You may have noticed from the medical records that

8 we sent you that we can actually see how it was found

9 out that ██████ had acquired HIV from the blood products

10 that he had received. I wonder if you could have a look

11 at WIT0040154.

12 This is a request for an outpatient consultation by

13 your GP, dated 21 March 1986. It's to

14 Ninewells Hospital to Dr Forsyth. It explains:

15 "This is the little baby I spoke to you about on the phone.

16 I was informed by the community medical department that

17 he had received HTLV positive plasma. I have explained

18 the implications of this to the parents and naturally

19 they are upset and anxious about the future. I would be

20 grateful for your advice about the baby. Thank you very

21 much for seeing him."

22 Underneath that I think you will see:

23 "Appt 1 April To see me SF."

24 I think we can probably assume that is Dr Forsyth

25 saying he will see on you 1 April and he will be the one

1 that sees you not another doctor there.

2 In fact it appears from the medical records -- and
3 you may have noticed this when you saw them -- that
4 Dr Forsyth already knew about your son having acquired
5 HIV.

6 I wonder if you could, please, look at WIT0040153.
7 This is a letter from Dr Brookes, a regional director of
8 the East of Scotland Blood Transfusion Service and it's
9 dated 12 March 1986.

10 It's addressed to Dr Stuart Forsyth at the special
11 care baby unit at Ninewells. Dr Brookes refers to the
12 donation number 602211:

13 "I have today received confirmation that this
14 donation, plasma from which was given to your patient,
15 has been found positive at Edinburgh University by the
16 Western Blot technique. This confirms the Positive
17 result for anti HTLV III antibody found by the BTS using
18 the Wellcome assay and reported to you by me on
19 19 February 1986."

20 So it seems that there was a previous result that
21 has been confirmed now and that is what is prompting
22 this letter. It explains that the blood was donated on
23 [redacted] and fresh-frozen plasma was prepared from it
24 for clinical use:

25 "Its HTLV-III positive status was discovered in the

1 course of retrospective testing of stored samples from a
2 donor whose [redacted] donation was found to be positive."
3 It says in brackets that:
4 "Blood Transfusion Service began to test for
5 anti HTLV-III antibody in October 1985."
6 Then:
7 "Transfusion directors have agreed that they will
8 inform the clinician in charge of the case when a known
9 positive or suspect donation has been transfused, so
10 that the clinician is in a position to assess the
11 situation and decide on subsequent investigations.
12 I should be most grateful if you would let me know how
13 you have decided to manage the situation and how the
14 patient progresses."
15 So it seems that maybe Dr Forsyth found out first
16 from the Blood Transfusion Service and then through the
17 community medical team. Maybe from him, your GP found
18 out?
19 A. Yes.
20 Q. He came out to tell you about it. Can you remember
21 going to that appointment on 1 April with Dr Forsyth?
22 A. Not like -- because all through his life it has just
23 been constant hospital visits. So really that one would
24 probably be just like any of the others that we
25 attended.

1 Q. So can you remember getting any information from the
2 hospital in the very early days of you knowing about
3 [redacted] having HIV in respect of the virus?
4 A. No, I think it was just a matter of going up to the
5 hospital.
6 Q. They were monitor --
7 A. I don't remember getting anything, no.
8 Q. Okay. It appears from the medical records that [redacted]
9 was tested for the HIV virus at that appointment on
10 1 April 1986. If we look at WIT0040155, this is the
11 test result, suggesting, I think, at the top that the
12 specimen date is 1 April 1986 but the report is dated
13 24 April 1986 confirming that [redacted] is infected with
14 HTLV-III as it was then known.
15 Could we go back to your statement, paragraph 7,
16 which is on page WIT0040002? You tell us in
17 paragraph 7 how you then started to attend regular
18 hospital appointments at Ninewells Hospital with [redacted]
19 and these would vary between three and six monthly
20 clinics depending on his state of health?
21 A. Hm-mm.
22 Q. You say towards the end that:
23 "We were told we would have to be extra careful and
24 take care to clean up using gloves and cleaning with
25 bleach."

1 Can you remember roughly when you were told that?
2 A. I think it probably would have been from, like, the
3 first appointments, you know, with the doctors.
4 Q. Right.
5 A. But we were always, like, made aware that we would have
6 to be careful.
7 Q. Yes. So you think that from the early days of knowing
8 ███'s diagnosis you were warned about the risk of
9 infection and told to be extra careful, as you say
10 there?
11 I wonder if we could look, please, at WIT0040156.
12 This is a further clinic appointment letter about an
13 appointment with Dr Forsyth in May 1986. This is when
14 you went in to discuss the result of ███'s HTLV-III
15 tests and Dr Forsyth has obviously been speaking to your
16 GP on the telephone and he notes you:
17 "have accepted this problem extremely well and
18 have a realistic understanding of the problem."
19 He is telling your GP that he will arrange to see
20 you at intervals:
21 "but, if there is any cause for concern between
22 times I'd gladly see him at any time."
23 I think Dr Forsyth was the consultant in charge of
24 ███'s care initially?
25 A. Yes.

1 Q. Was he?

2 A. From the very early days.

3 Q. In the early days?

4 A. Yes.

5 Q. Then when he left, Dr Tarnow-Mordi took over.

6 A. Yes.

7 Q. So what happened when you went to each appointment?

8 A. They would be checking, like, his blood, the glands and

9 just really his welfare.

10 Q. Yes. How far was the hospital from your home?

11 A. It was about ███ miles.

12 Q. ███ miles?

13 A. Hm-mm.

14 Q. So did you drive ██████ to and from his appointments?

15 A. No, I took the bus.

16 Q. Took a bus. Were you working at that time?

17 A. Yes.

18 Q. Yes. So were you having to take time off work to go to

19 his appointments?

20 A. Yes.

21 Q. In paragraph 12 of your statement -- we don't need to go

22 to it -- you tell us that ██████ developed problems with

23 his ears?

24 A. Yes.

25 Q. Yes. What were the problems?

1 A. It was when he was at the toddling stage, we found that
2 he was getting very frustrated and, like, his speech, it
3 was hard to make things out and I took him to the
4 doctors and it was later diagnosed that he did have
5 a hearing impairment.
6 Q. Right.
7 A. That he is more or less deaf in both ears without the
8 aid of hearing aids. But I think this could all be
9 related to, like, the breakdown, when he was first born,
10 with everything that went wrong.
11 Q. Relation to the trauma of his birth?
12 A. Yes.
13 Q. Has anybody ever suggested to you that his hearing
14 problems might be related to his HIV?
15 A. No, no. Not to do with that, no. I think it was mainly
16 to do with everything that happened at birth, like, just
17 a breakdown in the body.
18 Q. Right. Did he have grommets inserted at some time when
19 he was younger?
20 A. Yes.
21 Q. Which is quite a common thing for children to have?
22 A. Yes.
23 Q. Was [redacted] treated any different in hospital when he
24 went in, for example, for an operation, compared to
25 other children because of his HIV?

1 A. I'm not quite sure about in hospital. I know, like,
2 when it was anything to do with dental practice, he was
3 always last to be seen. So whether or not it was the
4 same at hospital, it might have been. But, like, I know
5 in the early stages, like, we were in a room on our own
6 when we visited sometimes.
7 Q. Do you think that was deliberate?
8 A. Maybe it was my way of thinking but I felt like we were
9 sort of isolated, but then that could have just been my
10 way of thinking because I know, like, in the early
11 stages as well there was one doctor on the ward that
12 actually blamed myself for giving [redacted] HIV [redacted]
13 [redacted].
14 Q. In what way did he blame you?
15 A. Through breast milk and, like, I said to him, if he had
16 looked at the notes, he would have been able to see that
17 it was through Ninewells.
18 Q. Okay. So he made an assumption?
19 A. Yes.
20 Q. Which was wrong?
21 A. Hm-mm.
22 Q. Okay. I think actually one of the letters in your
23 medical records shows that [redacted] was put last for an
24 operation because of his HIV. I think it was in
25 relation to the grommets. If we have a look at

1 WIT0040157, this is referring to his ear problems and
2 saying he needs bilateral syringotomy and grommet
3 insertion:
4 "Since he is HIV positive due to an infected blood
5 transfusion when he was born, it will be necessary for
6 him to have his operation at the end of my registrar
7 Wednesday morning theatre list as the last case. This
8 is because full precautions will have to be taken and
9 the theatre specifically cleaned at the end of the
10 procedure."
11 Were you aware at the time that [redacted] was being
12 held back to the end?
13 A. No.
14 Q. Did [redacted] suffer any symptoms of HIV as a child?
15 A. There was sweating, and I mean really, really wet,
16 where, like, his blankets and everything would be
17 absolutely soaking and so would he and there was, like,
18 rashes as well.
19 Q. Okay. I think if you have a look at WIT0040158, this
20 is a letter following a clinic appointment on
21 7 July 1988, and at this point [redacted] would have been
22 about three years old?
23 A. Hm-mm.
24 Q. Is that right? It records that clinically [redacted] has
25 been well. You have obviously told him that he

1 frequently wakes up during the night crying and often at
2 that time he was noted to be sweating excessively. He
3 is a bit of a fussy eater. That's probably not uncommon
4 at that age, but he is growing and developing normally.
5 He continues to bruise easily?
6 A. Yes.
7 Q. Was that a problem that [redacted] had as a child?
8 A. Yes.
9 Q. What was the cause of that?
10 A. I think it was just due to what he had.
11 Q. Right. It notes that he does have marked swollen lymph
12 nodes around his neck and arm pits and there were
13 a number of bruises. He has been noted to be
14 thrombocytopenic. Do you know what that means?
15 A. No.
16 PROFESSOR JAMES: Low blood platelets. It accounts for the
17 bruising.
18 MS PATRICK: Then Dr Forsyth explains that he has obviously
19 had a long discussion with you about these symptoms and
20 mentioned the possibility that if clinically [redacted]
21 deteriorates or if there is any evidence of progress of
22 the disease from blood tests, then they may consider
23 therapy, drug therapy with Retrovir, which I think is
24 AZT.
25 A. That's right, yes.

1 Q. He states that this has been introduced in a few
2 children. It is an oral medication and the children
3 have tolerated it well. He says:
4 "We will obviously discuss this further."
5 It is not something that they were doing right then
6 but he thought it would be helpful to introduce the
7 idea. Can you remember, was that the first time
8 treatment was discussed with you?
9 A. Yes, it would have been.
10 Q. What was explained to you about treatment for HIV?
11 A. Obviously, like, all the medication that was coming out
12 at the time, everything was new. So really they didn't
13 know what the side effects would be because, like --
14 this was the early stages. So all the new medications
15 that came out, it's like people like my son, it was just
16 really tested on them. But, like, the medications have
17 all advanced, you know, in the time.
18 Q. So how did you feel at that time about ███████ maybe
19 starting treatment?
20 A. Obviously anything that was going to help him and keep
21 him going, yes.
22 Q. Yes. Okay. I think it was over a year later, when
23 ██████ was four, that he did in fact start treatment
24 with AZT or Zidovudine. I wonder if you could look at
25 WIT0040161. Can you remember why treatment was

1 started then?

2 A. Really just to sustain, a better chance of living, to

3 help him against infections as well because obviously

4 with having low platelets, he would be less immune to

5 quite a lot of things.

6 Q. Had there been any worsening of symptoms between the

7 time you first discussed treatment and starting

8 treatment?

9 A. He actually always kept well, you know, and I think

10 it's due to the medication that he is on.

11 Q. Okay. It's now Dr Tarnow-Mordi who is looking after

12 [redacted] at Ninewells and he is saying he is pleased to

13 see that he has improved considerably since starting the

14 Zidovudine two weeks ago. You apparently report a much

15 better appetite. Was [redacted] not keen to eat at times?

16 He was still a fussy eater?

17 A. He was just a very fussy eater and still is.

18 Q. It notes there is no nausea, rash, diarrhoea or episodes

19 of cough, chest infections or colds and the night sweats

20 had obviously been continuing because they have slightly

21 improved during the last two weeks and are only once or

22 twice a week now. He has obviously not been walking as

23 far as you would have liked. Is that right? From the

24 last sentence it says:

25 "He is able to walk a little further and complains

1 less of sore legs when he is out with the family
2 shopping."
3 A. I had actually forgotten about that. I can't recall.
4 It just seems so far back.
5 Q. So it could have been a boy not enjoying shopping?
6 A. Probably.
7 Q. Okay. It notes that he had new swollen lymph nodes.
8 Then further blood tests are taken and then it says at
9 the bottom that you did discuss with them seeking
10 compensation for [redacted] having acquired HIV in the blood
11 transfusion. Did Dr Tarnow-Mordi help with you that?
12 A. Yes, it was mainly because my father lived in [redacted]
13 and, like I said at that time, we just didn't know how
14 long he would be with us and it was just really so that
15 he could meet his grandfather. So we all went [redacted]
16 as a family.
17 Q. Right. If we turn to WIT0040162, this is a letter
18 of March 1990, so it's about three months after [redacted]
19 has started taking his medication -- or not taking it as
20 the case may be. As you will see it notes that [redacted]
21 has lost weight, continuing to have night sweats and his
22 appetite is poor. It notes what you told us earlier
23 about his hearing and speech causing concern and it
24 explains that you have been having difficulty getting
25 him to take his AZT?

1 A. I think a lot of it was to do, like, with the taste and
2 the swallowing of the actual tablets.
3 Q. Right. In what form did he get the medication?
4 A. It came in all different forms, you know, tablets,
5 fluid.
6 Q. Syrup?
7 A. Yes. It was the taste that [redacted] didn't like.
8 Q. Yes. I think you will see from the third paragraph down
9 that your consultant suggests a gold star chart to
10 encourage [redacted] to take his medicine every day and he
11 prescribed capsules to try as an alternative to the
12 syrup. So [redacted] was obviously not enjoying the taste
13 of the syrup.
14 Then he notes that he has put you in contact with
15 another family with a similarly affected child and did
16 you get in contact with that family?
17 A. I think I did speak to the mother, yes, way back.
18 Q. Why did he do that for you?
19 A. I think so that it would be someone that we could relate
20 to in the same situation.
21 Q. Yes.
22 A. Yes.
23 Q. Because how were you handling [redacted]'s diagnosis with
24 HIV at that point? Had you told many people?
25 A. No, it was just immediate family.

1 Q. Right.

2 A. Just brothers, sisters, and parents on both sides and

3 that was it, no aunties, nobody else knew. And, like,

4 I felt the only person that I could really speak to

5 would be my sisters or my mum but then I felt like it

6 put, like, the weight on her because she couldn't speak

7 to anyone. That was hard.

8 Q. So you didn't tell any of your friends?

9 A. I think -- because at that time there seemed to be,

10 like, a stigma attached and, you know, nobody -- no.

11 Like I say, not even aunties or uncles, other immediate

12 family.

13 Q. Has that changed over time?

14 A. No, they still don't know. We haven't told any of them.

15 Q. So still it's just immediate family that know.

16 If we move on to WIT0040163, [redacted] obviously

17 enjoyed the star charts?

18 A. Hm-mm.

19 Q. Yes, and he returns with his magnificent star chart

20 showing that he had taken all his doses of AZT every day

21 for the last month. He is congratulated and given

22 a brand new one to keep going with. He has had no

23 diarrhoea, fever or loss of appetite and his weight has

24 shown an increase, and his swollen lymph nodes at that

25 point were unchanged.

1 I wonder if you remember this incident that's
2 referred to in the third paragraph. Would you like to
3 have a read of it? (Pause)
4 Do you remember that?
5 A. Yes.
6 Q. Can you tell us what happened?
7 A. I had taken him up to the hospital and the nurse there
8 was away to give him treatment. But like that, there
9 was no gloves or anything used, and I felt that I had to
10 tell her, whereas that shouldn't have been the case,
11 they should have been following procedures.
12 Q. So can we take it from that that it was a great concern
13 of yours that the infection was not spread and that you
14 had to --
15 A. Yes.
16 Q. -- look out for --
17 A. Yes, hm-mm. Because I feel that they should have been
18 taking precautions and that way I wouldn't have had to
19 say anything.
20 Q. You mentioned a bit earlier that ██████ took a treatment
21 to prevent infections as well. If we look at
22 WIT0040164, this would have been when ██████ was about
23 five, nearly six?
24 A. Hm-mm.
25 Q. Dr Tarnow-Mordi has taken advice from a colleague at the

1 Institute of Child Health in London and he has suggested
2 that ██████ starts nightly Septrin as prophylaxis
3 against pneumocystis pneumonia, which is one of the
4 infections of HIV. So a further medication is added for
5 ██████ to take at that pointed. Do you remember that?
6 A. Yes.
7 Q. You understood at that point why it was being
8 prescribed?
9 A. Yes.
10 Q. I think at this point you and your husband were
11 obviously still coming to terms with ██████'s diagnosis
12 and you touch, in paragraph 22 at the very end of your
13 statement, WIT0040005, on a very difficult time for
14 you. You tell us that you and your husband separated
15 14 years ago. That will be a bit longer now but was
16 that in about 1996?
17 A. About that, yes.
18 Q. About that. You mention there that you even tried
19 taking your own life as you had just had enough and that
20 this was when ██████ was about five years old?
21 A. Yes.
22 Q. So this was around this time you were really finding it
23 difficult to cope?
24 A. Hm-mm, yes.
25 Q. What support were you getting at that point from the

1 hospital?

2 A. It would just really be, you know, chatting away with

3 the doctor when I visited but, I mean, there was

4 times -- obviously I was going up there on my own and

5 just being constantly reminded, because I just tried to

6 keep it behind me but obviously I can't and it was,

7 like, every time I was going to the hospital, it was

8 like a constant reminder. And I know, there would be

9 times I would be going up there on my own and I would

10 have [redacted] in my arms or whatever and I would just be

11 crying on the bus coming home.

12 Q. Yes. We know from what you say in your statement that

13 there was a specialist nurse who became quite involved

14 with you and [redacted] and was a great help?

15 A. Hm-mm. That was [redacted].

16 Q. That was [redacted]. And she has provided a report,

17 WIT0040534, which I won't refer you to just now but it

18 seems she took up her appointment in 1993. Was there

19 anybody before her to help families like yours?

20 A. I know that we could have went to counselling but at

21 that time I just wasn't ready for anything like that.

22 Q. No. And who told you about counselling?

23 A. It would have been the GP.

24 Q. GP.

25 A. Yes. And obviously the doctors at Ninewells, but

1 I wasn't ready for anything like that. It wasn't until
2 later on, and I think I maybe paid two or three visits,
3 but, no.
4 Q. No. So were you seeing your GP about how you were
5 feeling at that time?
6 A. Hm-mm, hm-mm.
7 Q. Your GP has provided a report, which is WIT0040703.
8 And you have seen this?
9 A. Hm-mm.
10 Q. Yes. This explains that you were first referred for
11 support and counselling back in 1987. In 2003 you were
12 prescribed anti-depressant medication for symptoms of
13 depression and low mood, and again in 2004 you were
14 noted to have low mood and depressive symptoms:
15 "issues with supporting her son through his illness
16 I think caused a lot of stress in relationships at the
17 time resulting in mild depression and anxiety."
18 You say in your statement that you feel that
19 [redacted]'s diagnosis with HIV was a major factor in your
20 relationship with your husband ending?
21 A. Hm-mm.
22 Q. Is that right?
23 A. Hm-mm.
24 Q. We can see that you were referred in 2005 to The
25 Community Mental Health Service for counselling and

1 support and medication was prescribed. Your GP says
2 that he -- is it a he?
3 A. No, it's a she.
4 Q. Knows you "from consultations and there has always
5 been worries and anxieties over the health of her son
6 and managing his illness and trying to get him to comply
7 with treatments."
8 Thank you. Could we turn to paragraph 10 of your
9 statement, WIT004003? You tell us about a new
10 treatment, which ██████ started in July 1991, and this
11 was treatment with immunoglobulin?
12 A. Yes.
13 Q. What did each treatment involve?
14 A. It was actually fed through, like, a drip and this would
15 maybe take an hour/two hours -- a couple of hours.
16 Q. Okay. You say monthly. So it was every month?
17 A. Yes, yes. And then did it come down to every three
18 months? Because it was quite regular in the beginning.
19 Q. Did the doctors explain to you why they wanted to give
20 ██████ this treatment?
21 A. It was just to help, I'm sure, with, like, the
22 platelets, these platelet levels, to help his immune
23 system.
24 Q. Okay. So did you have to go to the hospital for this
25 treatment as well as carrying on your clinic

1 appointments?

2 A. Yes.

3 Q. So how were you managing that? Were you missing more

4 work?

5 A. I would try and, like, shuffle my days off, to make

6 these appointments and then if not, it would be my

7 husband that would take him. But it was mainly myself

8 that went.

9 Q. How did ██████ find getting this treatment?

10 A. I think it was just the long days in hospital.

11 Q. Yes.

12 A. And having to be on the drip.

13 Q. Okay. But, as you say, ██████ kept well, he started

14 school. How did he enjoy school?

15 A. He had no problems at all, even with the hearing

16 difficulties. He sailed through school.

17 Q. Good. Did he enjoy it?

18 A. Yes.

19 Q. I think you mention in paragraph 7 of your statement,

20 towards the bottom, that you didn't have to tell the

21 schools about ██████'s infection with HIV?

22 A. No.

23 Q. Did you mention --

24 A. Because I think there was policies and procedures at the

25 time as well that they had to follow. So if there was any

1 blood spillages or sickness, that they had to treat
2 everybody the same.
3 Q. Right. So were you given advice about that?
4 A. Hm-mm.
5 Q. From the hospital, about whether you needed to tell the
6 school?
7 A. Hm-mm.
8 Q. So you didn't tell the primary school?
9 A. I think, was it the headteacher -- I think was the only
10 person that had known at the time, but any of the
11 teachers throughout weren't.
12 Q. I think [redacted], whom you have mentioned before,
13 liaised with the school a bit on your behalf. Could we
14 have a look at her report now. It's WIT0040534.
15 You will see in the second paragraph down she states
16 that she had been involved with the care of you and
17 [redacted] from January 1993 to October 2001 and
18 from April 2005 until the present time.
19 Under her heading "response to paragraph 18", she
20 states that she joined [redacted] HIV Multidisciplinary
21 Service in [redacted] as part of a community nursing
22 team, whose remit was to provide information, care and
23 support for HIV positive patients and their families
24 within [redacted], and she worked with Dr Tarnow-Mordi. So
25 she didn't replace anybody there?

1 A. No.

2 Q. This was a new appointment?

3 A. Hm-mm.

4 Q. She talks in the second paragraph about organising

5 [redacted]'s monthly admissions to Ninewells for the

6 immunoglobulin infusions and states that the aim of this

7 was to give the HIV positive children protection against

8 infections, as you have told us.

9 She also talks about regular blood immunity testing

10 to determine whether or not a child was immune to

11 chicken pox?

12 A. The school would alert us if there was an outbreak of

13 chicken pox and I would be on the phone to [redacted] and then

14 it would be up to the hospital to get injections in the

15 leg, as a precaution against an infection.

16 Q. So chicken pox was a very bad thing for [redacted] to be

17 exposed to, was it?

18 A. Hm-mm.

19 Q. If he was exposed, he needed immediate treatment?

20 A. Hm-mm.

21 Q. What did that treatment involve? You mentioned the jabs

22 to the leg?

23 A. There was injections in the top of the legs.

24 Q. Right. So did he have to go to the hospital for that?

25 A. Yes.

1 Q. Was that if he came into contact with chicken pox?
2 A. No, it was just if there was an outbreak --
3 Q. Right.
4 A. -- at the school. He would have to go up --
5 Q. So how often do you think he had treatment in respect of
6 chicken pox?
7 A. I can't remember offhand but it was just any time there
8 was an outbreak, we had to go up and he would have the
9 injections.
10 Q. Okay. She explains that the local protocol was to bring
11 the child to the paediatric unit as soon as exposure to
12 chicken pox was determined for his Zoster Immunoglobulin
13 injections and a five-day course of an oral medication
14 to prevent the development of chicken pox. She notes
15 that ██████'s immunoglobulin infusions stopped
16 in October 1997, when combination antiretroviral therapy
17 became the more common treatment.
18 She notes that you were instructed on the importance
19 of these procedures by presumably Dr Tarnow-Mordi and
20 herself, and she states there that the head mistress of
21 ██████'s primary school was made aware of the diagnosis
22 and the reason for this was twofold: it was to tell her
23 to warn the family if there were chicken pox in the
24 school and also to give an explanation for ██████ having
25 to miss presumably a fair amount of school to go to his

1 hospital appointments.

2 She says:

3 "The parents were made aware of the modes of HIV

4 transmission, were advised that the other members of the

5 family were not at risk of HIV infection and were

6 instructed on the management of any blood injuries or

7 spills."

8 I think you have told us that you knew about that

9 before [redacted] took up post --

10 A. Yes.

11 Q. -- and had been given that information before?

12 A. Yes.

13 Q. It goes on to tell us about [redacted] being transferred to

14 the adult team when he is 16 and about:

15 "... a joint home visit to the family by both

16 Tarnow-Mordi and [herself] in January 1996, when the

17 parents informed us of their separation."

18 How did that meeting come about?

19 A. I can't really remember.

20 Q. It is some while ago.

21 A. Yes, and it's just all the different things that have

22 happened in the past.

23 Q. Right.

24 A. But I know there was a later one as well, when he was in

25 his teenage years but this was really more to advise

1 [redacted] about HIV.

2 Q. About his diagnosis? Yes, she comes on to that -- and
3 we are going to come on to that too -- saying that she
4 attended with Dr Tarnow-Mordi in October 1998, when
5 [redacted] was 13 years old and the whole family were
6 present during this long visit and information about the
7 virus was given in a form that was appropriate to the
8 age of the patient. She says that the aim was to give
9 you as flexible a support service as possible. Do you
10 feel that that has been given to you?

11 A. Oh, yes. She has always been there and I have always
12 been told that even out-of-hours I could contact her at
13 any time about anything and she has come to the house,
14 she has been a good support.

15 Q. Yes. She says that you have been encouraged to
16 discuss -- this is on the next page -- your feelings
17 with both herself and Dr Tarnow-Mordi and you have been
18 offered referral to their own dedicated psychologist but
19 have declined that on more than one occasion but you
20 have at some point taken up the offer of counselling
21 support. Is that right?

22 A. I did go for maybe, I think, three visits.

23 Q. Okay.

24 A. But then stopped.

25 Q. Did you find it helpful?

1 A. I think I came out feeling worse, to be quite honest.
2 Q. Did you? I think it can sometimes have that effect.
3 She continues to see [redacted] now, does she?
4 A. Yes.
5 Q. And yourselves?
6 A. Yes.
7 Q. Okay. Thank you.
8 If we could return to the treatment that [redacted] was
9 having. I think she touched on it there, that [redacted]
10 stopped his immunoglobulin in 1997, when he will have
11 been about 12 years old. Is that right?
12 A. Hm-mm.
13 Q. Can you remember what dual antiretrotiviral therapy he
14 started?
15 A. It was just like different medications because like
16 that, the medications were always getting more advanced,
17 but it wasn't everything that would agree with him. So
18 he was on a lot of different medications.
19 Q. The medical records show that he started Lamivudine and
20 AZT at that time. Does that sound familiar?
21 A. Yes.
22 Q. How did [redacted] find taking these two medications?
23 A. It was always a struggle with medications. I think
24 because of the size of the pills as well, and the taste.
25 Q. So the taste wasn't good?

1 A. No.

2 Q. At that point, [redacted] still didn't know that he had HIV.

3 So what did he think he was taking the medications for?

4 A. Well, we would just maybe say, like, to keep good

5 health.

6 Q. Right.

7 A. But we didn't really mention anything about that.

8 Q. Right. Did he suffer any side effects from the

9 medications?

10 A. Sometimes rashes. It was mainly rashes that he would

11 have, and sometimes the feeling of nausea as well.

12 Sickness.

13 Q. [redacted] touched on this in her statement, about telling

14 [redacted] that he had acquired the virus. According to the

15 medical records, this was done in about [redacted],

16 when [redacted] was about 13 years old. Does that sound

17 right?

18 A. Yes. We were visited by Dr Tarnow-Mordi.

19 Q. Sorry?

20 A. We were visited by Dr Tarnow-Mordi to the home.

21 Q. Yes. Who decided that this was the right time to tell

22 [redacted]?

23 A. I think it was ourselves, as parents.

24 Q. Right. You obviously discussed it with Dr Tarnow-Mordi

25 if he came along with you. And [redacted] came too?

1 A. Yes.

2 Q. Were you given advice on how to tell him?

3 A. It was mainly with the help and support of the doctors.

4 Q. Right. Who was at that meeting, which I think, was in

5 your home?

6 A. Yes, it was just Dr Tarnow-Mordi.

7 Q. And [redacted]?

8 A. I can't remember if [redacted] was there. I always remember

9 Dr Tarnow-Mordi.

10 Q. I think she suggests that she was?

11 A. Yes.

12 Q. Yes, she suggests that she was. And [redacted]'s brother?

13 A. Yes.

14 Q. So you and your husband were separated by that point?

15 A. Hm-mm.

16 Q. But were you together at that time?

17 A. Yes, we have always had a good relationship and still do

18 today, and it's mainly for the sake of [redacted].

19 Q. So was he there too at the time?

20 A. Yes.

21 Q. You told [redacted]?

22 A. Yes.

23 Q. So how did you tell [redacted]?

24 A. Well, really, it was mainly coming out with the HIV.

25 Q. Right. I think if we look at WIT0040191, this is

1 Dr Tarnow-Mordi's description of what happened when you
2 met.
3 He says that he saw [redacted] recently at home with
4 [redacted] and both parents and his younger brother
5 present:
6 "We went over the reasons for his regular
7 attendances at hospital and his frequent medicines and
8 in particular I explained the HIV virus, which is inside
9 his white cells and that the drugs he is taking is
10 helping to control this virus and prevent it from
11 damaging his white cells further."
12 He says:
13 "We emphasised the need for secrecy about his
14 diagnosis outside the family because people have been,
15 and still are, sometimes very cruel about this condition
16 because of their own fear of catching it. [redacted] seemed
17 to understand what was said and to accept it very well
18 and his parents seemed satisfied that he had made a good
19 start in understanding his diagnosis. They feel
20 prepared to build on this beginning and answering any
21 question he may have in the future with further
22 assistance from ourselves and yourself whenever
23 appropriate."
24 Did you feel the need to emphasise the secrecy
25 aspect of this to [redacted]?

1 A. Yes, I just feel that there was always, like, a stigma
2 attached but, like I have always said to ██████, even if
3 it was to get out, I mean, he should never feel guilty
4 because it wasn't through his doing. You know?
5 Q. What about the doctors? Did they give you advice about
6 this, about the need for keeping this to yourselves?
7 A. They did speak about it, yes.
8 Q. What did they suggest?
9 A. I think it was really -- sorry.
10 Q. It's all right. (Pause)
11 THE CHAIRMAN: We can have a break if you would like it.
12 MS PATRICK: Yes? Okay.
13 THE CHAIRMAN: We will have a break.
14 (10.47 am)
15 (Short break)
16 (11.15 am)
17 THE CHAIRMAN: Yes?
18 MS PATRICK: Thank you.
19 Amy, I would like to return to the letter we were
20 looking at just before the break, ending 0191. You will
21 see the second paragraph refers to a further change in
22 ██████'s medication at this time. It's noted that his
23 recent viral loads show an increasing level and
24 Dr Tarnow-Mordi has decided that he should change from
25 two drugs to three. You will see there that he is

1 changing it to Didanosine, Stavudine and Nelfinavir.
2 And the plan is for him to start these in the near
3 future and with a blood test being involved in that
4 process too.
5 I think shortly after this, in December 1998, it
6 appears that ██████ was admitted to the hospital for
7 a week's treatment because of chicken pox?
8 A. Hm-mm.
9 Q. Do you remember that?
10 A. Yes.
11 Q. If we look at WIT0040192, we see that he was admitted
12 to the ward for a week's treatment because of clinical
13 chicken pox and he was discharged home with further
14 medication to take for that. He remained clinically
15 well during that and his typical chicken pox rash
16 resolved uneventfully. He states there that they took
17 the opportunity while he was on the ward of changing his
18 medication at that point. It shows that ██████ vomited
19 his Nelfinavir to begin with but has restarted it and is
20 taking it with milk, which apparently washed away the
21 unpleasant taste. At that point he is continuing to
22 take Septrin.
23 Dr Tarnow-Mordi obviously felt it was helpful at
24 that time to be able to talk to ██████ a bit more about
25 his diagnosis with HIV. You will see that mentioned in

1 the second paragraph of the letter. Dr Tarnow-Mordi
2 obviously feels that it's easier to talk to [redacted] now
3 about his drug therapy and explaining why changes are
4 needed to it. He says:
5 "I don't think he understands the full implications
6 but he does know that he has HIV and that we are giving
7 him lifelong drug medicines to keep the virus under
8 control."
9 Did you remember how [redacted] at this time, when he
10 changed to three medications, managed with those?
11 A. It has always been a struggle.
12 Q. Always been a struggle?
13 A. And we had to watch certain medications because you
14 couldn't crush them or dissolve them, but [redacted] would
15 always look into how best he could take the medication.
16 Q. If there were other alternatives to what he was being
17 prescribed?
18 A. Yes.
19 Q. In the fourth paragraph it says that he is going to come
20 for a repeat blood test because his last viral load had
21 shown an increase to about 180,000 copies per ml, and
22 Dr Tarnow-Mordi saying he doesn't expect a full response
23 for a few months to the treatment but they are obviously
24 going to keep an eye on [redacted].
25 If we look at a letter from Dr Tarnow-Mordi

1 dated February 1999, WIT0040192, Dr Tarnow-Mordi notes
2 here that [redacted] is well and has been taking his new
3 regime of the three drugs regularly and consistently.
4 There are no new signs today and he is pleased to note
5 that his viral load three weeks after his new antiviral
6 regime showed a significant reduction and that his C4
7 count had increased.
8 I think that's about the time that Dr Tarnow-Mordi
9 is leaving and he moved away from the hospital and
10 another doctor took over [redacted]'s care?
11 A. Yes.
12 Q. As well as problems with his ears, did [redacted] have
13 problems with a blocked nose, rhinitis?
14 A. Yes. Was it -- I think you call them -- was it "polyps"
15 inside? They actually had to be cauterised. He had to
16 go in and get an operation because of the breathing
17 problems and, like, it was always like he was choked up.
18 So that helped.
19 Q. Did he see some doctors about those symptoms?
20 A. Yes, he would have been -- it would have been through
21 either Dr Tarnow-Mordi or I think it was maybe Dr France
22 at the time.
23 Q. Right.
24 A. That would have put him on.
25 Q. So he had that operation and was he given any other

1 treatment for it?

2 A. No.

3 Q. No.

4 A. I think maybe he did get nasal sprays for that but

5 I think it was really the operation --

6 Q. Did the nasal spray help?

7 A. Yes.

8 Q. It did. Were you ever told if that was a symptom of his

9 HIV? Please say if you can't remember.

10 A. Yes.

11 Q. If we look at WIT0040203, this is in September 2000.

12 The paediatric consultant there is Dr Murdock. Is that who [redacted]

13 saw after Dr Tarnow-Mordi left the hospital?

14 A. It could have been, yes.

15 Q. This is telling us that he has a low neutrophil count in

16 one of the white cells and they are thinking that this

17 may be occurring because of his Septrin, and so they are

18 going to stop the Septrin and see what happens. So

19 [redacted]'s Septrin treatment was stopped at that point.

20 The following year, in [redacted], if we look at

21 WIT0040204, [redacted] is now 16 or 15 years old and he is

22 doing well and his viral count and CD4 count are

23 described as satisfactory. There is mention at the

24 bottom of this letter of [redacted] now being transferred to

25 the adult infectious disease department and Dr France

1 there.

2 At this point were you still attending medical

3 appointments with ██████?

4 A. Yes, there has always been -- even up until now, it is

5 always regular visits, mainly three months apart.

6 Q. Three months apart. So does one of you to this day

7 continue to go with ██████ to his appointments?

8 A. Hm-mm. If it's not myself, it's his Dad.

9 Q. Thank you. I think we can see ██████'s first

10 appointment with Dr France was in January 2002 and this

11 is WIT0040205. This notes what you have told us, that

12 only close family are aware that ██████ has HIV.

13 Dr France notes physical examination is satisfactory and

14 his blood tests have been very encouraging, with a CD4

15 count of 682 and an undetectable viral load. The plan

16 is that ██████ will continue with the three drugs he is

17 being prescribed and they will see him again in three

18 months' time.

19 How was ██████ doing at school at this point,

20 because he must have had exams around this time?

21 A. He has always done well. The only problem was really

22 the hearing but he had a phonic aid, which helped him.

23 But, no, he has always done well at school.

24 Q. What sort of activities did he do as well as school?

25 A. Football, just -- mainly the football.

1 Q. What exam results did he leave school with?

2 A. I can't remember.

3 Q. Right. Other than obviously having to go to many

4 hospital appointments, do you think his diagnosis with

5 HIV affected his schooling in any way?

6 A. No.

7 Q. So his school work managed not to suffer, even though he

8 was missing school?

9 A. No.

10 Q. When [redacted] left school, what did he do?

11 A. He actually attended college, doing computer studies for

12 a year.

13 Q. How old was he when he left school?

14 A. He went right up to -- would it have been fifth year?

15 Q. Okay. He did a one-year course at college?

16 A. Hm-mm.

17 Q. Computer studies. Okay. The medical records show that

18 in about 2004 [redacted] started to have problems -- real

19 problems this time -- in adhering to his medication

20 regime and I think you touch on that in your statement

21 in paragraph 17, WIT0040004. You tell us there that

22 for a few years during [redacted]'s teenage years, he

23 actually stopped taking his medication, as he found the

24 tablets difficult to swallow and didn't like the taste.

25 At one point he said he didn't see the point in taking

1 the medication and then you tell us that more recently
2 he has started taking the medication again?
3 A. He has, yes. I think because he had been in and out of
4 hospital a couple of times and I think it was on the
5 last occasion, I think -- I think fear had been put into
6 him and I think that's how he started taking them again.
7 Q. Yes. If we go back to November 2004, if I could refer
8 to you a letter, WIT0040207. This is Dr France noting
9 that [redacted] hadn't come to a clinic that afternoon, that
10 he was getting his drugs delivered by one of the
11 clinical nurses who lived nearby, and it's saying it
12 doesn't get round the need for him having occasional
13 supervision of his therapy. So he is wondering if there
14 is a possibility of getting blood tests performed within
15 the community. Was that ever done?
16 A. No, we have always had to go to the hospitals.
17 Q. Right. Then if we could move on to WIT0040208, this
18 is written by an associate specialist to Dr France and
19 is dated November 2005 and [redacted] has been to the clinic
20 accompanied by his father. He had missed another
21 appointment in October. His CD4 count has fallen to
22 323, the CD4 count having been done on 5 September:
23 "but as you know, [redacted] stopped his treatment
24 in November 2004, so he was not on treatment for at
25 least ten months, when his recent blood sample was

1 done."

2 It's noted that he has a relatively small viral load

3 at 15,000, when his blood was checked on 5 September.

4 He notes:

5 ████ "generally feels well. He did not volunteer

6 any symptoms today. He does not sound keen on being on

7 antiviral treatment but he understands that his immune

8 system can deteriorate again to a level that he may need

9 antiviral treatment."

10 So that must have been in about the start of ███

11 that ████ stopped his medication. Were you aware at

12 that time that he had done that?

13 A. Yes.

14 Q. Yes.

15 A. Like, we tried to encourage and advise him to take

16 medications but because he was now a young man,

17 a teenager, well, I just felt it was his choice and we

18 could only advise.

19 Q. Was he still living at home at that point? He will have

20 been about 19/20.

21 A. I can't remember. Because I actually moved out the

22 family home.

23 Q. When was that?

24 A. I can't remember the year.

25 Q. That's all right.

1 A. I think he was about 22.
2 Q. So you think you moved out the family home when ██████
3 was about 22?
4 A. When he was about 22, yes.
5 Q. Did ██████ remain in the family home with his father --
6 A. With his brother; they share the flat together.
7 Q. Right. Why do you think ██████ stopped taking his
8 medication at that time? I mean, you have --
9 A. I really don't know because ██████ doesn't really talk
10 about it much.
11 Q. Right. If we move on to the following
12 year, December 2006, WIT0040210. This is a letter
13 from Dr France to ██████'s GP:
14 Once again ██████ has come to a clinic appointment
15 "accompanied by his father following a lengthy absence
16 from outpatient follow-up."
17 He notes that ██████ had discontinued treatment
18 in November 2004, which doesn't tally with what we were
19 saying earlier. I think we thought it was at the
20 beginning of the year but if we say around that time.
21 But ██████ at this stage is now thinking about
22 restarting treatment because he has had a few minor
23 infections. Were you aware when ██████ started to have
24 a few minor infections once he had stopped the
25 treatment?

1 A. Yes.
2 Q. What kind of infections were these?
3 A. One of them was really bad. It was like suspected
4 pneumonia and he had, like, GP visits. He had actually
5 gone up to the hospital for x-rays on the chest and they
6 did see a shadow, but they didn't think at that time it
7 was pneumonia and [redacted] was getting very breathless,
8 even just chatting for a short period of time on the
9 phone, and standing. He would have sore legs and
10 I think this went on for about a fortnight and I had
11 called NHS24 and the doctor came out and that's when he
12 was admitted to Ninewells, and I'm sure it was signs of
13 pneumonia.
14 Q. Yes, I think we will come on to that because his
15 condition started gradually deteriorating. I wondered
16 if you remembered how you noticed a deterioration at the
17 beginning, when he had stopped his treatment?
18 A. I think, like, the weight loss as well.
19 Q. Right, okay.
20 A. And feeling nauseous.
21 Q. Okay.
22 A. And I think the sweating as well was coming back to him.
23 Q. Yes, okay. In this letter in December 2006, Dr France
24 notes that he had a mild seborrhoeic dermatitis, a rash,
25 I think, on his face. Did you notice this start?

1 A. Yes, I think it could have been due to the change in
2 some of the medications as well.
3 Q. Right. If we turn to WIT0040211, this follows
4 a clinic appointment in January 2007 and Dr France notes
5 that [redacted] is quite keen to restart anti-Retroviral
6 therapy. He notes that [redacted]'s CD4 lymphocyte count
7 has fallen a bit since he was last there but is not
8 dangerously low and his viral load was only 4,100,
9 indicating a fairly low level of viral replication.
10 I think saying there that the virus is not replicating
11 that quickly even though he is not on treatment.
12 He notes:
13 "After a detailed discussion with him he would like
14 to recommence therapy."
15 And he suggests two new medications for him to take
16 once a day. He notes that:
17 "The principal side effects to look out for are
18 disturbance of renal function and vivid dreams or even
19 nightmares."
20 I think if we move on, the medical records suggest
21 that actually [redacted] didn't start these treatments and
22 I think he found them quite -- as you have touched on --
23 difficult to swallow. He found the pills quite big and
24 had difficulties taking this medication.
25 I think if we look at a letter, WIT0040214, this

1 is in June 2007. I think having not managed to take
2 Truvada and Efavirenz, the medications that were
3 mentioned before, Dr France during this period had
4 suggested another drug, Kaletra, but [redacted] is telling
5 him at this point that he has not managed to take it
6 because he cannot eat meals on a regular basis. So this
7 would be a contra-indication to the therapy.
8 Did [redacted] find the timings of when he had to take
9 medications difficult?
10 A. Sometimes, yes.
11 Q. Obviously some medications have to be taken --
12 A. Before food during.
13 Q. -- with food. So he found that difficult to manage?
14 Dr France notes:
15 "Overall I was left with the distinct impression
16 that he is seeking excuses for not being on treatment.
17 This is obviously a pointer to non-adherence to the
18 prescribed therapy. In such a setting he can only breed
19 resistance to the drugs and this would leave him in a
20 worse position than no therapy at all."
21 He suggests he go away to reorganise meal times and
22 see if he can start taking his medication.
23 If we move on to November 2007, WIT0040215,
24 Dr France records here in the first paragraph, having
25 reviewed [redacted] at his clinic at the beginning

1 of November things are not going terribly well:

2 "His CD4 count has dropped to only 87 and he remains

3 underweight at 53 kilograms."

4 Something that you touched on earlier, he is making

5 efforts for [redacted] to be seen by a dietician. He says:

6 "I have never been fully convinced that [redacted]

7 fully understands the stark choices he faces at

8 present. I pointed out that, in the absence of

9 treatment, HIV could kill him in the relatively near

10 future. However, specific treatments for HIV could

11 prolong his life very significantly and improve his

12 overall wellbeing. I have left him to go away and think

13 about this."

14 I take it [redacted] was aware of his need for

15 treatment? How did he get on with Dr France?

16 A. He didn't really like him at all. His bedside manner.

17 To be honest, I didn't either and, like, sometimes, like

18 leading up to the appointment, it was like he would make

19 up excuses, not even to go.

20 Q. Yes.

21 A. I think because we had such a good relationship with

22 Dr Tarnow-Mordi.

23 Q. It was quite a change for him to have moved to the adult

24 unit?

25 A. Yes.

1 Q. Then if we move on to May 2008, WIT0040218, Dr France
2 is recording:
3 "We have made no further progress."
4 That [redacted], he feels, has come up with a string of
5 excuses as to why he could not start taking the
6 antiRetroviral drugs. Essentially they are all part of
7 an avoidance strategy. The underlying problem is that
8 he really does not want to take the pills. And he
9 obviously has a frank discussion with [redacted]:
10 "I managed to get him to admit that in the absence
11 of treatment, he will almost certainly die fairly soon.
12 I explained to him that taking the treatments in
13 a half-hearted manner would rapidly breed resistance to
14 the drugs which would never work again."
15 I think at that point he leaves [redacted] to go away
16 and think about it and doesn't give him another clinic
17 appointment.
18 If we move on to October 2008, WIT0040220, I think
19 this is an appointment that you went to with [redacted] and
20 it records that [redacted] does now wish to recommence
21 anti-Retroviral therapy and you are offering to help
22 supervise the treatment. What do you think caused
23 [redacted] to change his mind at that point?
24 A. I really don't know.
25 Q. You don't know?

1 A. Because ██████ doesn't really discuss it much.
2 Q. Right.Dr France records that he has his doubts that
3 ██████ is fully committed to restarting his treatment
4 and wonders if he has agreed to it purely to stop people
5 from nagging him. Do you think that's fair to say?
6 A. I don't like the way that that is mentioned in that
7 letter. I don't think it's appropriate.
8 Q. That's obviously his view at the time.
9 A. Yes.
10 Q. And it wasn't your view?
11 A. No. We were never nagging him. We would advise and
12 encourage, and I just feel the way he has written
13 that -- I don't like that at all.
14 Q. Okay. Can we turn to WIT0040221? This is a referral
15 letter by Dr France to Dr Hobbs, Consultant
16 Psychiatrist, asking him to see ██████ and assess him
17 for a possible depressive illness. How did this come
18 about?
19 A. I can't remember.
20 Q. No. He says at the bottom paragraph there that he is
21 finding it difficult to pin down the main factors behind
22 ██████'s reluctance to take treatments and he tells us
23 there what he considers may be an explanation, which
24 I don't think we need to go into. I think if we turn to
25 page 2, it's noted that you were asking him if ██████

1 could have some anti-depressant pills and he said he
2 thought that a formal assessment by a psychiatrist would
3 be better first. Did you feel at that time that ████████
4 would benefit from --
5 A. I think he was actually feeling low as well and -- yes.
6 Q. So you thought that may assist him with all that was
7 going on at that time?
8 A. Yes.
9 Q. Yes, okay.
10 A. Because he doesn't really talk about it at all.
11 Q. No. Did ███████ see the psychiatrist?
12 A. I can't remember.
13 Q. Do you know? No.
14 There is a letter, which we don't need to look at,
15 WIT0040228, basically saying that ████████ didn't get in
16 touch with the mental health team and so had been
17 discharged from their service without treatment.
18 You touched earlier on the fact that ███████'s
19 condition did deteriorate and he was eventually admitted
20 to hospital. I think we can see the record of that at
21 WIT0040225. The second page of this letter is
22 actually 0224 and records that it is written by
23 David Wallace, who works for Professor Nathwani.
24 If we go back to the first page, this tells us that
25 ███████ was admitted on 17 January with a four-week

1 history of shortness of breath. He is not currently
2 receiving follow-up or medication for his HIV at this
3 time. He had a cough productive of green sputum and was
4 breathless on limited effort, with about 20 yards
5 exercise tolerance. A chest x-ray that was carried out
6 showed shadowing and [redacted] admitted to having
7 occasional nighttime sweats.
8 He was found to be extensively cyanosed in his nail
9 beds, with cold hands, good air entry with a few fine
10 crepitations.
11 So investigations were carried out. If you look
12 under the heading "Investigations":
13 "An initial diagnosis of ? PCP pneumonia or ?
14 atypical pneumonia was made."
15 He was started on Septrin at that point and it was
16 noted that his most recent CD4 count was
17 at November 2007, 60. He was also given steroids in
18 addition to the Septrin.
19 The induced sputum was found to be negative for PCP
20 but the decision was made to continue the Septrin and
21 this was changed to oral syrup.
22 The IV Hydrocortisone was changed to oral
23 Hydrocortisone as [redacted] felt able to take a small
24 tablet and he was discharged home on 23 January to
25 continue with his oral Septrin and his oral

1 Prednisolone.

2 If we turn to page WIT040226, we can see a letter,

3 which [redacted] obviously wrote at the time he was in

4 hospital, dated 20 January, and he is writing to

5 Dr Winter. Who was Dr Winter?

6 A. I think -- was it someone that [redacted], that had put us on

7 to -- to let him know how [redacted] was feeling being under

8 Dr France.

9 Q. And [redacted]?

10 A. She works alongside [redacted].

11 Q. Okay. [redacted] is writing to say that he feels that

12 communication has broken down between him and Dr France:

13 "I feel it hard to open up and express my feelings.

14 I'm starting to have negative thoughts about the outcome

15 of my visit before I've even seen Dr France. I feel

16 a change could do me good."

17 What was the outcome of this letter?

18 A. We did have a change of doctor. I'm sure it's Dr -- is

19 it Nithwani?

20 Q. Yes. Could we turn to WIT0040229. This is a letter

21 by a doctor who worked for Dr France:

22 "Having reviewed [redacted] in the clinic on

23 11 February 2009 ..."

24 It notes that he has had two admissions to the

25 hospital, the first with probable -- and I think what

1 was taken out there is PCP -- I am not sure quite why it
2 has been removed -- which we have looked at already. He
3 had a second admission for a flu-like illness but his
4 LFTs were noted to be abnormal but then settled and it
5 was thought to have been simply a viral infection.
6 At this time ████ has nearly finished his 21 days
7 of Septrin and he is continuing the Prednisolone. The
8 plan is to bring him back to clinic in two to three
9 weeks' time with a view to possibly starting his
10 antiretroviral therapy. As he struggles to swallow
11 tablets, the plan is to start him on Truvada, which can
12 be dissolved in juice, as well as some Nevirapine
13 liquid.
14 I think after that you went with ████ to a clinic
15 appointment on 19 March 2009. Could you have a look,
16 please, at WIT0040230? This refers to his previous
17 admissions and says in the third paragraph:
18 "It would be reasonable for his to commence on
19 antiRetroviral treatments."
20 He is going to start the Truvada once daily and
21 Nevirapine once daily for two weeks, followed by an
22 increased dose once a day. You obviously had
23 a discussion then about the side effects of the
24 medication and it's noted that these are the only
25 Retrovirals that they have managed to find that ████

1 can take in a liquid preparation, and it's noted that
2 their ability to give ███████ a range of antiRetrovirals
3 are limited because of his difficulty swallowing
4 tablets.
5 So in March 2009 ██████ started antiRetroviral
6 treatment again with these two drugs. How did that go?
7 A. He has actually been taking these medications great now.
8 He takes them all the time and his weight has gained.
9 Q. Good. I think we can see that they had good effect when
10 we look at a letter dated 28 April 2009, WIT0040231.
11 This is Dr Urquhart saying:
12 "I have reviewed ███████ in the clinic today and was
13 amazed at how well he is looking." He has put on weight
14 and he says he is feeling really well. He is managing
15 to take the medications as they are liquid or
16 dissolvable and he is remaining on Septrin, as his CD4
17 count remains below 200. He is eating well and his
18 father says he is much more talkative and outgoing.
19 She checks his blood and then comments at the end of
20 the letter:
21 "Once again, I have to say how pleased I am at how
22 well he's looking and feeling."
23 So there was obviously quite a significant
24 improvement in ██████'s condition within quite a short
25 period of starting the treatment?

1 A. Hm-mm.
2 Q. Has he had any more infections since then?
3 A. No.
4 Q. No?
5 A. No. Because I mean, he hardly ever gets a cold either
6 but I think it's due to the fact that the medication is
7 keeping everything at bay.
8 Q. Yes.
9 A. But he is looking a lot better.
10 Q. If we could look at a letter of July 2010, last year,
11 WIT0040232. This is from Professor Nathwani, noting
12 in the first paragraph:
13 "this is the best I have seen him look for
14 a considerable amount of time. He had clearly gained
15 weight and is generally feeling very well. He is tolerant with
16 his new medication of Nevirapine and Truvada and his last viral load
17 was completely suppressed and his CD4 count was stable at 141 (15%)."
18 He is going to remain on Septrin as his count is still
19 below 200.
20 He notes there:
21 "there is family history of cardiovascular disease
22 and I have asked him to pay particular attention to his
23 diet and we shall continue to monitor him from
24 a cardiovascular view particularly because he is of
25 relatively young age."

1 Were you warned that this could be a side effect of
2 [redacted]'s medication?
3 A. I can't remember.
4 Q. Okay. Then I think he refers there to [redacted] being
5 referred to a new consultant who is starting there,
6 Dr Evans. Is that who [redacted] sees now?
7 A. That's who he is with.
8 Q. If we turn to WIT0040238. I think last year did
9 [redacted] have problems with a skin rash again?
10 A. Yes, I think they thought it could have been related to
11 Septrin.
12 Q. Yes, that's right.
13 A. Because it was his eyes in fact -- the face was really,
14 really red and parts of the body.
15 Q. Yes. I think there was some uncertainty, was there,
16 about what might be causing that rash?
17 A. Yes.
18 Q. So they stopped the Septrin and that seemed to improve
19 things. Is that right?
20 A. Yes.
21 Q. This is the letter confirming that, if you could scroll
22 up, please. You will see that it's dated December 2010.
23 His last CD4 count has come up to 204 and it mentions
24 the concern about [redacted]'s skin deteriorating and
25 affecting his eyes and the thought that one of his drugs

1 may be causing this. They decided to stop Septrin to
2 see if this was the culprit:
3 "I'm glad to inform you that the skin seems to have
4 improved a lot."
5 Does that remain the case?
6 A. Yes.
7 Q. So [redacted] is not taking Septrin just now.
8 A. No.
9 Q. Could we move on to WIT0040239? This is the latest
10 letter we have in respect of [redacted]'s condition. We
11 will see it's noted under "Diagnosis" that a Septrin
12 allergy has now been recorded there along with HIV
13 infection, dermatitis and hearing loss. His skin is
14 still flaring up a bit but is much better.
15 A. Much better, yes.
16 Q. His viral load is less than 20 in 2010 and that's
17 controlled. So they are reassured that his current
18 antiRetroviral regime is adequate, although I think they
19 are hoping that his CD4 count will start to improve. So
20 does [redacted] continue to attend these clinic
21 appointments?
22 A. Yes.
23 Q. It is saying they are about four monthly?
24 A. Yes.
25 Q. So how is [redacted] doing now?

1 A. He seems to be doing fine. He has put on weight, he is
2 eating better. I think he appears happier within
3 himself now. Yes, much better.
4 Q. Has [redacted] ever worked? You said he did his computer
5 course.
6 A. He was signing on for a while and he got, like,
7 a Job Seekers thing through them, but because it was
8 outdoors and he was carrying heavy loads on his back...
9 Q. What was the work?
10 A. It was, like, gardening and things like that.
11 Q. That was provided through Job Seekers?
12 A. Yes, but because of his weight at the time, he was
13 having problems carrying this on his back and he was
14 actually off work for about a week due to this but he
15 felt that when he went back, it was like he was getting
16 picked on by the person that he was working under, you
17 know, so ...
18 Q. So did he stop?
19 A. He stopped, yes.
20 Q. Right.
21 A. And he has never really worked since.
22 Q. Right. And he lives with his brother?
23 A. That's right, yes.
24 Q. How does he manage financially?
25 A. He gets help from the Eileen Trust.

1 Q. Right. So do they give him a monthly allowance?
2 A. Yes.
3 Q. So how does he spend his time?
4 A. He doesn't really do a lot at all. He is in the house
5 quite a lot. If he is not with me, he will maybe be
6 with his dad or his granddad but he doesn't go out
7 drinking or pubs or anything like that. And he has
8 never had a girlfriend. He just sort of keeps himself
9 to himself.
10 Q. Right. Do you think he has any plans to find any work?
11 A. Like, he does look on the Internet and that but I think
12 at this moment in time, no.
13 Q. No.
14 A. Because I think too, his main concern was taking his
15 medications, because obviously he didn't want people to
16 see him on all those medications and ask questions why.
17 Q. Right.
18 A. So this could be another factor, I'm not sure.
19 Q. So he doesn't want people to know that he needs to take
20 medication?
21 A. Hm-mm.
22 Q. How has [redacted]'s infection with HIV affected you?
23 Sorry, I appreciate this is really difficult.
24 A. I'm really bitter and angry about what has happened.
25 I feel it should never have happened. I try to put it

1 behind. It has affected us all and I feel [redacted]
2 doesn't have much of a life either. I even feel guilty
3 for moving out of the home. I just feel that [redacted] has
4 to try and be independent as well but, even for the age
5 he is, he still wants me to go with him, you know, even
6 GPs, hospitals, you know, if he has to do anything down
7 town. He is very quiet and reserved. But I just feel
8 he is in the house all the time more or less.
9 Q. Unless there is anything else you would like to add,
10 thank you very much for going through this.
11 I appreciate it has been very difficult for you but we
12 are very grateful. Thank you.
13 THE CHAIRMAN: Gentlemen, are you content?
14 MR DI ROLLO: Yes, thank you, very much.
15 THE CHAIRMAN: Amy, thank you very much. We will adjourn.
16 (12.05 pm)
17 (The short adjournment)
18
19
20
21
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25

AMY 1

Questions by MS PATRICK 1

1 (2.00 pm)

2 MS PATRICK: Sir, this afternoon we have

3 Dr Alison Richardson.

4 THE CHAIRMAN: Dr Richardson, will you take the oath?

5 DR ALISON RICHARDSON (sworn)

6 Questions by MS PATRICK

7 THE CHAIRMAN: Yes, Ms Patrick?

8 MS PATRICK: Dr Richardson, I would like to start by looking

9 at the brief curriculum vitae that you provided to the

10 Inquiry. This is document [WIT0030166] and it should

11 come up on the screen in front of you.

12 Can you see it in front of you now? I'm hoping we

13 are going to enlarge it.

14 A. I'm hoping so too.

15 Q. There you go, can you read that all right?

16 A. I can.

17 Q. In the first section you tell us your educational

18 history, that in 1974 you obtained a Bachelor of Arts in

19 psychology from the University of Stirling and an MPhil

20 in clinical psychology at Edinburgh University, and in

21 1985 you completed a PhD in psychology, once again at

22 the University of Stirling?

23 A. That's correct.

24 Q. In the second section you recount for us your employment

25 history. You started as a psychologist in 1976 as

1 a research assistant specialising then in learning
2 disability?
3 A. Yes.
4 Q. At the University of Stirling. Then in 1981 you moved
5 to Gogarburn Hospital. Did you work as a clinical
6 psychologist there in the learning disability
7 department?
8 A. That's right.
9 Q. You also worked at the Royal Edinburgh Hospital. What
10 department was that in?
11 A. The department of psychiatry.
12 Q. Okay. In 1986 you became a senior clinical psychologist
13 and in that same year a honorary fellow in the faculty
14 of medicine at Edinburgh University. Then in 1987 you
15 became principal clinical psychologist until 2008. Was
16 that based at the Royal Edinburgh Hospital?
17 A. That was based in a number of places, first of all at
18 City Hospital and when that shut, At the Western General
19 Hospital and at the department of genitourinary medicine
20 in the Lauriston Building and finally in the
21 Spittal Street centre.
22 Q. What did your work there involve?
23 A. Primarily seeing patients who were infected with HIV but
24 secondarily seeing people, particularly gay men, who
25 were putting themselves at risk of HIV and who wanted to

1 change their behaviour.
2 Q. Okay. You mention Spittal Street in the top section
3 there of your employment history, at which point you are
4 a consultant clinical psychologist?
5 A. That's correct.
6 Q. As you say there, dealing with HIV and as you put it,
7 "drug problems". In the third section you tell us your
8 teaching experience and over the page you list for us
9 the grants that you have held for research, all of which
10 relate to HIV and most of them in relation to drug
11 misuse as well?
12 A. That's right.
13 Q. Then in the fifth section you list for us selective
14 publications, which you contributed to and once again
15 HIV is a recurring theme?
16 A. It is, yes.
17 Q. Yes. Thank you.
18 I wonder if you would, please, have a look again at
19 your statement, paragraph 3, which is at page
20 [PEN0161285]. You tell us at the beginning of that
21 paragraph really, I think, this is your first
22 involvement in relation to HIV in the work that you were
23 doing at that time. Is that right?
24 A. That's right.
25 Q. You say that in 1985 you started to see a trickle of

1 patients in connection with HIV at the Royal Edinburgh
2 Hospital, at that point you point out that it was known
3 as "HTLV-III" and these were patients who were
4 AIDS-phobic.
5 A. Yes.
6 Q. You say that that was an anxiety state about having or
7 acquiring AIDS?
8 A. Yes.
9 Q. You tell us in that paragraph about the trainee
10 psychologist working with you, who obviously knew a bit
11 about HTLV-III or HIV, and it seems that your interest
12 in the virus was piqued then, was it?
13 A. Yes.
14 Q. If we turn to the next page, paragraph 5, you tell us
15 that in 1986 you saw a job advertised for a psychologist
16 working with people with HIV and this was a job with
17 Lothian Health Board?
18 A. It was, yes.
19 Q. You applied for this job and were successful and started
20 working for the health board, taking referrals from the
21 two places which were dealing with patients with HIV,
22 and that was the Edinburgh Royal Infirmary, the
23 genitourinary medicines department and the infectious
24 diseases unit at the City Hospital. You say at the
25 bottom of that paragraph that the patients that you saw

1 in that post were mainly drug users and homosexual men?
2 A. That's right.
3 Q. In paragraph 6 you tell us that during your work in
4 about 1986 or 1987 you became aware that people with
5 haemophilia had also acquired HIV and in
6 about September 1987 you approached Dr Ludlam,
7 consultant haematologist. What was your purpose of
8 approaching him then?
9 A. Because I was a single-handed psychologist providing
10 a service for people with HIV in Lothian. I didn't want
11 to miss out the haemophiliacs or those who had been
12 infected through blood products, and I was aware that
13 the haemophilia centre looked after most of those.
14 Q. Right. So you told him that you would be happy to do
15 whatever you could to help him with the management of
16 these patients?
17 A. That's right.
18 Q. You say that your recollection is that initially he was
19 not particularly welcoming of that suggestion and you
20 think that he may have been worried about the
21 confidentiality of his patients at that point?
22 A. Yes.
23 Q. You know that at that time, at the time you approached
24 Dr Ludlam, there was a social worker working in that
25 department with him?

1 A. That's right.

2 Q. Who was Geraldine Brown?

3 A. She had been there for some time.

4 Q. Do you know how long she had been there for?

5 A. I don't recall, sorry.

6 Q. You tell us that towards the end of 1987, Dr Ludlam

7 allowed you to come in and sit in on the haematology

8 weekly team meetings?

9 A. That's correct.

10 Q. If we go over the page, at these meetings -- this is

11 about eight lines down -- you were discussing those

12 patients who were infected with HIV?

13 A. Not entirely the people infected with HIV. Anybody who

14 was posing problems for the unit at the time.

15 Q. Right. So these meetings weren't solely in relation to

16 HIV but that was an issue that might well be discussed?

17 A. That's right.

18 Q. You say further down, about half way, that by this time

19 most, if not all the haemophilia patients who were HIV

20 positive knew of their diagnosis?

21 A. I believe that's right.

22 Q. Yes. So you mainly discussed how they and their

23 families were managing this.

24 You say there that you discussed a number of

25 dilemmas too and you mention one specific dilemma. In

1 relation to this the Inquiry is being very careful not
2 to refer to evidence which may lead to the
3 identification of any individual. So I'm not going to
4 ask you about that and we are not going to include it as
5 part of your evidence.
6 If we move over the page to paragraph 8, you tell us
7 further on in your statement that you subsequently saw
8 individually and in groups some of the haemophilia
9 patients --
10 A. That's right.
11 Q. -- in respect of their diagnosis with HIV, and you were
12 made aware from that, from seeing these patients, that
13 there had been an urgent meeting with Dr Ludlam in about
14 1985, you say?
15 A. I can't be sure of the date but certainly two or thee of
16 the haemophiliacs discussed it possibly, I think, within
17 the group.
18 Q. Right. But you obviously weren't in post at that time?
19 A. No.
20 Q. Were you at that meeting?
21 A. No.
22 Q. No. You say further down that paragraph:
23 "From what I have heard from the patients I spoke to
24 subsequently, Dr Ludlam told them that some people with
25 haemophilia in Scotland were infected with HIV."

1 A. That's right.

2 Q. Yes, and you mention specifically what two of your
3 patients had taken away from that meeting?

4 A. Yes.

5 Q. This was that they were told at the meeting to use
6 condoms when having sexual intercourse with their wives.
7 The general feeling, you say, of those two patients
8 leaving that meeting was, "Well, thank goodness I don't
9 have it because if I had, he would have told me".

10 A. That's correct.

11 Q. Thank you. So, as you say, they left that meeting
12 thinking that they did not have HIV.

13 Moving on to the next page, the top, which is
14 a continuation of paragraph 8, you comment on a problem
15 at the time, which was patients who would not be tested
16 for the virus?

17 A. That's right.

18 Q. You say that you think there were about five of them.
19 What approach was taken to these patients in respect of
20 this?

21 A. I can't say for sure because I wouldn't -- I wouldn't
22 have seen them. The doctors in the unit would have been
23 handling that. What I believe is that they were
24 probably trying very hard to get the patients to agree
25 to have an HIV test in their own interest, but like many

1 other people who -- it may seem like a very good idea to
2 have an HIV test but the patients don't always agree
3 with that and they may have many different reasons why
4 they would prefer not to.
5 Q. You mention in paragraph 9, about half way down, that
6 away from the haemophilia department, one man or maybe
7 more than one man was referred to you by a GP so that
8 you could steer him towards having a test for HIV, as it
9 was known that he was HIV positive but this man himself
10 did not know?
11 A. That's right.
12 Q. If we could move over the page to paragraph 11 of your
13 statement, you tell us that in about 1987 or 1988
14 Dr Ludlam started referring people to you, presumably
15 for your input in relation to their diagnosis with the
16 HIV virus?
17 A. Or other psychological state.
18 Q. Right. So by the end of 1988 you were seeing some
19 people with haemophilia who were infected with HIV?
20 A. That's right.
21 Q. You say that out of the 11 patients that you knew about,
22 seven decided to meet with you in a group?
23 A. That's right.
24 Q. That was a group that you and Geraldine Brown set up?
25 A. That's right.

1 Q. All these 11 patients knew that they had HIV?
2 A. Yes.
3 Q. You say that four or five patients at that time didn't
4 want any psychological help.
5 Towards the end of that paragraph, you tell us that
6 you eventually did see all 11 of these patients?
7 A. That's right.
8 Q. Nine of them died, eight as a result of AIDS?
9 A. That's my recollection anyway.
10 Q. You add at the end there that they were people who had
11 suffered a great deal throughout their lives, had seen
12 the introduction of treatment which would help them and
13 alleviate their pain and their suffering and allow them
14 to have more normally lives only to find that it had
15 introduced a potentially fatal disease?
16 A. That's right.
17 Q. In paragraph 12 you tell us about the group, which you
18 have just mentioned that you set up with
19 Geraldine Brown, and you say that in about August 1989
20 you started the group with Geraldine Brown for those
21 with haemophilia who were infected with HIV and then you
22 started a separate group for their relatives?
23 A. That's right.
24 Q. You tell us there the topics that were discussed at
25 these groups and you state that they included anger

1 against the Blood Transfusion Service and Dr Ludlam,
2 suicide, wills, funerals, loved ones watching them all
3 the time for symptoms, being more irritable with family,
4 sexual anxieties and alcohol problems. In general terms
5 were these the impacts on these patients of their
6 diagnosis with HIV?
7 A. Mainly, yes.
8 Q. Yes. Was fear one that was discussed by the patients?
9 A. They were understandably very anxious about what was
10 going to happen to them, and of course at that time it
11 was very, very unclear what might happen.
12 Q. Yes. How about the stigma in association with the
13 virus? Did you discuss that at these groups?
14 A. I think we probably did. I don't have any absolute
15 recollection of doing so but certainly almost all of
16 them -- for them confidentiality was of paramount
17 importance, to make sure that their neighbours, friends
18 and for many of them other members of the family didn't
19 know about it.
20 Q. You say that many of the group believed that they had
21 been used as guinea-pigs?
22 A. Yes. They weren't always very rational meetings,
23 I would have to say.
24 Q. A lot of emotion at these meetings?
25 A. Yes.

1 Q. Can you tell us in what way the patients believed they
2 had been used as guinea-pigs?
3 A. I can't really remember. It was just one of these
4 themes that came up very frequently and I would think
5 that Geraldine and I would try and dissuade them that
6 that was the case.
7 Q. Thank you. The group for relatives, in general terms
8 what did you see as the impacts on relatives of their
9 own relatives' infections with HIV?
10 A. Very similar to the men themselves: a huge amount of
11 anxiety about the future, constant conjecture about how
12 it had happened and grief, I suppose, that this was
13 occurring to the people that they loved best.
14 Q. You tell us at the end of paragraph 12 that the groups
15 lasted one or two years and the membership of the
16 patients group got smaller and smaller, and in fact they
17 ended up watching each other die?
18 A. That's right.
19 Q. You tell us in paragraph 13 that you continued to see
20 a couple of those people with haemophilia as they were
21 well enough to continue and they wished to do so. The
22 busiest period working with the patients with
23 haemophilia was -- I take it this is for you -- between
24 1985 and 1991?
25 A. Between 1987 and 1992.

1 Q. Yes. Okay. Thank you.

2 In paragraph 15, further down that page, you say

3 that in about 1988 or 1989 or perhaps earlier, Dr Ludlam

4 or the Edinburgh haemophilia centre produced some

5 guidelines called "Guidelines for Counselling Pre- and

6 Post-HIV Testing for Patients Receiving or Likely to

7 Receive Factor Concentrate and Cryoprecipitate".

8 I wonder if you could have a look, please, at

9 [PEN0150502]. Are these the guidelines that you are

10 referring to there?

11 A. Yes, they are. Yes.

12 Q. They are headed up "Guidelines for Counselling Pre- and

13 Post HIV Testing for Patients Receiving or Likely to

14 Receive Factor Concentrate and Cryoprecipitate". Under

15 "Reason for advising HIV test":

16 "To monitor safety of blood products and because

17 knowledge of the HIV status might be important in the

18 management of the individual. Some people have been

19 tested in the past without consent. It is now important

20 to discuss testing with everyone and document each

21 person' consent continuing to HIV test now and in the

22 future. We will not test anyone who does not wish to be

23 tested."

24 It records that discussion about HIV testing must be

25 recorded, stating clearly what has been agreed, and the

1 haemostatic screen on the computer must be appropriately
2 updated.
3 This then has headings of what should be discussed:
4 "Implications of a positive result", "Implications of
5 a negative result", "Confidentiality."
6 Then over the page:
7 "Risk to others", "Sexual activity",
8 "Hygiene/Toilet" and "Further counselling". Who were
9 these guidelines produced for?
10 A. I assume for the haemophiliac and indeed perhaps others
11 who had received donated blood. Certainly the
12 haemophiliacs.
13 Q. Right. Who was it envisaged would follow these
14 guidelines? Do you know?
15 A. I would imagine all the staff in the haemophilia centre.
16 Q. Right. You mention in paragraph 15, going back to your
17 statement at [PEN0161291], that you think that these
18 guidelines may have been issued earlier than 1988 or
19 1989 as you don't think you had an input into these
20 guidelines?
21 A. I don't think so.
22 Q. Had you been in post, you think you would have done?
23 A. Possibly.
24 Q. Possibly but you might not have done, thank you.
25 Going over the page to the end of paragraph 15,

1 ending 1292. You are talking here, I think, about
2 testing with or without patients' consent, that the
3 discussions amongst the doctors never ended, they were
4 always discussing it and worrying about it?
5 A. That's right.
6 Q. Which doctors are you talking about here?
7 A. The doctors at the haemophilia centre at GUM and at the
8 City Hospital. The issues around testing at that time
9 were seen as of paramount importance. So the kind of
10 counselling session for somebody who was intending to
11 have a test for HIV was generally supposed to last about
12 an hour.
13 Q. Right.
14 A. It was taken very, very seriously.
15 Q. Yes. So when you mention they were always discussing
16 "it" and worrying about "it", this was the dilemma about
17 obtaining consent for testing?
18 A. That's right.
19 Q. Or was it about advising about test results, when
20 consent had not been obtained?
21 A. I think both.
22 Q. Okay. Thank you very much.
23 THE CHAIRMAN: Mr Di Rollo?
24 Questions by MR DI ROLLO
25 MR DI ROLLO: Yes, I would like to ask some questions, thank

1 you.

2 Dr Richardson, I wonder if you could just tell us

3 exactly what your role would be in relation to

4 counselling. You initially made an approach, I think,

5 to Professor Ludlam to actually assist, and I would just

6 like to know exactly what it was that you had in mind

7 that you would be able to provide at that stage?

8 A. Initially it would be to see individual patients who

9 were struggling psychologically, suffering from

10 depression or anxiety or any other psychological

11 problem; to see those people individually.

12 Q. So you would see them individually and what would you do

13 for them? What would you actually do?

14 A. That would vary enormously depending on what the problem

15 was. Somebody with an alcohol problem, for instance,

16 I would treat as you would treat anybody with an alcohol

17 problem. Some of the haemophiliacs were extremely

18 anxious and I would use ordinary anxiety management

19 techniques to try and help alleviate that anxiety.

20 Q. Would this be in one-to-one sessions with them?

21 A. Yes.

22 Q. Would that be more than one session, it would be

23 repeated?

24 A. It would be repeated sessions.

25 Q. Right. I think you indicated in your statement that when

1 you initially offered your services, Dr Ludlam was --
2 the way it's phrased in your statement is "not very
3 welcoming". Is that correct?
4 A. That's what I recollect but in fact Dr Ludlam and I have
5 discussed it and he doesn't recollect the same thing at
6 all. So one of us is wrong.
7 Q. That often happens. You don't recollect being
8 particularly welcome on the scene. That's your
9 recollection?
10 A. That's my recollection, yes.
11 Q. In terms of confidentiality and all the rest of it,
12 I take it as a professional person you would have to
13 respect confidentiality. That would be a paramount
14 consideration?
15 A. Absolutely.
16 Q. Do you know if the services that were available up until
17 your involvement were of a similar kind? What I mean is
18 would the people that were providing a service up until
19 your involvement have the same sort of qualifications as
20 you have?
21 A. No, there was a very poor psychology service to the
22 Royal Infirmary at that time. So although they would
23 have had access to the department of psychological
24 medicine, there were no psychologists working in that
25 department at that time.

1 Q. When you did eventually get involved, patients had
2 a number of concerns about things that had happened. Is
3 that right?
4 A. Yes.
5 Q. Was there discussion from their point of view as to the
6 way in which testing had apparently been carried out
7 without their knowledge?
8 A. Certainly.
9 Q. Was that something that they were concerned about?
10 A. Yes, they were very concerned about it and I would say
11 bewildered as much as anything else. They didn't really
12 understand, and neither did I, how it had come about
13 that they had become infected, partly because even in
14 1987, when I was there, there was much talk all the time
15 about Scotland being self-sufficient in Factor VIII.
16 Q. Was any attempt made to explain to them how it had
17 happened?
18 A. Not that I'm aware of.
19 Q. Do you think the fact that there was no such attempt
20 made things better or worse for them?
21 THE CHAIRMAN: There is a bit of a step in logic there,
22 Mr Di Rollo, from "not that I'm aware of" to the
23 assumption that it didn't happen. I think this is
24 sufficiently sensitive to be quite careful about --
25 MR DI ROLLO: I take your Lordship's point.

1 THE CHAIRMAN: It really has to be a hypothesis that, if it
2 didn't happen, you may have a comment but I doubt if at
3 this stage we can assume, since you weren't always
4 there that it did.
5 A. I would agree.
6 MR DI ROLLO: Taking the chairman's point there, in your
7 view would it be better if an explanation was given?
8 Would that assist a patient in that situation?
9 A. Only if they understood the explanation.
10 Q. Right.
11 A. And I think that was sometimes a problem. Patients may
12 well have had things explained to them but they didn't
13 understand it.
14 Q. The testing was something which was obviously a source
15 of concern to the patients that you saw, also the fact
16 that research was being carried out upon them, without
17 their knowledge, was that something that they were
18 concerned about?
19 A. Only to the extent that they thought that they had been
20 used as guinea-pigs.
21 Q. Right.
22 A. I don't think many of them, perhaps any of them, would
23 have understood that their blood being used for research
24 purposes did not make them guinea-pigs. Their thinking
25 was that they had been deliberately -- this had been

1 deliberately done and in that sense they were being used
2 as guinea-pigs.
3 Q. Do you think that if they had been informed about
4 whether research had been carried out upon them, that
5 might have avoided or at least lessened the risk that
6 they thought they were being used as guinea-pigs?
7 A. That's a difficult question to answer. My own belief is
8 that they had probably given at some point blanket
9 consent for their blood to be used for research
10 purposes, and it might have been many years later
11 that -- many years before HIV became a problem that they
12 had given that consent but I'm not sure of that.
13 Q. Well, I know you say that in your statement. You
14 suggest, I think, in your statement that it's possible
15 that blanket consent might have been given. It may be
16 that the perception is that a consent for research was
17 not given at any time. They didn't have any
18 understanding or appreciation that there was any consent
19 for research. I'm just trying to understand, would that
20 increase the feeling or make it more likely that someone
21 would feel that they were being experimented on without
22 their consent, if you like, the fact that they
23 discovered years later that research has been carried
24 out upon them or that their blood has been researched
25 upon?

1 A. I think, because the consequences of that research, if
2 that was a consequence of the research, they would be
3 bound to feel like that. But I think that -- there is
4 an enormous amount of trust between the haemophiliacs
5 and their doctors -- there has to be in order for the
6 relationship to work -- and I think if doctors in the
7 clinic, or indeed nurses in the clinic, had asked them
8 to tick a box, saying, "Yes, my blood can be used for
9 research purpose," they would probably have done it
10 without asking questions.
11 Q. Hm-mm.
12 A. But again, I'm surmising that.
13 Q. Then the meeting in 1984, I think you refer to that in
14 your statement. Can I just ask you, what was your
15 understanding of the problems from the patient point of
16 view in relation to the communication as far as that
17 meeting was concerned?
18 A. Certainly from what some of them said to me, they did
19 not understand what I would understand to have been the
20 purpose of that meeting, which was to warn them that
21 against all expectation, HIV had got into the blood
22 supply in some kind of fashion, and I think they were
23 being warned about that and warned about the -- warned
24 or at least advised, I would think, to take an HIV test
25 openly. But I suspect that some of them did not

1 understand that that was -- they would understand that
2 the purpose of the meeting was that they were being
3 informed that HIV was in the blood supply but not
4 necessarily that it might affect them.
5 Q. I think you know that because I think that's what they
6 told you. I think, as you have reported in your
7 statement, that --
8 A. I would certainly --
9 Q. -- at least some of the patients at any rate indicated
10 to you that --
11 A. They thought they were not infected.
12 Q. Exactly, and that was the very opposite of the true
13 situation?
14 A. I think that's possibly true.
15 Q. So then the difficulty for the patient becomes that
16 later on they discover that they are infected, having
17 thought that they weren't and understood in a positive
18 sense or been told that they weren't infected. Would
19 that not make things even worse than they already were?
20 A. It certainly affected their attitude towards the people
21 who were looking after them, yes.
22 Q. Did you get any understanding -- or an explanation for
23 your own part, as to why not simply tell each individual
24 patient at that stage that they had been infected? Did
25 you have any understanding as to why that wouldn't be

1 possible?
2 A. By the time I started working with the unit, all the
3 haemophiliacs that I saw already knew that they had HIV.
4 I wouldn't have had access to anyone who was infected
5 with HIV and did not know about it.
6 Q. So does that mean that you didn't have any understanding
7 of that or not?
8 A. I'm sorry, understanding of ...?
9 Q. What I'm trying to understand from you is whether they
10 would have appreciated whether they had been infected or
11 not -- it may be that it would be better to address
12 these questions to another witness. Perhaps I can deal
13 with another point.
14 One matter that you deal with in paragraph 7 of your
15 statement, if we could put that up on the screen.
16 THE CHAIRMAN: Is this a slightly different attack?
17 MR DI ROLLO: Yes, it is.
18 THE CHAIRMAN: I think there are one or two questions
19 I would like to ask about the general topic you were
20 involved in, Mr Di Rollo.
21 MR DI ROLLO: Yes, thank you.
22 THE CHAIRMAN: Dr Richardson, when you joined this part of
23 the service in 1987, I think we know that HIV antibody
24 testing was already established for 18 months plus
25 anyway and the tests were available, and if I have

1 understood what you have said so far, there came within
2 the range of your interest a group of patients who
3 already knew that they had been infected.
4 A. That's right.
5 THE CHAIRMAN: When they were told is perhaps not important
6 at this stage. You knew that but there was also another
7 group of patients who had refused to be tested.
8 A. Yes.
9 THE CHAIRMAN: They hadn't been informed and therefore they
10 didn't come to you at all?
11 A. That's right.
12 THE CHAIRMAN: Are those the two cohorts in effect that
13 existed?
14 A. Yes.
15 THE CHAIRMAN: Did any of the second group of people come to
16 get your help after that or, so far as you know, did
17 they all resist being tested indefinitely, as it were?
18 A. No, some of them certainly were tested and I saw
19 certainly one individual, but not until about the year
20 2000, I think. So it was much -- it was quite a long
21 time after he had been told that he had HIV before I saw
22 him.
23 THE CHAIRMAN: So people did move from the second cohort to
24 the first in time?
25 A. Yes.

1 THE CHAIRMAN: So far as you understand it, was there anyone
2 left out, even at the end of the day, as it were,
3 someone who died without ever coming to you for help?
4 A. There were certainly people who would have died without
5 coming to me for help because some people didn't want to
6 see a psychologist at all.
7 THE CHAIRMAN: I was about to say I understand that but
8 I understand the notion of people not wanting to see
9 you. What I would like to ask you about against that
10 sort of background is what you may have done when you
11 began to take a practical interest in the first group of
12 people, the people who knew about their infection.
13 At that stage we would understand that testing was
14 taking place at the point of collection of blood for the
15 antibodies to the virus. Did you investigate whether
16 there was any protocol for pre-test counselling at the
17 time you joined the service?
18 A. Well, my belief is that the document that was shown
19 earlier was in existence before I went to the unit. So
20 they had obviously given it much thought.
21 THE CHAIRMAN: So you weren't able to tell us, I think, so
22 far, when you may have come across that document first.
23 A. I don't remember.
24 THE CHAIRMAN: No. You don't remember seeing it as part of
25 the sort of general documentation that would have been

1 available when you arrived on site, as it were?
2 A. I could only speculate that it was probably given to me
3 quite early after I arrived as part of the discussions
4 about what is to be done about testing people.
5 THE CHAIRMAN: It really is perhaps going on to that second
6 aspect that I am more interested in because, as
7 I understand it, you would not have considered the
8 document to provide quite the right protocol for dealing
9 with people generally because it didn't contain some
10 things you would have wanted in it.
11 A. It covers the majority of the issues but in a rather
12 sketchy fashion, I felt. There were a couple of other
13 things that I would probably have put in it to do with
14 who is the person going to tell if they are given an HIV
15 positive diagnosis. And that was missing from it.
16 THE CHAIRMAN: Could we move on to that a little? Did you
17 have a role or was it accepted that you had a role in
18 advising on the discussions that ought to take place as
19 part of pre-test counselling, at or about the time of
20 your arrival?
21 A. I think we would have discussed that at some of the
22 weekly meetings or fortnightly meetings, I'm not quite
23 sure which.
24 THE CHAIRMAN: Well, they are frequent anyway. Who would be
25 at those meetings?

1 A. Myself, initially Dr George Masterton and the consultant
2 psychiatrist and psychological medicine, certainly
3 Professor Ludlam, one or two of the more junior doctors,
4 the staff doctors and certainly one or both of the
5 nurses that worked in the unit at the time.
6 THE CHAIRMAN: So quite a wide-ranging group?
7 A. Yes.
8 THE CHAIRMAN: Was there open discussion of the requirements
9 for proper counselling of people pre-test in your view?
10 A. I can't remember that.
11 THE CHAIRMAN: You can't remember?
12 A. I would imagine that there was because there wasn't
13 a meeting that went by without us discussing HIV in some
14 form.
15 THE CHAIRMAN: In that context was the question ever raised
16 whether there was a need to counsel those who had been
17 tested but, because they had not been retested, didn't
18 know of their infection? Is that sensible enough too?
19 Your second cohort?
20 A. The second cohort. Oh, there was certainly much
21 discussion about those who were refusing to have a test
22 or said they didn't want to have a test, when it was
23 known that they were infected.
24 THE CHAIRMAN: What was the thrust of that discussion?
25 A. I think in the end we always came to the conclusion that

1 it was not ethical to tell them that they were infected,
2 when they had not agreed to a test originally. So
3 I think the thrust was always that we would continue to
4 try and persuade those -- well, all the people who had
5 been at risk of HIV, whether they were haemophiliacs or
6 other patients, that we would continue to make efforts
7 without badgering them, to say that, "It's a good idea
8 for you to be tested".
9 THE CHAIRMAN: As a simple matter of logic, I find
10 a difficulty with that, unless it's implicit in it that
11 it was unethical to have tested them in the first place.
12 A. I think that -- I would absolutely agree with that. If
13 then was now -- that would never be passed by an ethics
14 committee now in my view, but I'm not at all sure that
15 the ethical views at that time, when you consider some
16 of the things that happened since then in ethics -- that
17 it would have been viewed as that then.
18 THE CHAIRMAN: Dr Richardson, I must press you a little
19 because what we are talking about discussions that you
20 took part in shortly after and continuously after you
21 arrived in 1987, and whatever may have changed in the
22 interval, the fundamental rules of formal logic haven't.
23 So could I press you on the matter? Once you were
24 discussing the ethical implications of disclosure, was
25 it not appreciated that it necessarily followed that

1 there were ethical implications of having taken the
2 test?
3 A. I don't recall that ever being discussed. I understand
4 exactly what you mean but it was a bit late by then.
5 What I would like to know is whether -- if I'm right in
6 supposing that patients who were asked for blanket
7 permission to use their blood for research purpose,
8 whether that had been through an ethics committee at the
9 time and whether an ethics committee at the time would
10 have passed it.
11 THE CHAIRMAN: I think that I know enough about current
12 ethics practice outwith this Inquiry to know that
13 certainly testing would be subjected to fairly rigorous
14 examination now by an appropriate ethics committee, but
15 I don't know that I have information about the practice
16 at the time that would help.
17 Can I come back to something that I mentioned just
18 briefly? When you arrived, I imagine you took a close
19 interest in what was going on in the way of testing and
20 how patients were approached. It seems to me to be
21 central to your interest?
22 A. Certainly, but that would be more relevant in the other
23 departments that I worked in because most of the testing
24 in the haemophilia unit had been done, and you know, in
25 GUM at the City Hospital there were new patients

1 arriving all the time that needed to be tested.

2 THE CHAIRMAN: I think the generality would help me at the
3 moment, not limiting it to haemophilia patients. If we
4 look at the practice in the GUM and infectious diseases
5 unit, what was the protocol or what were the protocols
6 for informing people pre-test there, at the beginning of
7 your period?

8 A. At the City Hospital there was a dedicated counselling
9 clinic and they carried out most of the testing, and
10 they took confidentiality extremely seriously and were
11 reluctant even to talk to people in the team about who
12 was coming for testing, let alone anyone outside that.

13 It was a bit more relaxed at genitourinary medicine
14 but most of the testing there was carried out by
15 dedicated health advisers whose main job was to discuss
16 tests, whether that was of HIV or other sexually
17 transmitted infections, with the patients.

18 Sometimes the doctors would carry out the testing
19 themselves for a variety of reasons: if they had
20 somebody in front of them and thought they were at
21 higher risk. And the doctors, I have to say, were
22 somewhat less rigorous in the way that they did the
23 pre-test counselling than the dedicated nurses.

24 THE CHAIRMAN: Yes. The following of protocols will be
25 something that would be imposed to the nurses, I take

1 it?

2 A. Exactly.

3 THE CHAIRMAN: But doctors would consider that a bit of

4 clinical independence gave them freedom to adapt to the

5 circumstances?

6 A. Exactly.

7 THE CHAIRMAN: If we tried to pin down the sort of critical

8 points in pre-testing counselling at that stage, what

9 would they have been?

10 A. Pre-test counselling would have involved, first of all,

11 establishing what kind of risk the person might have

12 been at because clearly many people came for testing who

13 had been at virtually no risk at all but were

14 particularly anxious about it and, as a psychologist

15 I would see those people too, to try and treat that

16 condition, the AIDS-phobia that I mentioned earlier.

17 So an assessment of risk, an assessment of how the

18 person might be able to cope with it emotionally.

19 Because certainly I can remember -- although I didn't

20 carry out much testing, I remember advising more than

21 one person that this was not a good time for them to

22 have a test, that it might be better to treat their

23 clinical depression first before them having a test.

24 Because some people did have catastrophic reactions and

25 tried to commit suicide after they had a positive test.

1 So a discussion of who the person might tell if the
2 test came back positive, the basics that are in the
3 haemophilia pre-test counselling document about the
4 difficulty of getting mortgages, about not being able to
5 get insurance, about not being able to travel to certain
6 countries, and that had to be updated all the time
7 because it kept on changing. Precautions to take, all
8 the things that were covered in post-test counselling
9 were covered in pre-test counselling.
10 THE CHAIRMAN: They were anticipated in some way as things
11 that might have to be developed, should it be positive?
12 A. Yes, and then you would do it all again if the test came
13 back positive and you would do it again and again,
14 because people in that kind of state of shock don't take
15 in everything that you are saying, so generally we would
16 bring back people very quickly in order to go over it
17 all again and to make sure they were okay.
18 THE CHAIRMAN: Could I just pick up something that you have
19 said, that people in a state of shock just don't take it
20 in. Is that a general characteristic that you find in
21 your practice in dealing with people that have to be
22 given quite serious news about their health status and
23 possible defects in the lives that they are going to
24 lead thereafter?
25 A. Very much so.

1 THE CHAIRMAN: I, as you can imagine, am confronted quite
2 often by people who say they just don't remember what
3 happened on that occasion. Would that be a natural
4 human response to the stress of the moment?
5 A. I'm sure that when I was being taught these kind of
6 communication skills -- and we teach it to a lot of the
7 doctors or we did teach it to a lot of the doctors --
8 I think I was told that nobody will take in more than
9 three things if they are being told that piece of bad
10 news.
11 THE CHAIRMAN: If the piece of bad news is very bad news,
12 that might limit the capacity further?
13 A. I suspect that would limit it to the one thing: the
14 piece of bad news.
15 THE CHAIRMAN: I think Professor James would like to ask you
16 a question.
17 PROFESSOR JAMES: Can I ask you two very brief things?
18 Do you know whether, when routine testing started at
19 the GUM clinic and at the infectious diseases clinic,
20 that protocols for pre-test counselling or discussion
21 actually were thought through and started from the
22 outset, or do you believe that the first tests there in
23 those two settings were also done without a great deal
24 of thought as to the outcome?
25 A. I suspect that it will have started in a fairly

1 haphazard fashion once the tests became available, but
2 very, very quickly -- for instance, at the City Hospital
3 the counselling clinic was funded very quickly by a
4 Scottish Office grant in 19 -- I can't remember,
5 1985/1986 maybe. So they were very well aware of the
6 need to do that, but before they had the money for
7 dedicated nurses, it would mainly have been done by
8 nurses and doctors who had not much, if any, training in
9 the topic of HIV.
10 PROFESSOR JAMES: Do you think that anybody had tests done
11 in those clinics at the very outset who was not told
12 that they were having that test?
13 A. No.
14 PROFESSOR JAMES: The second question very briefly is this:
15 do you think, bearing in mind everything you have said,
16 that if you are in a position where you know an
17 individual is HIV positive but that individual doesn't
18 know and you are "very keen for them to have a test",
19 that you are actually able to give a balanced
20 counselling to that individual as to the pluses and
21 minuses of what they might find from the result of the
22 test?
23 A. Yes, I think so because pre-test and post-test
24 counselling was a very hot topic at that time and
25 whoever was doing that would be even more careful, if

1 anything, to make sure that it was a balanced argument.
2 PROFESSOR JAMES: Thank you.
3 THE CHAIRMAN: Mr Di Rollo, I have taken over, rather, to
4 get answers to these matters but you may wish to come
5 back to some of them or go on.
6 MR DI ROLLO: I think you have dealt with one matter which
7 I was trying to get to but not quite succeeding,
8 I think. So I'm grateful to you, sir, for that.
9 One matter I would like to just ask you about -- and
10 it's really just to come back to some of the points that
11 have been raised -- is, if we are looking at the
12 situation -- obviously you were two or three years down
13 the line from the meeting in 1984, dealing with a number
14 of the patients -- what I think I was trying to ask you
15 about was what your understanding was as to why the
16 patients couldn't just simply be told what the outcome
17 was of the tests upon them.
18 A. I think the best answer I can give is about one of the
19 drug users that I saw who clearly didn't want the
20 test -- or in fact many of the gay men who actually
21 don't want the test. I think there are huge dilemmas
22 around this because you want to tell people that they
23 are positive, so that they can change their lifestyle,
24 change their sexual behaviour, use protection,
25 et cetera, and if people don't want to make that change,

1 they may be perfectly -- well, not perfectly well aware,
2 but they may have a very high level of suspicion
3 themselves that they are infected but they will not take
4 the test because they know that they will then come
5 under pressure to change their behaviour, and some
6 patients would just be in denial about what they are
7 doing.
8 Q. That's a bit different from a situation where somebody
9 has been infected with blood products, though, isn't it?
10 The situation with the haemophiliacs is that they have
11 been receiving blood products and have been infected as
12 a result of that route. We are not dealing with
13 changing behaviour or changing the lifestyle from that
14 point of view, but we are dealing with a different
15 situation, also with a situation where they would
16 presumably be in a situation where it has not been as
17 a result of choices that they have made that they have
18 got into that situation.
19 A. Yes, but I can envisage a similar situation where, let's
20 say, the haemophiliacs are being constantly counselled
21 about taking the HIV test, so that every clinic
22 appointment they come to somebody mentions having an HIV
23 test. It's still perfectly feasible that they would not
24 want to know the result of an HIV test. They might well
25 suspect that this meant they had HIV infection, but

1 didn't want to know. I can think of one patient, one
2 haemophiliac, in particular who I think was in exactly
3 that position.
4 Q. The problem, I think, appears to be that a number of
5 patients were in a situation where they didn't get the
6 counselling whether to have the test or not and weren't
7 aware of the fact they were actually infected with HIV,
8 and that's the practical situation.
9 A. They won't have known that, no.
10 Q. Yes. I think in paragraph 7 of your statement, if you
11 just go over the page, please -- it's the next page:
12 "Once I started ..."
13 I'm just reading your statement. This is the
14 second line down:
15 "Once I started working with the haemophilia unit,
16 I repeatedly heard the mantra that Scotland was
17 self-sufficient in blood products. I surmised from the
18 subsequent events that Dr Ludlam must have sent the
19 samples with the ability to identify the samples to
20 individuals."
21 Can I just ask you why you surmise that from
22 subsequent events?
23 A. Because if they hadn't been sent with identifiers, he
24 might have known that 30 haemophiliacs from his unit
25 were infected but he wouldn't have known which 30.

1 Q. If we go to paragraph 9, it says:

2 "I think that a GP with a drug-using population had
3 done the same thing as Dr Ludlam, ie sent some samples
4 to the haematologist in Middlesex to be tested for HIV.
5 I think this was done at the same time as Dr Ludlam sent
6 his samples in 1985."

7 Can I ask you: how do you know about the GP sending
8 samples to Middlesex at the same time?

9 A. I don't know. As I say there, that's entirely guesswork
10 because I can't think how a GP otherwise would know that
11 some of his patients were infected when the patients
12 didn't know themselves, and there was a great deal of
13 research being done on Hepatitis B at the time in that
14 part of the city.

15 Q. I would take it then that the reason that samples are
16 sent for testing is for research purposes rather than
17 for clinical reasons?

18 A. The blood would be taken for clinical reasons and,
19 generally speaking, I would expect that whoever was
20 taking the blood would ask for permission for blood to
21 be used for other purposes. I mean, to this day in
22 antenatal clinics people are routinely asked if it's all
23 right to take some of their blood for syphilis.

24 Q. Are we to take it then it's taken for clinical purposes
25 but used for research purposes? Is that what it amounts

1 to?

2 A. That is what I'm guessing, yes.

3 Q. You don't know whether consent was obtained or not?

4 A. No.

5 Q. But you are rather assuming that consent would be

6 required for taking of the blood and then using it for

7 research purposes, that some sort of consent would be

8 required for that?

9 A. I can't say for sure back in the mid 1980s. It

10 certainly would be now and I imagine it was in a far

11 more general sense back then.

12 Q. Well, obviously, that's what someone who -- you are not

13 here to tell us about medical ethics. I don't think

14 it's fair to ask you about those particular matters

15 perhaps, but your understanding would be that you would

16 expect that some sort of consent would be required. Is

17 that correct?

18 A. I would have thought so.

19 Q. And that expectation applies to both then and now?

20 A. Other than that I think it will have been much less

21 rigorous then than it is now.

22 Q. It's certainly written down now. It may not have been

23 written down then. Is that correct?

24 A. I couldn't speculate on that.

25 Q. Right. Do you know to what extent the people you saw

1 were aware that they were infected with non-A non-B
2 hepatitis?
3 A. I think I say somewhere in the statement that I don't
4 remember much discussion about non-A non-B hepatitis
5 because HIV was such a huge thing. I think my vague
6 recollection is that they knew about non-A non-B and
7 that they might well have it but it wasn't something
8 that they, or certainly that I, thought of as being
9 particularly dangerous back then, because, of course,
10 the organism hadn't been identified in the time when it
11 was called non-A non-B.
12 Q. Thank you, sir, I have no further questions.
13 THE CHAIRMAN: Mr Anderson?
14 MR ANDERSON: I have no questions, thank you, sir.
15 THE CHAIRMAN: Mr Sheldon?
16 MR SHELDON: No questions, sir, thank you.
17 THE CHAIRMAN: Is there anything arising out of that that
18 you would like to follow up in any way?
19 MS PATRICK: No.
20 THE CHAIRMAN: Dr Richardson, thank you very much.
21 MS PATRICK: Sir, that's the final witness for this
22 afternoon.
23 THE CHAIRMAN: So we will adjourn now until tomorrow.
24 (3.14 pm)
25 (The Inquiry adjourned until 9.30 am the following day)

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