

Thursday, 16 June 2011

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(9.30 am)

MR GARDINER: We have Geraldine Brown here this morning,
sir.

THE CHAIRMAN: I understand you wish to affirm.

GERALDINE BROWN (affirmed)

Questions by MR GARDINER

MR GARDINER: Good morning, Mrs Brown.

A. Good morning.

Q. Good morning. I think you have provided us with
a statement about your evidence, which is [\[PEN0120401\]](#).

A. Yes.

Q. I think you have a copy of that in front of you. Is
that right?

A. Yes.

Q. I don't think we have a CV for you, Mrs Brown, but
perhaps you could tell us about your experience and
qualifications, please?

A. Yes. I have actually written at the start of my
statement a brief description --

Q. That's paragraph 2, I think, is it?

A. Yes. In terms of my academic qualifications, I did
a history degree at Edinburgh University and immediately
followed it with a diploma in social administration,
followed by a year's work in a community based social

1 work team. I then returned to the university and did
2 a diploma in social work, which gave me a professional
3 qualification to practise. After a gap, I started work,
4 initially part-time, in a community-based team doing
5 a range of social work tasks. After I think, about two
6 years, I moved to work in the Royal Infirmary, again
7 part-time, doing a range of hospital social work tasks.

8 In 1984 -- at the end of 1984 --

9 Q. Before we get on to that, could you describe the kind of
10 tasks that you were doing during this period, the social
11 work tasks?

12 A. In the community the work was mainly in relation to
13 children and families, to supporting families and
14 ensuring children's safety. That was the main focus of
15 it, although I did some work with older people as well.

16 In the hospital I started working initially in
17 the -- what was the geriatric unit at that time, working
18 with elderly people, supporting them, supporting
19 families, organising care, organising nursing homes.
20 I had no specific experience of working with haemophilia
21 or with disabled people until I moved to the
22 haemophilia centre.

23 Q. Yes. You mention a diploma in social work and the
24 associated professional qualification. What's the
25 associated professional qualification?

1 A. Well, the diploma is the academic qualification, which
2 at that time was recognised by the body which awarded
3 the professional qualification. So it was a recognised
4 qualification by -- I think it was recognised by CCETSW
5 as a professional qualification in social work.

6 Q. What's that qualification?

7 A. The Central Council for Education and Training in Social
8 Work. I'm sure it doesn't exist any more but that was
9 in 1971, I think, 1972, but I don't think it exists any
10 more.

11 Q. Yes, thank you. Before you started working with people
12 with haemophilia, did you have any experience of
13 counselling?

14 A. Yes, counselling would be part of the social work task
15 at that time. I think the social work job has changed
16 very much since then. Social work is now, I think,
17 a much more -- in place to assess -- to offer
18 assessments, particularly to assess people for services
19 but at that time there was a strong element of
20 counselling in the role, and certainly there was in my
21 training, an emphasis on establishing relationships and
22 working with people on their feelings, ensuring that
23 they looked at their problems in a helpful way. That
24 was part of what I did.

25 Q. Is that what you would understand by "counselling"?

1 A. Well, I think counselling -- there will be many
2 definitions of "counselling" and certainly in the
3 context of HIV there is a large element of
4 information-giving, I think, as part of the counselling
5 process but, yes, that's substantially what I would
6 understand.

7 Q. Yes, thank you. I think you were going on to tell us
8 about the work that you started in about December 1984.
9 So could you carry on telling us about that?

10 A. Yes, I was asked -- what happened in the hospital is
11 that people tended to move around between units. They
12 became interested in a certain area and might work there
13 and move on and I was asked if I would be interested in
14 moving to work in haemophilia. The social worker who
15 had been working there was leaving, and someone was
16 required to fill that space.

17 There had been a limited amount of time allocated to
18 social work at that time. It was only about nine hours
19 a week. So that would be a quarter of someone's job.
20 At the time I started that had been renegotiated to
21 18 hours, which would be half of a social work job and
22 although -- I don't think I have said it in my
23 statement. I think there was some further increase in
24 time a little later. I'm a bit fuzzy about that but
25 there was an extra few hours added on to that 18 hours,

1 really to meet the need as things progressed.

2 Q. So initially you were being asked to fulfil a position
3 that was becoming vacant?

4 A. Yes.

5 Q. Who asked you?

6 A. The social work manager at that time.

7 Q. Could you just tell us what happened next?

8 A. What happened next? Well, I spoke to the colleague who
9 had been working in haemophilia about what the job
10 entailed and also to another colleague who had
11 previously had some -- done some work in the
12 haemophilia centre. So I got some information from my
13 colleagues about the sort of problems that haemophiliacs
14 were facing. This all pre-dated HIV and AIDS. So the
15 emphasis was really on the problems of having a chronic
16 illness and the associated physical disability, the
17 implications for finance, employment, education, family
18 implications. So that was the kind of -- the kind of
19 standard work that had been done with haemophiliacs
20 until HIV and AIDS appeared.

21 My understanding when I started work was that there
22 would be considerable extra work because of the
23 infection of a group of people with HIV and that the
24 extra hours were to accommodate that.

25 Q. Would you be able to say when you were having these

1 preliminary discussions with colleagues?

2 A. In the period -- I think in the period
3 around December 1984. November/December 1984.

4 Q. It might have been November?

5 A. I can't remember exactly when I was asked to do this.
6 I think it probably -- most likely was November, yes.

7 Q. November?

8 A. Hm-mm.

9 Q. How did you find out about the specifics of the job that
10 you were going to be asked to do?

11 A. By speaking to Dr Ludlam, who told me what the situation
12 was then, the understanding of the situation then.

13 Q. What date would that have been approximately?

14 A. That would have been around December 1984, just at the
15 time I -- prior to the meeting that was called
16 in December 1984.

17 Q. Yes.

18 A. At some point prior to that.

19 Q. Just taking your time and doing the best you can, how
20 much before the meeting do you think it was that you
21 first saw Dr Ludlam?

22 A. I would say at least a month.

23 Q. So it's at the end of November/beginning of December?

24 A. Yes, probably.

25 Q. I'm sorry, I interrupted you. What did Dr Ludlam tell

1 you about the position?

2 A. He told me that a group of patients had tested positive
3 for exposure to HIV, that -- I suppose the significance
4 of this, the medical significance of this, was not
5 entirely clear to people at that point. There was
6 obviously some information about HIV infection, about
7 the numbers of people who might go on to progress to
8 AIDS. But I think the emphasis was that there wasn't an
9 awful lot -- there were a lot of uncertainties about
10 what the significance of this was.

11 That the patients had been infected by blood
12 products, Factor VIII blood products, that -- there was
13 an issue about whether it was useful for them to know
14 their HIV status at this point, partly because there
15 were uncertainties about stigmatisation, about being
16 disadvantaged financially and in terms of their
17 day-to-day living. The feeling was that the best way
18 forward was for people to be treating themselves -- all
19 haemophiliacs to be treating themselves as infected in
20 terms of possible transmission.

21 Q. Sorry to interrupt you there, but what you are telling
22 us at the moment, does this all come from your first
23 meeting with Dr Ludlam?

24 A. It comes from my contact with him prior to the meeting
25 in December. I'm not sure if we had one meeting.

1 I can't remember that sort of detail but my feeling is
2 that in December 1984 I had a pretty good idea of what
3 the problem was and what I was going to be needing to
4 do. There was also a lot of discussion in the press,
5 I think, at that point.

6 Q. Yes. So you told us there that you had been told that
7 a group of patients had been infected?

8 A. Yes.

9 Q. Were you told how many?

10 A. I'm not sure if I was told how many at that point.
11 I was told that it was not a large group in relation to
12 the patient group. I was told that there were fewer
13 comparatively infected in Edinburgh, certainly than in
14 some of the haemophilia centres in England. But I was
15 at some point in the -- pretty quickly made aware of how
16 many people were infected.

17 Q. Apart from the things that you have mentioned as being
18 the issues which Dr Ludlam told you were important
19 before the December meeting, is there anything else?

20 A. Anything else -- in terms of who I spoke to?

21 Q. No, anything else in terms of the issues.

22 A. Oh, the issues. I think there was a great deal of
23 emphasis on confidentiality. That was a major issue
24 because there was a real concern that people who were
25 infected would be seriously stigmatised by this

1 knowledge. So there was a great feeling that things
2 needed to be contained.

3 Q. Thank you. Would you be able to say how many meetings
4 you had with Dr Ludlam between the first meeting and the
5 public meeting, the December public meeting?

6 A. I wouldn't be able to say. We had, I would say, pretty
7 frequent contact, telephone contact, as well, because we
8 were working in the same building. So we had telephone
9 contact and regular contact, I would say. He took
10 plenty of time to talk to me about what was happening.
11 He did make great efforts to prepare me for what I had
12 to do.

13 Q. Yes. What were those preparations?

14 A. Well, some of what I have described already but also
15 discussion of the kind of -- the haemophilia network,
16 I suppose, the national haemophilia network, in terms of
17 the specialist group for haemophilia social workers,
18 which had been in existence for some time. I'm pretty
19 sure he told me who the contact people were. The
20 Haemophilia Society and the importance of the
21 Haemophilia Society to patients in terms of information
22 and support; the sort of network of people that I got to
23 know as I began to work in fact.

24 Q. Yes. So Dr Ludlam discussed with you a proposed meeting
25 at which patients would be invited to attend. Is that

1 right?

2 A. Yes, yes.

3 Q. What did he tell you about this proposed meeting?

4 A. My memory is he told me that the meeting had been called

5 to update patients because there had been a lot of

6 discussion in the press. Really to update patients and

7 give them as much information, clear information, as he

8 could about HIV or HTLV-III as it was described then.

9 To tell them that a group had been infected, to give

10 them preliminary advice about transmission and keeping

11 safe and really just to have a forum for discussion.

12 Q. Yes.

13 THE CHAIRMAN: Mrs Brown, could I ask you a little please

14 about contact with the Haemophilia Society and with the

15 British Association of Social Workers special interest

16 group?

17 A. Yes.

18 THE CHAIRMAN: Did you have contact with them before

19 the December meeting?

20 A. If I had contact, it would only have been to introduce

21 myself. I did not have any significant contact with

22 that group.

23 THE CHAIRMAN: You didn't collect information from them

24 prior to the December meeting?

25 A. Not prior to the December meeting, no. Very soon

1 afterwards but not prior --

2 THE CHAIRMAN: Just to find out the sequence of it.

3 A. In fact I think my job officially didn't start until the
4 beginning of the following year and the December meeting
5 was really a preliminary to my work.

6 THE CHAIRMAN: Sorry, Mr Gardiner.

7 MR GARDINER: Thank you, sir.

8 Before the meeting did you meet anybody else apart
9 from Dr Ludlam in connection with this new job?

10 A. I met the haemophilia nurse at that point, whose name
11 I can't remember. I also probably met -- I think I met
12 the nurse -- the sister who was in charge of the ward
13 where most of the haemophiliacs were if they were
14 inpatients in hospital.

15 Q. Do you remember her name?

16 A. Her name is Margaret Macsween.

17 Q. Do you remember a nurse called Mrs Philp?

18 A. I think she was -- was she -- probably the nurse who was
19 there when I started, who left shortly afterwards. I'm
20 sorry, I just can't remember her name but certainly the
21 nurse who was there when I started work was there for
22 only a short time and moved on.

23 Q. Yes. What did Dr Ludlam tell you that your role would
24 be at this meeting?

25 A. I did not have a role at the meeting. I was there

1 really just to listen and observe. I wasn't taking any
2 part in the discussion. That wasn't expected of me.

3 Q. Yes. What did you discuss about your role after the
4 meeting, if anything?

5 A. Well, my role after the meeting would be -- the job
6 I was going to do would be partly the traditional
7 support of haemophiliacs and their families and partly
8 looking, with people who had been infected, at issues
9 they were facing at that time in terms of information,
10 family situations, financial situations, general
11 support, issues of bereavement and loss. All of these
12 things that people would be facing.

13 Q. Yes. Could we call that "counselling"?

14 A. Counselling would be part of that, yes.

15 Q. Thank you. To your memory, Mrs Brown, how was it
16 proposed that the patients were to hear of this meeting?

17 A. I don't think I know that. I don't think -- I don't
18 know if I was told. I would assume they would be told
19 by letter but I couldn't say clearly.

20 Q. You don't have any personal knowledge of that?

21 A. No, no.

22 Q. Thank you. Well, perhaps we could come to the specifics
23 of the meeting now as best you remember.

24 First of all, do you have a date for the meeting to
25 the best of your recollection?

1 A. I think it was -- it was late December but I haven't got
2 a date, no. Just before the Christmas break, I think.

3 Q. We have some documents which help with the date and I'll
4 just show you one, if you don't mind. Could we look at
5 [\[SGH0026498\]](#). This is a document that we have recovered
6 from Scottish Government files. If you see the top
7 left-hand corner:

8 "PS/Mr Mackay."

9 That is, we understand, the private secretary to
10 John MacKay, health minister at the time. You will see
11 the heading is "AIDS". This is from Mr Davies, you see
12 there at the bottom, and it's dated 19 December 1984.
13 We understand that Mr Davies was a civil servant,
14 drafting a minute to the minister:

15 "I refer to your minute of 12 December. A meeting
16 of Scottish haemophiliac patients is being held this
17 evening, at which the position is to be explained to
18 them. We now understand that 15, not as hitherto
19 thought, 16 patients treated with Scottish produced
20 Factor VIII have antibodies to HTLV-III.

21 "The Yorkshire Post article is expected tomorrow. A
22 copy of a draft Press Release, agreed with medical
23 interests and SIO, is attached. SIO intend to issue it
24 at noon tomorrow."

25 So would you agree with us that it looks as though

1 the meeting was on 19 December?

2 A. Yes, I would say that would be correct.

3 Q. Thank you. You see reference there to a Yorkshire Post
4 article. Before the meeting, did you have any knowledge
5 of press interest in this story?

6 A. It's difficult to think back. There was certainly
7 discussion in the press but I can't really specifically
8 remember -- I can't specifically remember anything in
9 relation to haemophilia and the local situation.

10 Q. Thank you. Just going back to the meeting, do you
11 remember what time of day it was?

12 A. It was in the evening.

13 Q. About what time?

14 A. About 7/7.30, that kind of time.

15 Q. Whereabouts was it held?

16 A. It was held in the Royal Infirmary, in one of the large
17 lecture theatres, which was really just almost at the
18 front entrance to the old Royal Infirmary. It was very
19 easily accessible for people.

20 Q. Yes, thank you. Would you be able to estimate how many
21 people were in the audience?

22 A. I have been asked this before. My memory of it is it
23 was quite a large meeting and I have given a figure in
24 my statement.

25 It's difficult, really, really difficult for me to

1 be precise about it. It felt like a big meeting.

2 I think it was partly because it was in a very big

3 lecture theatre. I remember I was sitting near the

4 front. The seats were ranged up behind me. I think

5 that's really all I can say about it. It felt like

6 a big meeting. Whether it was or not, I don't know.

7 I know that certainly not everyone who was invited came.

8 Q. Just to focus on how many people were there, would you

9 say more than 20?

10 A. More than 20, yes.

11 Q. More than 30?

12 A. Yes.

13 Q. More than 50?

14 A. I think I have said less than a hundred in my statement,

15 50-ish. Between 50 and 100. I really can't be more

16 precise than that.

17 Q. So sitting here this morning and trying to remember,

18 your best estimate is between 50 and 100?

19 A. Yes, maybe the lower end.

20 Q. Closer to 50, maybe?

21 A. Yes.

22 Q. Were you able to say at any point where the members of

23 the audience had come from, which part of Scotland they

24 had travelled from?

25 A. No, no. I mean, I think -- I'm assuming the patients

1 were patients from the catchment area of the Edinburgh
2 haemophilia centre, which was the East of Scotland, but
3 I don't know if it was wider than that. I can't
4 remember. And I didn't know any of the patients then.
5 I hadn't met any of them. So I didn't recognise them.
6 So, no, I don't know.

7 Q. Why did you assume that?

8 A. Why did I assume that ...?

9 Q. That they were from that catchment area?

10 A. My memory of how the haemophilia service was organised
11 was that the significant -- the major responsibility for
12 Scotland was divided east/west, between Edinburgh and
13 Glasgow. So the Glasgow centre and the Edinburgh centre
14 had wide-ranging, overall responsibility for the
15 service, although there were, in other cities and
16 towns -- there would be provision for patients. It was
17 the big centres in Edinburgh and Glasgow had the overall
18 responsibility. So I'm assuming, if it was organised
19 from Edinburgh, then it would cover their area of
20 responsibility, at least, which was the entire of the
21 East of Scotland.

22 Q. But only that area?

23 A. Well, maybe not. I don't know. I can't remember.

24 Q. Okay, thank you.

25 A. Hm-mm.

1 Q. How many other people were there, other than the
2 audience?

3 A. Dr Ludlam was there. I think there may well have been
4 Dr Forbes from Glasgow there. Other than that, I can't
5 remember. I think my difficulty is I didn't really know
6 these people then. I think a few months later, when
7 I had met many of the people concerned, I would be
8 clearer about who had been there, but I didn't know the
9 people who were involved apart from Dr Ludlam at that
10 point, and the nursing staff. And I don't know if the
11 nurse was there or not, I can't remember.

12 Q. So at least two doctors were there, perhaps more than
13 two?

14 A. Perhaps more than two, I can't really remember very
15 clearly.

16 Q. I think that Dr Forbes was there and he was from
17 Glasgow?

18 A. Yes.

19 Q. But you are not able to help us with whether any
20 patients from Glasgow were there?

21 A. No, I just can't remember.

22 Q. Thank you. Just help us with the layout: where did the
23 doctors sit?

24 A. At the front, at the point where a lecturer would sit or
25 stand, facing the audience, which was ranged behind, as

1 I remember.

2 Q. Yes. Who spoke first?

3 A. Dr Ludlam, I think, spoke first. That would be my
4 memory. He would introduce the meeting and say why it
5 had been called.

6 Q. Yes. We know it's an awful long time ago but just doing
7 the best you can at the moment, Mrs Brown, can you
8 remember what Dr Ludlam told the meeting?

9 A. Erm...

10 Q. I see you are looking at your statement?

11 A. I'm trying to concentrate. I'm not looking at my
12 statement really. It's actually quite small print.
13 It's difficult for me to say.

14 Q. Just take your time.

15 A. Yes. Just going away -- thinking about what I went
16 away -- the knowledge I went away with from the meeting,
17 I felt pretty clear about the current situation
18 affecting -- certainly affecting the patients in
19 Edinburgh. So the statement would be about a group of
20 patients having been infected, that this was discovered
21 by testing their blood because a test had become
22 available to identify antibodies to the virus, that
23 medical knowledge was more limited and uncertain perhaps
24 than they would like but that it was developing, and
25 more information was becoming available and more

1 research was being done; that it wasn't clear if the
2 people infected would go on to develop AIDS. It wasn't
3 clear what the prognosis would be, it wasn't clear what
4 the timescales would be for any progress of the disease.
5 That people could have -- the patients who were infected
6 could have that information, if they wished to have it.
7 That he was open to seeing patients to discuss that with
8 them, that all patients should consider themselves --
9 should treat themselves as infected, that they should
10 all behave as though they had been infected with the
11 virus in terms of keeping themselves safe, keeping their
12 family safe. That there would be more detailed
13 information, written information, sent out very soon
14 from the haemophilia centre, really just putting on
15 paper the current information and knowledge about HIV.

16 Q. Yes. The first thing you said there was that Dr Ludlam
17 told the meeting that a group had been infected. Was he
18 more detailed than that? Which group?

19 A. He was talking about the Edinburgh group, I suppose.
20 The people who had been infected in Edinburgh. He was
21 no more specific about it than that.

22 Q. So am I right in thinking what you are telling us is
23 that he said that some patients from the Edinburgh
24 centre had been infected?

25 A. Hm-mm.

1 Q. You also said that Dr Ludlam told the meeting that
2 people could have more information --

3 A. Hm-mm.

4 Q. -- about testing, if they wanted?

5 A. Hm-mm.

6 Q. Did he explain how they would get that information?

7 A. By contacting him. He would be the person to discuss
8 that with them.

9 THE CHAIRMAN: Could I follow this just a little?

10 Mrs Brown, it could be very important to know just
11 exactly how this was put. For example, if there were
12 people there from the Glasgow sphere of influence,
13 a statement by Dr Ludlam that people in his group were
14 infected might be interpreted as distinguishing his
15 group from the rest of Scotland.

16 So knowing whether Dr Ludlam did say, "It's people
17 under my care, people in my group have been infected,"
18 could be quite important. I would like you to think
19 very carefully what was said, if you can, and it's
20 extremely difficult.

21 A. Yes, my memories of it -- and maybe it's because that's
22 where I worked and that's where I got to know
23 patients -- this was about the Edinburgh group but that
24 may not be an accurate -- that might be a retrospective
25 thing. It may have been more complex than I'm

1 remembering it, is what I'm saying. But I'm quite clear
2 that patients, Edinburgh patients, would know how to get
3 that information.

4 THE CHAIRMAN: That's a secondary point.

5 A. I can't remember the complexity of it.

6 THE CHAIRMAN: What I think I have to be conscious of is
7 that you attended that meeting with a very particular
8 focus on the work you were going to be doing, which was
9 Edinburgh-related, and I can understand you coming away
10 from the meeting knowing that patients you would have to
11 deal with included people who were infected. But it's
12 the prior stage as to the information communicated and
13 which you arrived at at that stage that interests me at
14 the moment.

15 A. I don't think I can be more specific than I have been.

16 THE CHAIRMAN: You can't be more specific?

17 A. No.

18 MR GARDINER: Thank you, sir.

19 Just to help us evaluate your evidence, Mrs Brown,
20 because we are all trying to work out what happened so
21 long ago, can you tell us if you have discussed recently
22 with anybody else your recollection of these events?

23 A. With the Counsel for the Inquiry and for the health
24 service -- the health service legal Counsel, yes. But
25 no one else.

1 Q. No one else?

2 A. No one else.

3 Q. Thank you. You told us that you had discussions with
4 Dr Ludlam at that time before the meeting?

5 A. Hm-mm.

6 Q. When he outlined things that he thought were important
7 to discuss at the meeting, and you have just told us
8 your recollection of the knowledge that you had after
9 the meeting, having been at the meeting. How clear are
10 you that what you have just told us is what was said at
11 that meeting? What I'm trying to suggest is there any
12 chance that --

13 A. That information I got later has --

14 Q. Actually, I'm thinking of information that you received
15 before the meeting, which helped you understand what was
16 being said at the meeting. Just take a moment and think
17 about that. (Pause)

18 A. My -- my feeling is that it was clearly explained at the
19 meeting.

20 Q. Thank you. Is that all that Dr Ludlam said, to the best
21 of your recollection; those things that you have just
22 described?

23 A. Yes, these were the significant things, yes.

24 Q. Do you remember if any other doctors spoke to the
25 meeting?

1 A. I can't remember. I just can't remember.

2 Q. Thank you. After the doctors had stopped speaking to
3 the meeting, were any questions asked by the audience?

4 A. There was some discussion, yes. I can't remember the
5 details or the nature of it but there was some
6 discussion.

7 Q. Can you remember any of the topics that were raised by
8 the audience?

9 A. No, not specifically. There was a lot of dismay and
10 anger about the situation generally, I think, and people
11 feeling under great pressure, but I can't remember the
12 detail of the discussion.

13 Q. So your recollection is that there was dismay expressed
14 by members of the audience?

15 A. Hm-mm.

16 Q. So how was that done? Was that simply a statement to
17 the meeting that they were --

18 A. Erm, I suppose -- more the general tone, the feeling
19 around the place, the way -- body language, the way
20 people were talking to one another, and the tone of
21 maybe any comments that were made indicated that people
22 were under great pressure. It was very difficult for
23 them.

24 Q. Yes. You said "anger" as well. Could you expand on
25 that?

1 A. Well, I think in general people were angry that the
2 treatment that they had relied upon to make them better
3 and had made a great difference to their lives had
4 become a source of infection. It was something that was
5 very significant infection in fact. And a feeling that,
6 "Well, something should have been done to stop this,"
7 the feeling of, "Someone is responsible for this". That
8 would be an understandable reaction in the
9 circumstances.

10 Q. Yes. Is it your recollection that statements made by
11 members of the audience at the meeting expressed the
12 anger that you have just discussed?

13 A. Yes, yes, I would say that that was the feeling, the
14 general feeling.

15 Q. Thank you. Are you able to tell us how long you think
16 the meeting lasted?

17 A. It's really very difficult for me. It is such a long
18 time ago. An hour/an hour and a half, that kind of time
19 maybe. I remember that there was a problem with the --
20 it was a very cold night and that there was some problem
21 with the heating and it was belching out -- it was
22 throwing out cold air rather than hot air. So it was
23 physically very uncomfortable to be there. I remember
24 that quite clearly.

25 Q. Do you think that that made a difference to how long the

1 meeting lasted?

2 A. I remember there was a bit of coming and going to try to
3 get the heating sorted out and I suppose people wouldn't
4 want to linger too long because it wasn't very
5 comfortable.

6 THE CHAIRMAN: Mrs Brown, if the meeting lasted an hour to
7 an hour and a half, communication of the basic
8 information by Dr Ludlam might have taken a relatively
9 small proportion of that total time, the introduction,
10 as it were; and that could suggest that there had to
11 have been quite a lot of exchanges between the audience
12 and the platform unless other doctors had spoken. Are
13 you able to give us any impression about what the
14 balance might have been? Was it a short introduction
15 followed by a fairly angry exchange, "How can this have
16 happened to us?" or were there detailed questions and
17 answers? Can you help us?

18 A. I can't, no, I just can't remember. It's almost 30
19 years ago and I don't have any written record of it.
20 I can only talk about my memory as best I can, and
21 I couldn't put figures on things when I'm not confident
22 about it.

23 THE CHAIRMAN: It's just an impression.

24 A. No.

25 THE CHAIRMAN: I think you can take it that judges are

1 accustomed to treating recollections of events of this
2 kind as flawed on a whole number of levels. So one
3 wouldn't expect very particular recollection. In fact
4 it would probably be untrue, as it were, and more likely
5 to be influenced by what others had told you later, but
6 anything you can do to help would be welcome.

7 A. I think, my memory -- there was information given, there
8 was discussion of. That's really all I can say,
9 I think. As I say, my specific memory is about the cold
10 in the room in fact. That's certainly something
11 I remember very clearly.

12 The other memory I have was of Dr Ludlam being very
13 concerned the press didn't get into this meeting, that
14 it was a private meeting for patients. And I think
15 I was asked before it started if I would kind of be on
16 the door and keep an eye open for the press -- although
17 I don't know how I was supposed to recognise them. But
18 there were no press there in fact, but I remember that
19 was a big -- you know, a big issue was to keep this
20 private. This was just for the patients and not for
21 anybody else.

22 THE CHAIRMAN: I don't think they would be carrying press
23 cards "please admit", but I have to say that to tell 50
24 people at a meeting, or 50 plus, that they weren't to
25 tell anybody about it seems rather a forlorn hope but

1 that was the idea, that it should be kept quiet.

2 A. The idea was that it was private, it was confidential
3 and there should be no members of the public, no members
4 of the press there.

5 THE CHAIRMAN: This meeting would clearly have made a very
6 big impression on the haemophilia people and their
7 families.

8 A. Yes.

9 THE CHAIRMAN: It must have made quite an impression on you
10 because you went away knowing the sort of problem that
11 you were going to have to face up to.

12 A. Yes.

13 THE CHAIRMAN: Were there particular people who expressed
14 anger about products, for example? Do you remember
15 anything like that?

16 A. Not particularly at the meeting, no. I mean, I think
17 the general feeling amongst the patients was that the
18 Scottish products had been safe but I don't remember
19 a lot of detailed discussion about that, no.

20 THE CHAIRMAN: Yes.

21 MR GARDINER: Thank you, sir.

22 The patients who attended the meeting, were they
23 told not to tell anybody about the news or was it just
24 that the meeting itself was private?

25 A. They weren't told not to tell -- I think the assumption

1 was that most people would want to be careful with this
2 information anyway. They wouldn't want to be
3 broadcasting it to the world, that a group of patients
4 had been infected with HIV, but I don't remember them
5 being instructed not to tell anyone, certainly.

6 Q. Thank you. How was the meeting brought to an end, do
7 you remember?

8 A. I don't remember the details of how it was brought to
9 the end but there will be some emphasis on Dr Ludlam
10 being available certainly, to speak to his patients
11 about their situation. There was never any doubt that
12 people would have an opportunity to come to him and
13 speak about their own status.

14 Q. At what point was that envisaged to happen?

15 A. At what point was ...?

16 Q. At what point were patients told that they could come to
17 see Dr Ludlam?

18 A. At some point during the meeting they were told that
19 they could have information about their HIV status.

20 Q. Yes, but not at the end of the meeting?

21 A. Presumably -- I'm not sure. I'm not sure. Probably not
22 at the end of the meeting, no.

23 Q. What I'm trying to get at is whether, after the meeting
24 finished, there was any other discussions: groups of
25 people, questions asked to the doctors and so on? Do

1 you have any recollection of that?

2 A. No, no.

3 Q. The meeting ended and everybody left?

4 A. Well, in the way meetings end with small groups of

5 people talking to one another for a while and then

6 melting away. I think that's quite a normal way

7 a meeting would end. They wouldn't just all go out but

8 people would speak to one another perhaps and then move

9 on.

10 Q. You don't have a recollection of patients approaching

11 the doctors?

12 A. I don't have a recollection of that but it doesn't mean

13 to say it didn't happen. I don't have a recollection of

14 it.

15 Q. Yes.

16 Sir, I'm going to move away from the meeting now.

17 Do you have any more questions about that?

18 THE CHAIRMAN: No, no, I think that that is all.

19 I understand that you want to structure this morning

20 rather differently from usual and break when it's

21 suitable?

22 MR GARDINER: Yes.

23 THE CHAIRMAN: I would be happy if you would just let me

24 know when you wanted to have --

25 MR GARDINER: Thank you, sir.

1 Could we move to after the meeting now, Mrs Brown?

2 What was your next involvement with the patients?

3 A. We had an arrangement that -- at that point there was no
4 physical haemophilia centre in the way that there is
5 now. People were seen as outpatients in the medical
6 outpatients department. They were seen on the ward if
7 they were inpatients and I think they were seen by
8 doctors, probably in their own offices or in medical
9 outpatients. So it was a kind of arrangement whereby
10 you didn't go to a physical place, which was the
11 haemophilia centre, and the patients all came in there.

12 So the arrangement we had initially was that I would
13 go to medical outpatients during the clinic, the
14 outpatient clinic, and that I would meet patients after
15 they had been seen, really just to introduce myself to
16 people and to discuss anything that they wanted to
17 discuss at that point.

18 Q. Yes.

19 A. I know that Dr Ludlam also made patients aware --
20 I don't know how he did this -- that there was a new
21 social worker attached to the unit and that I was
22 available to see people, but certainly a lot of the
23 introductions were in the medical outpatients
24 department. If there was a patient on the ward having
25 treatment, then I would go along and introduce myself

1 there. So I gradually met patients in that way.

2 Q. Yes. You told us that at the meeting you remembered

3 Dr Ludlam telling the audience that they would be

4 provided with written information subsequently?

5 A. Hm-mm.

6 Q. Do you have any personal knowledge of that taking place?

7 A. Yes. I mean, it did take place. It was sent out.

8 I see I have got a document in front of me here.

9 Q. Yes, before we come to that, could you tell us what

10 communications, to your personal knowledge, were made

11 along the lines that Dr Ludlam discussed at the meeting?

12 A. I'm not sure if I understand.

13 Q. Sorry, that's a bad question. You told us that

14 Dr Ludlam informed his patients that written information

15 would be provided to them --

16 A. Yes.

17 Q. -- after the meeting at some point?

18 A. Yes.

19 Q. I think you have just told us that to your knowledge

20 that did happen?

21 A. Yes.

22 Q. How was that done?

23 A. My memory is they were sent out -- the written

24 information was sent to patients.

25 Q. In what form was that information?

1 A. A written sheet with advice about the current scientific
2 knowledge, the risks, transmission, et cetera,
3 et cetera.

4 Q. Yes. An advice sheet, if you like?

5 A. Yes, yes.

6 Q. At what time are we talking about?

7 A. I would say the beginning of 1985. I mean, I think it
8 was fairly quickly after the end of the Christmas season
9 and the start of the New Year it went out.

10 Q. Did you see this advice sheet before it went out?

11 A. No, I don't think I saw it, no.

12 Q. Right.

13 A. I don't have any memory of seeing it before it went out.

14 Q. Just to be thorough, how do you know that it was sent,
15 Mrs Brown?

16 A. Well, I got a copy so I assume that it did exist. If
17 someone tells me something has been sent out, I accept
18 that.

19 Q. So --

20 A. I also subsequently, I think, talked to patients about
21 what was on it. That's my memory. I would speak to
22 some patients about what was on this sheet.

23 Q. Who told you that the advice had been sent out?

24 A. Dr Ludlam.

25 Q. Who gave you a copy of the advice sheet?

1 A. I think he would give me a copy.

2 Q. Yes, thank you.

3 Could we have [\[PEN0120495\]](#), please? I think you
4 have a copy in front of you. Is that right?

5 A. Yes.

6 Q. Is that the document that you are talking about?

7 A. Yes.

8 Q. Okay. Perhaps you could tell us a little bit about this
9 document. To your understanding, what was the purpose
10 of sending this document to patients?

11 A. To give them as much up-to-date information as possible
12 about the virus in general and implications for those
13 who had been infected in terms of safety.

14 Q. Yes. Let's just have a look at it. So we see that it
15 is called "Advice sheet for adult patients and
16 families". The heading is "AIDS" on the first page.
17 I see there at the bottom of the first paragraph, it
18 says:

19 "If, however, you have any major anxieties in the
20 meantime, please do not hesitate to phone your centre
21 director for a personal appointment."

22 There are numbers for Glasgow and Edinburgh there.
23 So was it your understanding that these advice sheets
24 were sent to Glasgow patients as well as Edinburgh
25 patients or ...?

1 A. I think -- yes, I think they were. I think that they
2 were the product of discussion between Dr Ludlam and
3 other doctors who were involved and that would include
4 the Glasgow haemophilia centre, yes.

5 Q. So would you be able to estimate how many patients in
6 the Edinburgh area would have been sent this advice
7 sheet?

8 A. No, I don't know the patient numbers, no.

9 Q. Thank you. But certainly, I think, you have told us
10 that in meetings that you had with patients
11 subsequently, patients referred to having received the
12 advice sheet?

13 A. Yes.

14 Q. Is that right?

15 A. Yes.

16 Q. Thank you. So if we just go through the paragraphs, we
17 see --

18 THE CHAIRMAN: I wonder if I could ask just one question.

19 Mrs Brown, I am looking at this document without any
20 background information but I would be more than a little
21 surprised if it were sent out in a plain envelope
22 without a covering letter. Did any of your patients
23 ever come to you with the complete package as it were?

24 A. No. I would assume it would be sent out with a covering
25 letter too but, no, I don't remember seeing a covering

1 letter.

2 MR GARDINER: Thank you, sir.

3 If we just go through the document, please,

4 Mrs Brown, paragraph 1:

5 "What is AIDS?"

6 Paragraph 2:

7 "Where does it come from?"

8 Paragraph 3:

9 "Who does it affect?"

10 Paragraph 4:

11 "Why does immunity alter?"

12 Then on to paragraph 5:

13 "How does AIDS affect patients?"

14 Paragraph 6:

15 "What is the virus?"

16 Then paragraph 7:

17 "What are the implications?"

18 That paragraph contains advice at (a):

19 "You should make up and handle your own bottles of

20 concentrate. Great care must be taken not to

21 contaminate work surfaces with spilled concentrate.

22 Care must be taken with used needles and syringes and

23 they must be returned in cin bins for disposal in the

24 centre."

25 So that's advice about using concentrates. (b):

1 "If anyone in the family wishes to help prepare
2 concentrates and injections they should wear gloves and
3 disposable plastic aprons."

4 (c):

5 "As sexual intercourse has been shown to be involved
6 in the spread of the disease the wearing of a condom ...
7 during intercourse. You should abstain from rectal or
8 oral sex. Also if you wish to consider having a baby
9 you should discuss this with your haemophilia director
10 in advance."

11 (d):

12 "All relatives living in the same house with the
13 family should refrain from giving blood. This is
14 a simple precaution only."

15 (e):

16 "The problem of dental care will also have to be
17 organised and further advice will be given about this."

18 And then:

19 "It is emphasised that these are only simply
20 precautions for you and your family. No changes need
21 occur in your day-to-day life with friends, neighbours
22 at school or at work."

23 Then paragraph 8:

24 "So what is being done?"

25 That's over the page. The explanation:

1 "As of now, all Factor VIII concentrate is being
2 heat-treated to destroy the virus. You will be given
3 heat-treated Factor VIII as soon as possible.

4 "In addition, the transfusion service is making
5 every effort to ensure people who have a greater than
6 average risk of exposure to AIDS do not donate and all
7 donors are required to sign that they are not in a high
8 risk group. Also we hope that in the near future it
9 will be possible to test all blood donations for the
10 presence of HTLV-III antibody."

11 And so on. Then the final paragraph, "Reassurance":

12 "We realise how worried some of you may be and this
13 is the reason that we have called a series of meetings
14 of patients and relatives. We will keep you informed of
15 all new developments. If anyone wishes a further
16 discussion, please phone your centre director for
17 a private chat. Bring your spouse if you wish.

18 "Remember that you must continue to treat yourself
19 with the concentrates as the risks are much greater of
20 bleeding than contracting the rare disease of AIDS."

21 Some of the things that are in that advice sheet are
22 in the same area as the things that you remember
23 Dr Ludlam telling the meeting about?

24 A. Hm-mm.

25 Q. But the advice sheet is quite detailed about all the

1 different topics. Is that a correct picture to have?
2 Is there more information in the advice sheet than was
3 provided at the meeting?

4 A. Probably, yes, I think. It's difficult to say but
5 probably yes.

6 Q. Thank you. One of the things that you remember
7 Dr Ludlam saying to the meeting was telling the patients
8 that if they want any more information, I think about
9 their own status, they could contact him?

10 A. Hm-mm.

11 Q. To your knowledge, did anything happen in the next month
12 after the meeting in connection with that?

13 A. I can't say if it was within the next month. I know
14 that people did make contact -- gradually begin to make
15 contact with him and discuss really whether they
16 should -- whether it was useful for them to know whether
17 they were HIV positive in the first place, but I can't
18 say if that happened within the first month or when it
19 happened, but it was a gradual process, that people
20 thought about -- obviously thought about what had been
21 said and approached him to talk about. I think he
22 was -- he was always someone who would be very available
23 to his patients. So there was never any difficulty
24 about arranging to see him. He was very available.

25 Q. How do you know that patients contacted him to have

1 those discussions? Is that from what you have been told
2 by him or by patients?

3 A. By both, I think. Patients would tell me they had seen
4 him to talk to him about it.

5 Q. So would you be able to estimate when you started to see
6 patients?

7 A. Very quickly, I think. I think within the first month
8 or two months of the year. I mean, I was back at work
9 in January and I would begin seeing patients then.

10 Q. Yes. Were you personally involved in the process of the
11 lead up to testing, organising testing, discussions
12 about whether a test should be taken or not?

13 A. No, the testing had all happened before I became
14 involved, the testing had all happened. I'm not sure
15 exactly when the tests became available but I think some
16 time in 1984, the end of 1984. I wasn't involved in
17 that.

18 Q. Were you involved in discussions about whether a patient
19 should ask for their results?

20 A. I certainly spoke to patients about that, yes. There
21 was a lot of -- it's difficult looking back on it now.
22 It was a very different atmosphere then in terms of
23 knowledge and patients were very aware that they were
24 identifiable as a group, haemophiliacs were identifiable
25 as a group, that there was public knowledge about

1 transmission of HIV and AIDS, that they were already
2 seen in the community as people who were potentially
3 infected with HIV.

4 There was concern about the fact that someone who
5 had been infected with HIV, interfering with their --
6 the provision of services to them of a variety of kinds
7 on a financial level, insurance companies' questions,
8 mortgage lenders' questions. There were concerns about
9 discrimination in terms of the provision of medical
10 services. There was concern that surgeons wouldn't
11 operate on them if they were known to be HIV. There was
12 a kind of feeling around at that time of this great
13 anxiety about what would happen if people knew you were
14 HIV positive.

15 There was also, of course, an acknowledgment that
16 there wasn't really any treatment going to be available
17 to patients. So knowing that they were HIV positive, it
18 wasn't like getting another medical diagnosis which
19 would immediately throw in a treatment programme,
20 because at that point there really wasn't anything being
21 offered in terms of treatment, although anyone who was
22 infected with HIV would benefit from being followed up
23 medically. The haemophiliacs were being followed up
24 anyway because they were being seen regularly at the
25 hospital. So people were weighing up the pros and cons

1 really of knowing that they were infected with HIV.

2 And also, I think, for some people -- I think the
3 way you deal with significant medical information about
4 yourself sometimes is you don't want to know. You might
5 just put it aside and prefer to carry on, you know, as
6 you are.

7 So people had lots of issues that they discussed
8 really prior to asking for the information.

9 Q. What time are we talking about here? You started
10 probably around about January 1985. How long did that
11 period go on for, the period of patients or some
12 patients weighing up the pros and cons, as you put it?

13 A. It's difficult for me to be really precise. It did vary
14 tremendously. Some people were keener to move on and
15 know quickly and others weren't. It's difficult for me
16 to say, to be precise about that.

17 Q. Do you remember what happened about some of these
18 patients finding out their results at the beginning of
19 the year?

20 A. What happened -- you mean how they were told or ...?

21 Q. Well, were patients told?

22 A. I think some patients were told reasonably quickly but
23 I can't tell you when, you know. I just can't remember
24 that. My memory is it was a sort of gradual process
25 that people began to approach and ask to be told.

1 Q. Yes. You would know that from discussions with whom?

2 A. Sometimes with the patients and sometimes I would be
3 told by Dr Ludlam that so and so had approached him.

4 Q. Perhaps you are referring to patients who had received
5 their results and who then had meetings with you
6 subsequently?

7 A. Yes, yes, yes.

8 Q. But you can't help us with the timing?

9 A. Not really, no, no.

10 Q. I think I'm right in saying, Mrs Brown, that at that
11 time, the beginning of 1985, some of the Edinburgh
12 patients had not been tested. Did you have any
13 discussions about the pros and cons of organising a test
14 with them?

15 A. No, no, not that I'm aware of. No, not that I remember,
16 no.

17 Q. So that would be --

18 THE CHAIRMAN: Paragraph 6 of the note tells the recipient
19 that the marker was available and:
20 "... these tests are now available and will be
21 carried out on your routine visits to your centre."
22 Does that help you remember whether people were
23 advised about testing?

24 A. No, no. I don't remember being involved in any
25 discussion about testing.

1 THE CHAIRMAN: It wasn't strictly your area --

2 A. It wasn't. Let me think ...

3 No, no, no.

4 MR GARDINER: Just a final question, sir.

5 We looked at the advice sheet, Mrs Brown. To your

6 knowledge was there any other communication with

7 patients after the December meeting? Written

8 communication I mean?

9 A. Not that I'm aware of. I know that the Haemophilia

10 Society were providing regular updates to patients and

11 I'm not sure again, about when the timescales for all of

12 that, except that was a regular thing, but I don't

13 remember anything else from the centre. I don't

14 remember seeing --

15 Q. Nothing else from the centre?

16 A. Not that I remember seeing myself, no.

17 Q. Thank you.

18 Sir, that would be a good moment.

19 THE CHAIRMAN: We will have a break at that stage.

20 (10.51 am)

21 (Short break)

22 (11.41 am)

23 THE CHAIRMAN: Yes, Mr Gardiner?

24 MR GARDINER: Thank you, sir.

25 Mrs Brown, before the break I was asking you some

1 questions about when patients received their results.
2 I think you told us that some patients were told
3 reasonably quickly and that it was a gradual process.
4 A. Yes.
5 Q. When you say "reasonably quickly", what do you mean,
6 approximately, please?
7 A. I would think that within the first three months of the
8 year people were asking -- some people were asking to be
9 told their HIV status. Within that first quarter of the
10 year I think people were beginning to ask. But I can't
11 really be more specific than that.
12 Q. What about being told?
13 A. In terms of ...?
14 Q. Being told the results.
15 A. People were beginning to ask for their results during
16 that immediate period.
17 Q. Were they being told their results?
18 A. Yes, as far as I am aware, they were being told their
19 results if they asked for them.
20 Q. So within the first quarter of 1985?
21 A. Yes.
22 Q. So when you refer to the "gradual process", that's from
23 the end of 1984, if you like, to about the middle of
24 1985?
25 A. I think around that, yes.

1 Q. So when you said the first quarter -- sorry, have I gone
2 too far?

3 A. No, I think people began within the first quarter and
4 then there was a process after that, with more people
5 asking. It's difficult to be specific about how long it
6 took in fact for everyone to ask and be told their HIV
7 status. I can't really say that.

8 Q. I understand. If you could just do your best to try to
9 remember. Are you able to say approximately how many of
10 the patients had received their results by this period,
11 the end of first quarter of 1985?

12 A. No, I couldn't say. I couldn't say that.

13 Q. By the end of 1985?

14 A. I would think that within a year most people would have
15 known, yes.

16 Q. Do you base that on your personal conversations with
17 patients after results had been given?

18 A. Yes, it would be based on my own contact with patients,
19 discussing their results really, yes.

20 Q. By the end of 1985, had everybody who had tested
21 positive received their results?

22 A. No, I don't think so. I think there were one or two
23 people who had not asked for their results. So not
24 everyone.

25 Q. Yes. When you say one or two ...?

1 A. I can think specifically of one patient who didn't have
2 his results for some considerable time after that.

3 Q. Can I just stop you there, just to insert a caveat. I'm
4 sure you know this but we are being very careful not to
5 use the names of patients.

6 A. Absolutely not, no.

7 Q. Sorry, I interrupted you.

8 A. Yes, I can think of one specific patient who didn't have
9 his results for a very long time in fact. I can't think
10 of anyone else who delayed all that long. But
11 I couldn't say that everyone apart from him had his
12 results by the end of 1985. I couldn't say that.
13 I can't specifically say that. But I do remember one
14 patient who certainly didn't have his results then.

15 Q. If we think into 1986, do you think there were any more
16 than one patient who hadn't received their results?

17 A. I think probably not. My feeling would be probably not.

18 Q. Thank you. The Inquiry heard evidence earlier this week
19 from a witness whose anonymised name has been given as
20 "Mark". Did you meet the witness, Mark?

21 A. Yes.

22 Q. Mark gave evidence to the Inquiry and what I would like
23 to do now is to give you a two-part summary of his
24 evidence on one particular topic and then ask for your
25 reaction. So could you just listen while I give you the

1 summary.

2 Firstly, Mark told the Inquiry that when any form of
3 testing was mentioned to him, he made it clear that if
4 there was anything wrong, he wanted to know. So that is
5 the first part.

6 The second part of the summary is that he also told
7 the Inquiry that, in relation to the perception of those
8 who saw him at the Royal Infirmary, that he didn't want
9 to know the result of any HIV result on him, that any
10 such perception was wrong and that all he had ever said
11 was that he didn't want to know the detail of laboratory
12 measurements of his results, for example iron levels or
13 something like that.

14 Have I made it clear to you what those two summaries
15 are? Are you clear about that?

16 A. Hm-mm.

17 Q. What we would like to know is your response to that
18 evidence, from your personal experience.

19 A. Yes. My contact with him was substantially, I think,
20 after he had been told. So he didn't ever discuss with
21 me what he did or did not want to know, and any
22 perceptions I have are based on reports from other
23 people, other staff in the haemophilia centre, and the
24 discussions that took place at the meeting, not on my
25 personal interaction with him. Certainly, it was the

1 clear opinion of all the staff who were involved, as far
2 as I can remember, that he did not want to know his test
3 results, that he avoided contact with the centre for
4 long periods in order to avoid speaking to staff.

5 I think there was also a suggestion at one point
6 that haemophiliacs had to come in to collect their
7 Factor VIII and that he would choose his time to come in
8 when there weren't going to be many people around.

9 I think the opinion of the people who knew him was that
10 he was avoiding knowing -- having this information and
11 that is what was presented to me by the staff in the
12 centre. And there was concern about that. There was
13 great concern about that.

14 Q. So that view that you have just expressed is based on
15 your discussions with medical staff?

16 A. With all of the people who were involved: with the
17 nursing staff, there were discussions at the weekly
18 meeting that we had. Everyone who was involved really.

19 Q. Just to move away from the topic of testing and just to
20 ask you very generally, Mrs Brown: the work you did with
21 these patients over the next few years, could you tell
22 us what that was?

23 A. I talked to people about the implications of their
24 infection for themselves and their families. I gave
25 them emotional support, talked to them about bereavement

1 and loss. I got to know some of the families, some of
2 the spouses and had contact with them. I helped them
3 with practical issues. There was a lot of activity
4 generally to ensure people who were infected with HIV
5 had maximum social security benefits, including
6 discretionary diet allowances, which were considered
7 very important to maintain general health. So I helped
8 people a lot with that.

9 I dealt with local authority services for people who
10 needed aids and adaptations in their houses. I was
11 involved a lot with the MacFarlane Trust in helping
12 people with applications for financial support, and
13 I discussed on a regular ongoing basis new information
14 that was coming out and the implications of that for
15 people's situations.

16 Q. What period would this work cover?

17 A. Well, a long period of time because a lot of the
18 patients died, but not all of them, and people lived for
19 quite a while with this knowledge and this condition.

20 I worked in the centre well into the 1990s and
21 I would still be seeing families and relatives then.

22 Q. Would you be able to estimate how many hours a week you
23 were spending on this particular work?

24 A. I was working full-time from the middle of 1985 and
25 18 hours of that was in haemophilia, 18 hours was in

1 other hospital work. I think my 18 hours allocation to
2 haemophilia was increased for a period in response to
3 the increased need but I can't specify when that
4 exact -- exactly when that was, but certainly HIV and
5 AIDS took over the haemophilia time quite significantly.
6 I spent much more time with people who were infected
7 with HIV than I did with other haemophilia patients.

8 Q. Were these one-to-one meetings that you had with
9 patients?

10 A. One-to-one meetings, home visits and meetings with
11 husbands and wives. There was also a group which ran
12 for a short time, an evening group, for -- and I think
13 two or three couples attended that. I saw people when
14 they were on the ward, in my office, at home -- at their
15 homes, in a variety of places, yes.

16 Q. Would you be able to describe to us how patients reacted
17 to their situation during this period?

18 A. Well, as I said earlier, there was some understandable
19 anger at their situation and the fact that they had been
20 infected in this way by a treatment which was vital for
21 them and which really had transformed the lives of some
22 of the older haemophiliacs who, when they were young had
23 had very limited treatments. Dismay, great anxiety
24 about the future, concern for their families, concern
25 about confidentiality, concern about being -- some

1 haemophiliacs lived in small communities and they were
2 known to be haemophiliacs -- concern that people were
3 talking about them, concern that their children might
4 suffer because of their infection.

5 But great stoicism as well. Haemophiliacs had been
6 used to great difficulties in their lives from birth and
7 they had a very stoical attitude. You know, they were
8 very -- they took things on the chin, you know?

9 Q. I'm sorry, I should have asked you before but the
10 interviews that you had with patients, did they include
11 patients who had tested negative for the virus as well?

12 A. Yes, I saw all the patients, yes. Well, almost all the
13 patients I would see over a period of time. Sometimes
14 haemophiliacs who hadn't been infected with the virus
15 needed to talk about other practical things. So
16 I didn't just see people with HIV, but that was the
17 major bulk of the work.

18 Q. Would you be able to estimate how many patients you saw?

19 A. I would have been able to tell you these figures a few
20 years ago but I just -- I saw all the people who were
21 infected and many, many others as well.

22 Q. More than 50?

23 A. I can't say, I can't say.

24 Q. I think that you also set up a group. Is that right?

25 A. There was a group which -- what happened was that when

1 I started to work in the haemophilia centre, there was
2 a kind of expansion of its staffing really, to
3 accommodate the new needs and that included -- well, new
4 accommodation, more nursing staff, more medical staff
5 and also the involvement of the clinical psychology
6 service and also the department of psychiatry at the
7 Royal.

8 So the group was set up in conjunction with
9 Alison Richardson, the clinical psychologist who was
10 doing some work with patients, and it was an evening
11 group and I can't remember -- in practice I think it was
12 attended by a few couples. I think it was really an
13 opportunity for spouses to come along too and for people
14 to share information and concerns.

15 It was a small group.

16 Q. Yes. Perhaps we could have a look at your statement at
17 page 3 of [\[PEN0120401\]](#). This is the third page in at
18 the top, the second paragraph, where you talk about the
19 group that you have just mentioned. Do you have that in
20 your statement?

21 A. Yes.

22 Q. You say:

23 "A small number of patients and their wives
24 attended."

25 You:

1 "...maintained contact with many patients and their
2 families for a long time, continuing to see the families
3 of some of the patients who died for some time after
4 their bereavement."

5 You talk about staffing levels improving:

6 "There was a staff nurse as well as a sister."

7 Do you remember the name of the staff nurse? Is
8 that the one that you mentioned earlier?

9 A. No, I didn't mention the staff nurse earlier. I spoke
10 about Margaret Macsween, who was the sister on the ward,
11 and I spoke about the first sister, who I think left
12 shortly after I started.

13 The nurse I remember working with is
14 Billie Reynolds. And the sister who was there at that
15 time, her name has gone, I can't remember her name, but
16 Billie Reynolds was a staff nurse. There was a sister,
17 and in fact Billie became the sister when the other
18 sister left. So she was there for quite a long time.

19 Q. You say here that:

20 "The clinical psychology service was involved as
21 well as the department of psychiatry."

22 A. Yes.

23 Q. "There were regular weekly multidisciplinary meetings
24 where individual patients were discussed. Staff could
25 raise general issues of concern and seek advice from

1 colleagues."

2 Could you perhaps give us a description of the kinds
3 of things that would be discussed at these
4 multidisciplinary meetings?

5 A. I suppose the focus was on -- for me certainly, was on
6 how patients were coping, how they were managing. There
7 would be some discussion maybe about medical issues,
8 about whether people were requiring treatment, whether
9 they had moved on a stage in the progression of the
10 condition and how they were managing their lives,
11 whether there were family issues, emotional issues,
12 whether there needed to be a referral -- whether someone
13 seemed to be clinically depressed, whether they needed
14 to be referred to the psychiatrist, just how they were
15 coping with their lives and how their families were.

16 Q. So who would be at these meetings? Would Dr Ludlam be
17 at the meeting?

18 A. Yes.

19 Q. And the psychiatrist that you mentioned?

20 A. Yes, I think he probably didn't come to every meeting
21 but he had a regular pattern of attendance, although
22 maybe not at every meeting.

23 Q. Is that Dr Masterton?

24 A. Yes.

25 Q. Thank you.

1 A. Alison Richardson would be certainly at some of the
2 meetings, maybe not all of them. The medical staff and
3 the nursing staff would be there.

4 Q. Yes. So how long might one of these meetings last for?

5 A. They were lunchtime meetings, I think, like at 1 o'clock
6 or half past 12, and it would just go over the lunch
7 hour really.

8 Q. Yes. About an hour?

9 A. Yes, about an hour.

10 Q. Thank you. Just reading on in your statement, you say:

11 "My impression in general was that patients were
12 up-to-date with developments through discussion with the
13 doctors. There was also a good deal of information
14 available in the media. Most importantly the
15 Haemophilia Society was active in keeping its members
16 informed and in working on their behalf."

17 You say:

18 "My work was supported in a variety of ways, through
19 attendances at conference and study days, through
20 membership of the Haemophilia Social Workers Special
21 Interest Group, and through links with the Social Work
22 Department and with voluntary agencies."

23 You:

24 "... attended a major international conference in
25 Newcastle ... It was very useful as there were

1 presentations from workers from the United States."

2 What sort of things did you learn when you attended
3 these sort of events?

4 A. They were medically led. So there was a lot -- well, as
5 much information as was available really about medical
6 and scientific aspects. In terms of the first
7 conference in Newcastle and the input from the
8 United States that -- they had been working, I think,
9 with this virus for longer there. They were certainly
10 more aware of the issues that people were facing in
11 dealing with it. And although they were medically led,
12 as I remember, there were certainly nursing staff from
13 the States talking about their own experiences in
14 working with patients.

15 As I remember, there were probably plenary
16 presentations and smaller specific groups, which were
17 looking at separate professional issues; like there
18 might be a meeting at the conference of the social
19 workers from the special interest group, looking at
20 social work issues, sharing experience, highlighting
21 things.

22 Q. Yes, thank you. Again, if we look at your statement in
23 the paragraph that begins:

24 "The Haemophilia Social Workers Special Interest
25 Group met twice yearly. The focus of discussion was the

1 social work task, the support of individuals and their
2 families, addressing bereavement and loss and ensuring
3 appropriate financial and material provision."

4 Then in the next paragraph you talk about:

5 "The Social Work Department [being] involved with
6 other agencies in developing strategies to meet the
7 needs of those affected and their families. The vast
8 majority had been infected through intravenous drug
9 use."

10 Then you say:

11 "The emphasis in policy development was on meeting
12 the needs of all affected groups and some of the
13 services made available were used by a number of
14 haemophiliacs, for example Milestone House."

15 Could you tell us a bit about Milestone House,
16 please?

17 A. Milestone House was a hospice which was set up -- it was
18 built in the grounds of the old City Hospital. I'm not
19 sure of the background to it. There was certainly a lot
20 of fundraising for it and there would be money, I think,
21 provided by the local authority. And it was really
22 a hospice to provide terminal care for patients with
23 AIDS but also to provide support for them and their
24 families. And it was certainly used by one or two of
25 the patients.

1 Q. Yes. Thank you.

2 In the next paragraph you talk about being aware
3 that the patients that you talked to were aware of the
4 ongoing programme of research in haemophilia, and then
5 in the next paragraph you talk about your individual
6 case files. Could you tell us what records you kept at
7 this time of your work with the patients that you saw?

8 A. My records would record meetings with patients. They
9 would record any significant discussions that took place
10 between me and other members of staff about particular
11 patients. They would include all of the correspondence
12 relating to individual patients. But everything -- all
13 contact would have been recorded.

14 Q. Yes. So these were kept separate from medical records?

15 A. Yes, these were social work files. They were kept quite
16 separate.

17 Q. Yes, thank you. Could we just go over to the final page
18 of your statement? You say that you worked in the Royal
19 Infirmary until your retirement. From 1985 you worked
20 full-time:

21 "Half my time in the haemophilia centre and the
22 other half initially at the City Hospital but latterly
23 in the Royal Infirmary."

24 Were you involved with care for people with
25 haemophilia in the City Hospital as well?

1 A. No, when I was working at the City Hospital, I was
2 working, I think, with care of the elderly wards and for
3 a time in respiratory medicine. So I wasn't involved in
4 the unit at the City Hospital for patients with HIV and
5 AIDS.

6 Q. Yes. Then you say that in 1989 you were promoted and
7 gradually over a period of time moved to specialise in
8 children's services. You were still involved in working
9 with haemophiliacs until well into the 1990s but you
10 can't be exact about the date.

11 Mrs Brown, I would like to just go back to something
12 that we discussed previously.

13 You will remember that I was asking you about how
14 many patients you thought did not receive their results
15 in the time after the December meeting, 1985/1986, and
16 so on. I would like to tell you about some other
17 evidence which the Inquiry has heard. The Inquiry has
18 heard evidence from the widow of another Edinburgh
19 patient and it seems clear from that evidence that this
20 patient was not told of his HIV status
21 until December 1986. And it has been suggested that
22 this man and Mark, who we talked about earlier, are not
23 the only patients who did not find out for a period of
24 years that they had tested positive for the virus.
25 Could you let us have your response to that?

1 A. I can't give you figures about who knew when. I think
2 the point to emphasise is that if people did not know
3 they were infected, it was because they didn't ask.
4 I think it was quite clear to people from the start that
5 this information was available to them and they could
6 have it and I think that in a sense the ball was in
7 their hands, when they were told that a group had been
8 infected. It was quite clear that they did need to make
9 the approach and discuss it. That's my understanding of
10 all of the discussions that we had.

11 Q. Yes.

12 A. That it was up to the patient to approach the doctor and
13 ask.

14 Q. Did you form an opinion from your discussions with
15 medical staff that this issue about passing on results
16 was something that was causing a concern to the medical
17 staff?

18 A. If it went on too long. In the case of Mark, yes. And
19 that was because treatments were being developed and it
20 was quite clear that it was in the patient's interest to
21 know if they were infected with HIV, as the knowledge of
22 the virus increased and treatments were developed.

23 But I think that -- the position of the staff was
24 that they did expect the patient to approach them and
25 they would be open to that approach and they would tell

1 the patient exactly what the situation was.

2 Q. I imagine during the period that we are talking about,
3 from 1985 to, let's say, 1987/1988, when you were
4 discussing possible treatments with patients, the
5 position changed quite radically. Is that right?

6 A. Well, the position was changing all the time. I think
7 that -- there was an enormous amount of research going
8 on. There was a huge amount of experience being
9 developed. It was a very fluid situation, so people --
10 you needed to update and talk about new things to people
11 all the time.

12 I was looking at the papers that -- the few things
13 I had kept, which I gave to the archive, the Royal
14 Infirmary archive, and I just kept things very
15 haphazardly but there was an enormous amount of
16 information, Haemofact from the Haemophilia Society.
17 Every month or two there would be something coming in.
18 So there was always something new to discuss with the
19 patients because the patients would be getting this
20 information as well. It wasn't just coming to me, it
21 would be coming to members of the society and they would
22 want to discuss it.

23 Q. So you received Haemofact yourself?

24 A. I received all the information from the Haemophilia
25 Society.

1 Q. Would you discuss new treatments with medical staff
2 during your meetings as well?

3 A. Yes, we would discuss what was available, yes.

4 Q. Would you then in turn discuss those things with
5 patients in your meetings?

6 A. Yes -- I mean, certainly in hospital social work,
7 obviously I was not a medical person, I wasn't medically
8 trained, but my expectation is that I would know enough
9 about a condition and about treatments to have
10 a discussion with patients about it. So it was quite
11 important for me to be updated as well, yes.

12 Q. Can you just bear with me, Mrs Brown? (Pause)

13 I have no further questions, sir.

14 Thank you very much, Mrs Brown.

15 THE CHAIRMAN: Mr Di Rollo, do you have any questions?

16 MR DI ROLLO: Yes, I do, thank you.

17 Questions by MR DI ROLLO

18 THE CHAIRMAN: Are these matters that have been anticipated
19 in discussion with Mr Gardiner or not?

20 MR DI ROLLO: We intimated some lines of questioning and
21 there was one or two points that have arisen this
22 morning, one of which has been dealt with but there are
23 one or two things I would like to ask arising from that.

24 Mrs Brown, I think it's fairly clear that your
25 involvement began towards the end of 1984 and you had

1 not actually started your work formally until the
2 beginning of 1985?

3 A. Yes.

4 Q. So the meeting that was held in December, you were
5 obviously fairly new to whatever it was you were going
6 to be doing?

7 A. Yes.

8 Q. You had had a brief discussion with Dr Ludlam before the
9 meeting. Do you recall whether there was any urgency
10 about having the meeting at that particular point?

11 A. I don't recall any significance in the timing. I mean,
12 there may well have been but I don't recall.

13 Q. Were you aware of the possibility that the press had
14 hold of a story that they were going to release and that
15 it was necessary to have a meeting --

16 A. Certainly I was aware that there was a lot of press
17 interest and there was a lot of discussion in the press.
18 I don't remember -- I don't think I knew that it was in
19 response to a particular risk of a story getting out
20 but -- I was aware that there was a lot of press
21 interest and there was a lot -- and there was a desire
22 to put things -- to be straight, you know, with people
23 with about how things were, rather than having some kind
24 of sensational media discussion about it. Because there
25 was a lot of sensational discussion of HIV in the press.

1 Q. As far as the meeting itself, as I understood your
2 evidence, you said, I think, that you sat at the front
3 looking towards the doctors who were giving the
4 presentation. I think Dr Ludlam was one of them. You
5 weren't able to help us with who else was there?

6 A. I thought Dr Forbes might have been there.

7 Q. Dr Forbes, but anybody else apart from that?

8 A. I wasn't clear, no.

9 Q. Were members of the nursing staff present perhaps?

10 A. I don't even remember that actually. I don't remember
11 that.

12 Q. Do you know if it was just patients or patients and
13 their spouses?

14 A. My memory, it was patients and families, patients and
15 spouses, yes.

16 Q. So making up the numbers would include whichever the
17 patients were and whichever patients had brought any of
18 their loved ones with them?

19 A. Hm-mm.

20 Q. Is that right?

21 A. Hm-mm.

22 Q. As far as the meeting itself was concerned, do you
23 remember if there was any discussion about whether, from
24 now on, blood would be heat-treated?

25 A. I can't remember if there was a discussion at that

1 meeting about that but I know that that was something
2 that was very quickly -- I think it perhaps had been
3 introduced by then. I'm not sure of the exact
4 timescales of these things and I can't remember if it
5 was actually discussed at the meeting.

6 Q. You mentioned "anger" -- I think that was the word you
7 used. Was there any anger expressed by patients that
8 saw you subsequently? What I'm trying to see is whether
9 the anger that you recall is something that emerged
10 afterwards rather than being expressed at the meeting?

11 A. I think that there was anger expressed to me by patients
12 over a period of time, and that's a normal response
13 to --

14 Q. Surely.

15 A. -- information of this kind. It's a kind of healthy
16 response. Are you thinking about anger directed at
17 specific people or anger that things weren't done?

18 Q. You mentioned that there was anger expressed at the
19 meeting. I was wondering whether in fact perhaps there
20 wasn't that much anger at the meeting but it was more
21 subsequently that anger was expressed.

22 A. There certainly was anger subsequently, yes.

23 THE CHAIRMAN: I don't think it's a precise answer to the
24 question, Mrs Brown. As you recollected, was there
25 anger at the meeting?

1 A. There was anger. There was dismay and a kind of
2 generalised feeling of anger about the situation at the
3 meeting, and subsequently in discussions with me,
4 patients talked more specifically about their feelings
5 and their anger at the situation that they were in.

6 THE CHAIRMAN: Sorry, Mr Di Rollo. I didn't think we were
7 getting quite to the denouement but is that --

8 MR DI ROLLO: I think we have got to the denouement now and
9 I'm very much obliged.

10 The counselling that you have indicated you
11 undertook, what exactly did that consist of? Can you
12 explain that to me? What is it that you did in order to
13 counsel patients?

14 A. In terms of counselling, I think in general people have
15 all sorts of different views about what counselling is,
16 but in terms of counselling people with HIV and AIDS,
17 there was an information sharing aspect to it in terms
18 of clarifying people's understanding of the situation
19 and of their -- of their condition and what it would
20 involve. So there was an information sharing element.
21 The rest was really about looking at their feelings
22 about their situation, talking these things through,
23 talking through any anxieties they had.

24 Q. When was that done with patients?

25 A. That was done over a period of time. It wasn't -- it

1 wasn't the case that if someone was told they were
2 infected with HIV, they would then have three
3 counselling sessions to sort it all out. It was an
4 ongoing process really, in my relationship with them
5 over a long period of time, and sometimes things would
6 be relatively straightforward and stable and then there
7 would be other issues which would emerge and would need
8 to be discussed.

9 Q. Was it you that told the patient that they had HIV?

10 A. No, no, no.

11 Q. Never?

12 A. Never, no.

13 Q. So if counselling was to be carried out, it would be
14 after they had been told of that fact?

15 A. Yes, yes.

16 Q. Were you ever involved in discussing with a patient
17 whether or not they should go and ask for the test?

18 A. Yes.

19 Q. How did that come about? Did the patient come and see
20 you first?

21 A. Yes, the patient would come and see me and we would talk
22 about it.

23 Q. Had they been to see the doctor first or had they just
24 gone to see you?

25 A. The patients were seeing the doctors all the time. You

1 know, they were in and out of the hospital and the
2 centre, seeing the doctor, seeing the nursing staff.
3 They might as well have discussed it with the doctor
4 before they discussed it with me but some patients
5 certainly did speak to me before they approached
6 Dr Ludlam and asked.

7 Q. So some would have approached Dr Ludlam without speaking
8 to you first and some wouldn't?

9 A. Yes.

10 Q. Sometimes after they had spoken to Dr Ludlam they would
11 come and see you?

12 A. Yes.

13 Q. But they may or may not come to see you, depending on
14 whether they wanted to come and see you or not?

15 A. I think I saw everyone who was told they were HIV
16 positive. I'm pretty sure I saw every patient who was
17 infected.

18 Q. Are you sure about that?

19 A. I'm sure about that, yes.

20 Q. When you say you saw them, did you actually speak to
21 them? What did you actually say to them at that point
22 then? What did that consist of?

23 A. Well, we would discuss -- if they had just been told
24 this, we would discuss the impact of this information.
25 I can think of one or two patients who did not want to

1 have any ongoing contact with me but I still saw them at
2 least once, and that was established. They didn't have
3 to see me if they didn't want to. I think -- it was
4 a very long process. It was a process of getting to
5 know people, forming a relationship with them, getting
6 their trust. It wasn't done just in one or two
7 sessions.

8 Q. As far as the meeting itself was concerned, the
9 information that the patients were given before that
10 meeting by way of the letter, you never saw the letter
11 that they were given before the meeting itself?

12 A. Which meeting?

13 Q. In the December 1984 meeting.

14 A. No, I don't think this document was available before the
15 meeting. I don't think -- it was sent out after the
16 meeting, I think.

17 Q. I think patients who went to the meeting
18 in December 1984 were advised of that in some way.

19 A. Yes.

20 Q. Were you involved in any of that, in setting up the
21 meeting of December 1984?

22 A. No.

23 Q. Or giving the information telling the patients about
24 what that meeting was to be about?

25 A. No, because I didn't know any patients before the

1 meeting.

2 Q. So you had no involvement?

3 A. I hadn't met any patients.

4 Q. Have you ever seen the letter that they were sent, or
5 anything of that kind, for the meeting of December 1984?

6 A. No, I don't think I saw it, no.

7 Q. Right. Sorry, what was that? You didn't see it then?

8 A. I didn't see the letter inviting them.

9 Q. Have you seen it subsequently?

10 A. Not that I'm aware of, no.

11 Q. If a patient didn't attend the meeting in 1984, then
12 obviously they wouldn't know what was said at that
13 particular meeting, and I think we do know that there
14 were some patients from Edinburgh that did not attend
15 that meeting. There may have been one or two that
16 didn't attend that meeting. Other than the information
17 sheet that we have seen, was there any other information
18 that they were given as to what had occurred at the
19 meeting in December 1984 that you are aware of?

20 A. I'm not sure aware of them getting any other
21 information, although I would assume it would have been
22 discussed with Dr Ludlam when he saw the patients.

23 Q. If he saw the patients?

24 A. If he saw the patient.

25 Q. It's just that you indicated in one of your answers to

1 my learned friend that patients knew that they needed to
2 make an approach. It was up to the patient to find out
3 their results?

4 A. Hm-mm.

5 Q. If a patient hadn't been at the meeting in
6 1984, December 1984, at all, then presumably they
7 wouldn't know that they needed to make an approach to
8 find out the results?

9 A. I'm not sure. I don't know what it says on this
10 document here, if it says --

11 Q. Which document are we talking about?

12 A. I'm looking at the advice sheet that everyone did get.

13 Q. Perhaps we should look at that together then.

14 A. I'm not sure --

15 Q. Perhaps it could be put up on the screen.

16 I think there is some suggestion that there is
17 something there -- if we carry on down. I think it was
18 paragraph 6. I think my learned friend did refer to it.

19 A. Yes, it does say that 10 per cent in Scotland have
20 exposure.

21 Q. It does say:

22 "The tests are now available and will be carried out
23 on your routine visits to your centre."

24 I think that's about it as far as putting the onus,
25 as it were, on the patient to come forward to find out

1 their results.

2 A. Hm-mm. I don't know if there was any other written
3 information, more specific information, sent out and
4 I don't know what -- I don't know the content of
5 Dr Ludlam's discussion with patients.

6 Q. No.

7 A. If he, in fact, in his discussions said, "There is
8 a group of infected patients here", I would assume he
9 did have these discussions with people. He was seeing
10 people quite lot but I wasn't at these discussions so
11 I can't say.

12 Q. I think there may have been one or two patients that
13 didn't attend for whatever reason in 1985 or 1986,
14 potentially at least. They may or may not have seen
15 Dr Ludlam. You, of course, don't know anything about
16 that?

17 A. No.

18 Q. Did any patients, either in meetings with you
19 individually or in group meetings that you had, express
20 anger about communication issues, about whether they had
21 been told their results?

22 A. I don't recall anyone expressing anger about not being
23 told their results, no.

24 Q. So that was never expressed to you?

25 A. No.

1 Q. That you recall?

2 A. No.

3 Q. Did anybody express concern about the fact that tests
4 had been carried out without their knowledge?

5 A. There was certainly some acknowledgment of that.

6 Q. What do you mean by "acknowledgment"?

7 A. People were aware. People would make the point that
8 permission hadn't been given. I didn't get the sense
9 that people were angry about that. They were more
10 resigned. I think people were aware that in a sense
11 they were part of an ongoing research project because
12 the treatments had been developed over a period of time,
13 that they were being monitored and being refined, and
14 people were aware that -- they were guinea-pigs in
15 a way.

16 Q. Were they aware that they were guinea-pigs?

17 A. I think people were aware that blood was taken, yes, and
18 used for research purposes.

19 Q. How were they aware of that?

20 A. I don't know how they were aware of it. I didn't tell
21 them that. Just from my conversations with them, they
22 were aware that blood was -- their blood was used as
23 part of research projects. They were aware that
24 Dr Ludlam had ongoing research.

25 Q. How were they aware?

1 A. I think he probably told them.

2 Q. Is that a supposition on your part?

3 A. Did he tell me he had told them? I think he probably
4 did tell them that there was -- I think he did tell them
5 there was ongoing research, yes.

6 Q. When did he tell them?

7 A. I don't know.

8 Q. How did he tell them?

9 A. I don't know.

10 Q. Why do you say then that he told them?

11 A. Because that was something that was acknowledged by the
12 patients, and the implication was it came from their
13 discussions with him, with the medical staff in the
14 centre.

15 Q. Did no patients complain at any time to you that they
16 hadn't been told that there had been this research going
17 on?

18 A. No, I didn't get a sense of people complaining about
19 that. There was an acknowledgment that it was
20 happening, a kind of informal acknowledgment that it was
21 happening. I think people were influenced in their
22 reactions by the benefits that had come out of previous
23 research programmes. They were aware that good
24 treatments had come out of that.

25 Q. One of the difficulties with a meeting may have been

1 that patients may not have realised that they themselves
2 had been infected. Even those that attended the meeting
3 may not have appreciated that they as an individual had
4 been infected, and they may not have realised that in
5 order to find out whether they had been infected they
6 had to come forward.

7 A. On the basis of my attendance at the meeting, the people
8 who attended would know that there was a group of
9 infected patients in Edinburgh, that they might be
10 a member of that group and that if they wished
11 clarification of that, they could approach Dr Ludlam.

12 Now, if they hadn't attended the meeting, obviously
13 that would be quite different. I don't know if any
14 other information was sent out to people who did not
15 attend but anyone who left that meeting should have been
16 quite clear that there was an infected group, that they
17 might be in that group and that if they wanted to know
18 they had to ask.

19 Q. I think there were people at that meeting who didn't
20 appreciate that. Weren't clear of that. And that's
21 a fact, at least from their point of view it is?

22 A. I think -- it's very difficult to -- I think giving
23 information to people of this kind, people who are in
24 this situation, it can't just be a one-off thing.
25 I think all sorts of things interfere with the way

1 people process the information that you give them, which
2 is why it was really important to have written
3 information after the meeting, which people could read
4 at their leisure and refer to.

5 I think that -- it is difficult to give people
6 information about such issues. I was a disinterested or
7 a -- not an uninterested, a disinterested observer in
8 the sense I wasn't personally involved. For me the
9 information was quite clear but I can see that for other
10 people perhaps it wasn't.

11 Q. You see, you had had the benefit of speaking to
12 Dr Ludlam before the meeting.

13 A. Yes.

14 Q. Perhaps he had explained to you what he had in mind. So
15 it wasn't the first time that you had heard this
16 information. You had had an opportunity of processing
17 the information.

18 A. Hm-mm.

19 Q. Is that right?

20 A. Well, I had had some discussions with him, yes.

21 Q. And also you weren't someone who was likely to be in the
22 situation where you were a haemophiliac --

23 A. I wasn't emotionally involved in it, no.

24 Q. Indeed not. So it might be easier for you to actually
25 understand what was being said perhaps than it would be

1 for a patient or a relative at the meeting. Is that
2 reasonable?

3 A. Well, yes, I mean, I made that point myself. I think it
4 is difficult when you are emotionally involved, to
5 process information like that when it's given in that
6 kind of setting.

7 Q. It does appear that there may well be patients who were
8 positive but didn't realise that in order to find out
9 their results, they had to come forward and ask for
10 them, even patients that attended the meeting. That
11 does appear to be the case. I'm suggesting that you
12 appear to be conceding that that could well have
13 happened.

14 A. I think it is difficult for people to take on that kind
15 of information, yes. But I left the meeting quite
16 clear.

17 THE CHAIRMAN: Mr Di Rollo, can we just make it clear that
18 the last series of questions and answers did relate to
19 the December 1984 meeting?

20 MR DI ROLLO: Of course.

21 THE CHAIRMAN: Because maybe it's just the way it came up in
22 the text but it is not clear at the first question.

23 MR DI ROLLO: I'm obliged.

24 The question I wanted to ask you, and I think you
25 may well have covered this already, just in case

1 I haven't clarified it: how many positive patients did
2 you see? You say you saw them all but I'm not sure that
3 tells us how many that is?

4 A. I'm trying to think. I could have told you the figures
5 a few years ago. I think around 18 to 20 people were --
6 that's the figure I have in mind of the people who were
7 infected. There was one other patient who was infected
8 by a blood transfusion I saw, who wasn't part of the
9 haemophilia group. But I saw all of these patients.

10 Q. When you say you saw them, I mean, it might have been an
11 extremely brief meeting?

12 A. Very few it would be an extremely brief meeting, but the
13 bulk of the patients I saw over a period of time, quite
14 a lot.

15 Q. Just one other point. We discussed anger at the meeting
16 and I think we had clarified that -- or the chairman
17 did, rather. As far as anger after the meeting was
18 concerned and as time went on, are you able to tell us
19 what anger was expressed about?

20 A. The anger at having become infected with HIV in this
21 way, I think, was the main thing. I think there was
22 anger at lack of financial compensation, really lack of
23 acknowledgment of the plight of people who were infected
24 with HIV through blood and blood products. I know when
25 the Macfarlane Trust was set up, it was not designed to

1 give compensation to patients but it was a trust fund to
2 improve the quality of their lives, and it was only
3 after a period of time that I think a small amount of
4 money was given in compensation. I think my memory is
5 correct. And that actually made people feel a bit
6 better, that it was an acknowledgment.

7 Q. Was any anger expressed about the guinea-pig issue, if
8 I can put it like that?

9 A. No, I think patients realised it was important. It was
10 in their own interests, it was for their own benefit,
11 that research of this kind into haemophilia and
12 treatments was going on. I didn't get a sense that
13 people were angry about that.

14 Q. I think it's fairly clear that for at least some of the
15 time patients did not know that research was being
16 carried out on them or at least --

17 A. They didn't know they had been tested for HIV.

18 Q. Yes.

19 A. And I think people were not all that happy about that.

20 Q. Was anger expressed to that extent?

21 THE CHAIRMAN: Mr Di Rollo, I'm slightly anxious about the
22 words "research was carried out on them". I think you
23 have to be rather more specific if you are going to put
24 an allegation like that.

25 MR DI ROLLO: I'll take that out. That was careless.

1 THE CHAIRMAN: I think properly what Mr Di Rollo was talking
2 about was research relating to their cases.

3 MR DI ROLLO: Indeed, that's exactly what I meant. I did
4 not mean it in any other sense. I want to make that
5 clear.

6 A. I think people knew that it was in their interest, that
7 they had benefited from research in the past. That it
8 was vital really to continue to research both
9 haemophilia, HIV and to look at treatments.

10 Q. Right. I think the next question I was asking you and
11 I think you were dealing with, was concern expressed by
12 patients that they had been tested without their
13 knowledge. I think you indicated -- at least I thought
14 you indicated -- that some concern was expressed by
15 patients about that?

16 A. Yes, I think people were not all that happy about that.
17 I think --

18 Q. Can you just explain that for us?

19 A. Yes, I think it's difficult because I think attitudes
20 now to blood testing have changed. Everything has been
21 firmed up a bit because you would always expect to be
22 asked if you are giving blood yourself -- you would
23 expect to be told what it was for and give your
24 permission for it to be used in that way.

25 I don't know. I don't know if things were the same

1 in the 1980s, if things were just less formal and fixed.

2 Q. I'm not sure that's what I'm asking you. What I'm
3 really asking you is about their concern. You were at
4 meetings with them, either individually or possibly with
5 more than one of them at a time, and you are indicating
6 that concern was expressed.

7 A. Yes. I think they thought it would have been polite to
8 be asked, really, if their blood could be tested.

9 Q. Polite, you think.

10 A. I think it would have been courteous to have that put to
11 them.

12 Q. Do you think it perhaps was a little bit stronger than
13 that?

14 A. That was my feeling about the bulk of the people I spoke
15 to. Maybe others were a bit stronger in their views but
16 most people were feeling that it could have been
17 explained, they could have been asked.

18 THE CHAIRMAN: Mrs Brown, I have to say that I would be
19 a wee bit surprised at the expression "it might have
20 been polite to ask me", and I rather suspect that it
21 would be more direct than that, "You would have thought
22 they would have asked me before they did it".

23 A. Yes, that kind of thing.

24 THE CHAIRMAN: So really you are interpreting what would
25 have been a fairly more basic complaint about not being

1 asked.

2 A. Well, yes, it was acknowledged as something they weren't
3 happy with, yes.

4 MR DI ROLLO: You are using the passive, "it was
5 acknowledged". Acknowledged by whom?

6 A. The patients were acknowledging they weren't happy with
7 it.

8 Q. I think that's perhaps a social work expression?

9 A. Jargon.

10 Q. Yes.

11 A. Acknowledged.

12 Q. It was acknowledged that ...?

13 A. They acknowledged that they weren't all that happy about
14 it, no.

15 Q. I'm obliged.

16 Sir and that's all I have to ask.

17 THE CHAIRMAN: Mr Anderson, do you have any questions?

18 MR ANDERSON: Just one matter, if I may, sir.

19 Questions by MR ANDERSON

20 MR ANDERSON: Mrs Brown, good morning to you. There has
21 been quite a lot of discussion about the December 1984
22 meeting and you have told us that Dr Ludlam invited
23 those present to contact him if they wished to know
24 their results.

25 A. Hm-mm.

1 Q. My friend, Mr Di Rollo, invited you to assent to
2 a proposition that it would be different if, of course,
3 people hadn't attended the meeting, do you remember
4 that?

5 A. Hm-mm.

6 Q. I think we have already in front of us the advice sheet.
7 We have in front of us paragraph 6, which explains that
8 about half the patients in England and about
9 ten per cent in Scotland had had exposure and are
10 positive. Do you see that?

11 A. Hm-mm.

12 Q. Could we have, please, the first paragraph of that
13 sheet? I think we see there, about half way down the
14 first paragraph, it states:

15 "As you will appreciate, the pace of research is
16 moving very fast and we will be in touch with you and
17 your family as further information becomes available."
18 Do you see that?

19 A. Hm-mm.

20 Q. Then it says:

21 "If, however, you have any major anxieties in the
22 meantime, please do not hesitate to phone your centre
23 director for a personal appointment."
24 And then it gives the Glasgow telephone number and
25 the Edinburgh telephone number. Is that right?

1 A. Hm-mm.

2 Q. So whether people had been at the meeting or not, there
3 was still an invitation disseminated to all haemophilia
4 patients that if they had concern, they could contact
5 their haemophilia director. Is that right?

6 A. Hm-mm.

7 Q. Does that sound about right?

8 A. Hm-mm.

9 Q. Am I right in thinking that this advice sheet went out
10 to all haemophilia patients in Scotland?

11 A. Yes, that's my understanding, to all haemophilia
12 patients.

13 Q. Thank you very much, I'm obliged.

14 THE CHAIRMAN: Mr Sheldon?

15 MR SHELDON: Nothing from me, thank you, sir.

16 THE CHAIRMAN: Mr Gardiner?

17 Further questions by MR GARDINER

18 MR GARDINER: I have one point of clarification for
19 Mrs Brown, if I may.

20 Mrs Brown, earlier on this morning when I was asking
21 you questions, I think I'm right in saying that you said
22 you weren't involved in discussing with patients whether
23 they should be going for a test, you only discussed with
24 them whether they should be going to get their results?

25 A. Yes.

1 Q. So distinguishing between getting a new test --

2 A. Yes.

3 Q. -- and getting results which are already available?

4 A. Yes.

5 Q. But when Mr Di Rollo was asking you questions just

6 a short while ago, he asked you a question about whether

7 you had discussions about whether patients should go for

8 a test, and you said "yes"?

9 A. Did I? Did I say that?

10 Q. We have it here. It's page 67, line 9.

11 "Question: And were you ever involved in discussing

12 with the patient whether or not they should go and ask

13 for the test?

14 "Answer: Yes ..."

15 A. It's the test result in fact. That's a mistake. It was

16 the test result. They discussed with me often before

17 they went and asked for their test result whether they

18 should be doing this, what the implications were if they

19 did that.

20 Q. Thank you very much.

21 THE CHAIRMAN: Mrs Brown, thank you very much indeed.

22 A. Okay.

23 THE CHAIRMAN: That's very helpful. Right, is that the

24 morning's business?

25 MR GARDINER: Sir, we don't have any more witnesses today,

1 so the next witness will be Dr Ludlam tomorrow morning.

2 THE CHAIRMAN: So you may certainly go quite happily,

3 Mrs Brown.

4 A. Thank you very much.

5 THE CHAIRMAN: Very well, is there any other business or do

6 we adjourn?

7 MR GARDINER: No.

8 (12.50 pm)

9 (The Inquiry adjourned until 9.30 am the following day)

10

11

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