Penrose Inquiry

The following transcript is for Day 32 of the Oral Hearings of The Penrose Inquiry, held on 14th June 2011.

Please note that this session comprised two parts:

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

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

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

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

Tuesday, 14 June 2011

(9.30 am)

THE CHAIRMAN: Good morning.

DR PATRICIA WILKIE (sworn)

Questions by MR GARDINER

THE CHAIRMAN: Yes, Mr Gardiner.

MR GARDINER: Thank you, sir. Good morning, Dr Wilkie.

Dr Wilkie, I think I'm right in saying that you have given a statement to the Inquiry.

A. That's correct.

Q. And if we may just have that up on the screen. It's PEN0161297. I think you have a hard copy in front of you. Is that right?

A. Yes.

Q. Thank you. If you just go to the back of that, the statement at page 1304, the last page -- do you see that?

A. Yes.

Q. That's your signature at the end?

A. That's correct.

Q. That's the date, 15 April 2011?

A. That's correct.

Q. Thank you. We don't have a CV for you, Dr Wilkie, but perhaps if we can just take your qualifications and experience from the statement here, I think in

paragraph 1 you say that you are a social scientist. Your qualifications are MA, PhD, FRCR (Hon), FRCG (Hons). What are those letters, please, "FRCR"?

A. It's an honorary degree from The Royal College of Radiologists, an honorary fellowship from the Royal College of Radiologists and an honorary fellowship from The Royal College of General Practitioners. It's not a degree, it's a gong.

Q. You say that your first degree is a joint honours in sociolology with social and economic history.

A. That's correct.

Q. And your PhD examines the social and psychological implications of inherited disease and it's from the department of psychology at Stirling University?

A. And with a link to the department of medicine at Glasgow University.

Q. Yes, thank you. Perhaps you could just tell us a little bit more about that PhD?

A. Right. I graduated as a mature student from Edinburgh in 1972 and I was offered a research project. Can you hear me because I have a very soft voice?

Q. Could you maybe lean towards the microphone a little bit.

A. Yes. I was offered, immediately on graduation, a five-year research contract from the Scottish Home and

Health Department to test the acceptability of having a national genetic register. This wasn't my idea, by the way, this was the brainchild of Professor Alan Emery at Edinburgh University in the department of genetics.

I worked on this project for five years, working with patients and their families and my medical colleagues on looking at setting up this register. The register had an acronym, RAPID: register for the ascertainment and prevention of inherited disease. It was thought -- not my thinking by the way, but it was thought that if people were informed of the risk of inherited disease -- serious genetic disease -- and we were only looking at those with a risk of greater than one in ten -- that people would not have children. Well, that's not the case and it was obviously not the case at the beginning, but that was the objective, for me to test the acceptability of having this at a national level. UK national, by the way, not simply Scottish national.

Q. Yes.

A. So I had a lot of interest in -- and I trained in counselling over that period so that I could give genetic counselling as well. There was no course for genetic counsellors at that time, neither for non-medical people and certainly not for medical staff.

Q. Yes. What do you mean by genetic counselling?
A. Finding out what patients want, giving information to them about the particular disease, whichever type it is, the implications of that disease, whether there is a treatment for it and what the treatment is, what the morbidity might be like, what their job opportunities, whether they would get insurance, all these different issues.
Q. Yes.
A. And their families of course, and also whether they should have children or not.
Q. Yes. I think you just said that you had some training in counselling during that period?
A. Yes.
Q. Would you just tells what that was?
A. Sure. I did a rather long part-time course at Edinburgh University in counselling. I also did a course with the Scottish Council on alcoholism. It started in Glasgow but it also happened in Edinburgh, and that was over about a year, one or two weekends a month.

This is a different sort of counselling but I did that because at that time the Scottish Home and Health Department thought that people who had an alcohol problem who were in employment could, if they received

counselling, then continue with their work and it was short and sharp. It wasn't the sort of counselling that I was used to but it seemed important to open all horizons and try all things. So I did that as well.

Q. Yes. So what did the course involve in terms of practical training for counselling?

A. One worked with patients, one was video-recorded, which was way ahead of its time. It's only relatively recently that general practitioners in training are video-recorded interviewing patients. So it was way ahead, and then you were fed back your errors of what you could do better or whatever.

Q. Yes.

A. The University of Edinburgh, one had a small exam at the end, on academic things.

Q. Yes, thank you.

I'm told that we do have a CV for you. So perhaps we could have a quick look at that. That's WIT0030382. At the top this lists your current professional and related interests. You are a member --

A. I should have retired.

Q. So I see. You are still busy?

A. Very.

Q. I don't think we need to go through all of that. We can all see what that is. If we go down to recent and past

activities, we see that between 2002 and 2007, you were the first lay observer, counsellor of the Academy of Medical Royal Colleges, lay chairman, member of several academy committees and working groups. Between 1996 and 2008 you were a member of the GMC Public and Patient Reference Group. 2006 and 2008, you were a member of the GMC working group on consent. Between 2007 and 2009, a member of the CMO/DH committee for health professionals. 2007 and 2009, co-chair of the Academy of Medical Royal Colleges. 2006 to 2008, member of the Boyd group and so on.

If could we go on to page 2. There we have a list of all of your involvements in many different committees and advisory boards. If we could go on to the next page --

THE CHAIRMAN: What is the Maverick trial?

A. The maverick trial had to do with using a new pathology test for cervical cancer. It came from Manchester.

THE CHAIRMAN: Who were the mavericks?

A. I don't know who thought up the name? But he was Scottish.

MR GARDINER: Could we just go right back to page 4? We will see that you started as a research associate in 1972. Then 1977 to 1979, temporary lectureship. 1979 to 1980, research fellow Edinburgh University. 1983 to

1991, research fellow on project funded by Social Work Services Group. 1982 to 1988, genetic counsellor, renal unit, Glasgow Royal Infirmary, haemophilia/HIV counsellor, haemophilia unit, Glasgow Royal Infirmary.

Above that, 1982 to 1988, research fellow in the department of psychology at the University of Stirling and department of medicine, University of Glasgow, at Glasgow Royal Infirmary, to carry out two studies.

Then if we could go back to page 3, please. 1989 to 1991, senior research fellow, department of general practice, St George's Hospital, London. To carry out large study into cost shifting in prescribing at GP hospital interface.

What we are with really interested in, Dr Wilkie, in that period that you had on page 4, between 1982 and 1988. So I think we can put that CV away now, thanks.

Could we go back to your statement? Paragraph 2:

"In the early 1980s, I lived in Edinburgh, working as a researcher at the university of Edinburgh. From 1982 to 1988, I worked as a research fellow, employed at the University of Stirling in conjunction with The universities of Glasgow at Glasgow Royal Infirmary and carried out two studies."

It's the second study that we are interested in, which is:

"The coping strategies of haemophilia families in the presence of HIV and AIDS and the implications for counselling."

The first study is one to do with polycystic kidney disease, and you started that before the HIV and AIDS study. Is that right?

A. Yes, I did, yes.

Q. Now, in the next paragraph you say:

"In 1982/1983, as part of the project, I started commuting to Glasgow Royal Infirmary from my home in Edinburgh to work with kidney patients."

You have put 1982 to 1983. Could you try to help us a bit with the dates there and explain why you have put that time period?

A. I think it was confusing with the beginning of the work with haemophilia. I have a pay slip from 1982 for working with the renal patients a Glasgow Royal. I have nothing, absolutely nothing left, and I have tried to find out when I actually started work in the haemophilia unit, but we did get a grant, which we started looking at in early 1983.

Q. Yes.

A. Which had to be developed.

Q. Yes. So you found a pay slip from 1982, which is to do with the kidney disease study?

A. Yes.
Q. How soon after starting the kidney disease study did you do the haemophilia study?
A. I'm sorry, I have tried to remember but what I do know, that I had to think about it all the time, because we were developing this research project. One doesn't get a grant, as you know, without a lot of work and we had to build up the research project. And in fact that project was the first grant that was ever given to people to work with HIV and AIDS in the haemophilia population.
Q. Just trying to focus in on the date, Dr Wilkie, could it be as much as a year -- this pay slip -- until you started on the haemophilia study?
A. Possibly less.
Q. Yes.
A. Possibly less.
Q. Your best estimate is less than a year?
A. Possibly less, yes.
Q. When does the pay slip date from? Do you remember?
A. It dates from August of 1982.
Q. Okay. So --
A. But I had started working before I got paid because I had to develop the research project for the polycystic patients.

Q. Are you saying that from August 1982 to the period when you started working on the haemophilia project, it's a little bit less than a year? Is that your best --

A. I would think so, but I'm really very sorry, I cannot remember accurately.

Q. No --

A. I feel inadequate in that --

THE CHAIRMAN: Dr Wilkie, was it a Research Council grant or what?

A. It was Scottish Home and Health Department.

THE CHAIRMAN: We have contacts with the Scottish Government here. It shouldn't be beyond the wit of the representatives to find out the precise date, if that would help. If you can give us any further information about the title. Were you the lead researcher?

A. No, Ivana Markova was the -- you cannot be a grant holder if you don't have a permanent post, and she was the grant holder in that respect, and that was from Stirling. For both studies.

THE CHAIRMAN: Yes, I wonder, if you could find out. There must be a register of grants and I don't think Dr Wilkie should be embarrassed by lack of precise information on this.

A. I'm mortified.

THE CHAIRMAN: I might even relax my usual prohibition on

mobile telephones at this session -- although I see from the computer that someone has one on.

Could your solicitor perhaps make contact with SHHD? We have the rough period. We know the subject and we know the lead researcher, so it shouldn't be difficult.

A. I tried Stirling University.

THE CHAIRMAN: I'm assuming that the pay master might be more reliable in this respect.

A. Well, Stirling University was the pay master because the money had gone there.

THE CHAIRMAN: Oh, so the money had gone there.

MR GARDINER: Dr Wilkie, doing the best you can, your very broad estimate of when you started to work on the haemophilia project is about March/April 1983?

A. Yes, in early summer, I would think, of 1983.

Q. At that stage what specific experience did you have as a counsellor?

A. Well, I had been working with haemophilia patients on the original genetic study in Edinburgh, some of whom were the same patients as in Glasgow, very few of them but some of them. So I was familiar with the problems of haemophilia. I was working with Ivana Markova, who, with Charles Forbes -- I'm sorry, I'm using Christian names and I'm not giving them their titles -- had already written quite a lot about the problems of living

with haemophilia and had already been published. So I was very familiar with that because I had been working with Ivana and been registered with her to develop my PhD.

Q. So the focus of that counselling, am I right in thinking that is really to do with the decision about whether to have children or not?

A. It is much, much more than that. How one copes with the diagnosis, whatever the diagnosis is, what one is going to do about it, how one is going to live, who is one going to tell, what are the problems of confidentiality, do you tell your GP, for example? Or should your GP know, and what about partners.

Q. I'm talking about the genetic counselling at the moment.

A. Yes.

Q. Yes.

A. It's the same thing.

Q. Thank you.

A. There were many incidences in families, particularly with Huntingdon's disease, where the affected person did not tell their husband or wife that this illness in their family had serious repercussions for each and every conception.

Q. Yes.

A. They did not tell them. And I understand that that

still happens but to a lesser extent. It's fear too.

Q. Yes. So when you started on the haemophilia project, you had a considerable amount of experience of counselling. Is that right?

A. Yes.

Q. Yes. Could you just lean a little bit further forward to the microphone, Dr Wilkie, so that you can all hear you?

A. Is that better?

Q. That's great, thank you.

Could you go back to your statement and have a look at paragraph 3. What you say there is:

"While I was already working in Glasgow, in 1983 ..."

And I think we are to understand early summer 1983:

"... Dr Charles Forbes, consultant haematologist, contacted me late in 1983 and asked me to work with his haemophilia patients. There was an emerging realisation at this time that it was possible that a new virus, then called HTLV-III and later called HIV, might be transmitted through blood and blood products."

Then you go on to say:

"Dr Forbes had recently returned from a haemophilia conference in USA where it had been reported that HTLV-III had been found in the blood of some patients

with haemophilia."

And you say:

"Dr Forbes had brought back some testing kits from the USA which were not yet licensed and which could detect the presence of HTLV-III in the blood."

If we just stop there, Dr Wilkie, what is written there in that statement, that is your recollection based on your conversations with Dr Forbes at that time. Is that right?

A. Yes.

Q. How confident are you that those conversations took place --

A. Well, it was a phone call.

Q. It was a phone call?

A. Yes. From somebody who was agitated about what to do next. I should say that Dr Forbes had wanted me to work with him for some time and I had been reluctant to do so, not because of Charles himself but because I was much more interested in diseases that were transmitted in a autosomal dominant way, rather than haemophilia that had been well researched. So he said, you know, "You must come and work with me now, please".

Q. Could you just explain to us what you mean by autosomal dominant?

A. Autosomal. There are several ways of transmission of

a genetic disorder. Autosomal dominant means that if I have the disorder, let's say I have adult polycystic kidney disease, each and every one of the conceptions that I have has a 50/50 chance that they have not inherited the gene but equally a 50/50 chance that they have. And if they have inherited it, they will develop the illness; not necessarily today but some time in the future.

Q. How is that different from haemophilia?

A. Haemophilia is sex-linked recessive. In autosomal dominant it can be either the male or the female that carries the gene. In sex-linked recessive it is the female who carries it and only males are effected, in the normal course of events. Females can be manifesting carriers. They can have problem with their periods but they are not so severely affected as the men.

Q. Am I right in thinking that at that time, sex-linked recessive disorders like that were quite well researched?

A. In haemophilia -- I don't know about throughout the whole of the UK but certainly in Scotland and particularly in Glasgow Royal, there had been a lot of work done about different aspects of haemophilia. I mean, haemophilia had been well researched from the medical side but this was the psychological and social

side -- had been very well researched by Charles and Ivana. And published. I mean, it's in the literature.

Q. As opposed to the autosomal dominant?

A. Very little, hardly anything. Nothing about adult polycystic kidney disease.

Q. Is that why you were less attracted to researching --

A. Yes, and it was Charles Forbes who introduced me to Arthur Kennedy, who was then professor of renal medicine -- or professor of medicine but renal medicine was his speciality -- who allowed me to work in the unit.

Q. Yes. So how long would you say that Dr Forbes had been trying to persuade you to come and help with this project, the haemophilia project?

A. He didn't have to persuade me to work on this project. The minute he explained to me, I said okay, but he had been trying beforehand -- he had been trying to encourage me. He was -- is a man of great vision and the fact that he had worked with Ivana Markova, a psychologist and in fact a social psychologist with a particular interest in language, was really quite remarkable.

Q. Yes. So what was he trying to persuade you to become involved in before that?

A. Doing more work with haemophilia patients on the genetic

side.
Q. On the genetic but not on the coping side, the psychological side?
A. Not particularly, no, no.
Q. When Dr Forbes phoned you and proposed that you help with that aspect, did you immediately say yes?
A. I said, "I'll come and speak to you".
Q. Yes. Is it your recollection that it was shortly after he had come back from America?
A. Yes.
Q. Okay.
A. But I don't know -- I'm sorry, I really don't know the dates of this precisely.
Q. Yes. Yes.
A. It's a long time ago.
Q. We understand. We are all struggling with the dates a bit. Is it possible that, instead of 1983, we are talking about 1984 here?
A. Well, it would need to have been the beginning of 1984.
Q. Why are you so sure that it would have to be the beginning --
A. I'm not -- because I had started -- I mean, I can see from the work I have done and the thinking that has gone into it and my notes, some of which I still have, about writing and about the work with HIV and the cuttings

from the newspapers and the journals, that I had already been collecting them by then.

Q. These are your own handwritten notes?

A. Yes, some of them, jottings, most of which I have burned now. I have boxes of cuttings from newspapers and academic journals about HIV and they date from 1983 onwards.

Q. Yes. What are the earliest notes that you have that relate specifically to this project?

A. I don't date my notes, I'm sorry.

Q. Okay. Right.

A. I would do so now, though.

Q. Yes. But it could be 1984 that we are talking about here. That's possible, is it?

A. It could be but I genuinely don't know. I'm really sorry.

Q. That's fine. If we could just go back to your statement at page 2, at line 5 you say:

"Dr Forbes had anonymously tested the blood samples of a couple of patients with haemophilia and discovered that both samples were HIV positive."

Can you expand on that, please?

A. This is what he told me, and that he had realised that this should not go any further and that's why he phoned me.

Q. Yes.
A. I was already a member of a research ethics committee in Edinburgh and I had a very great interest in ethics and how things should be done and consenting people and transparency, things that are still not quite with us. They are getting better but they are not perfect.
Q. Yes. You said that Dr Forbes sounded agitated?
A. Yes.
Q. Yes. Do you know how quickly he had carried out these tests after he came back from America?
A. I had understood that was very quickly but, I mean, again, it's recall.
Q. Of course. By "anonymously", do you mean that Dr Forbes didn't know which patients he had tested?
A. That's what I had understood.
Q. Yes.
A. I'm sorry, I don't know -- I mean, how they are marked in the fridge. I mean, there must be some way of tracing them back to whichever the patient is but I really don't know. That wasn't my field at all.
Q. Yes. Thank you. Just reading on in that paragraph, you say:
"Dr Forbes did not know if the samples belonged to severe or mild haemophiliacs. He had done nothing wrong in testing these samples ..."

And so on. Then the last sentence in that paragraph:

"He was very concerned about the results of the tests and I think he stopped testing for ethical reasons."

It might seem an obvious question, Dr Wilkie, but why was he very concerned about the results of these tests?

A. Well, what was he going to do next? That was one of the problems, and if there were two people who were positive, then how many more and what was the size of the problem in GRI? I mean, it opened up a can of worms -- that's not the right expression, not an appropriate expression but I can't think of a better one at the moment.

Q. Yes. Thank you. Are you able to tell us who Dr Forbes had obtained these kits from?

A. I had understood that he had brought them back from the States, that's all I know.

Q. Thank you.

A. It was never something that we discussed. I mean, things were moving at such a fast rate that it was never something that was again brought up.

Q. Yes. Okay, thank you. Just moving on to paragraph 4 you say:

"The reason Dr Forbes had contacted me was because he was agitated about the test results. He wanted me to use my skills to help his patients. He wanted me to establish what people with haemophilia knew about HTLV-III and if they knew about the existence of the virus and whether the patient thought that they may be affected. Also he wanted me to find out if the patients would like to be tested for the virus if a test was available."

Given these questions that Dr Forbes was interested in you exploring with his patients, did you form the view that Dr Forbes had not talked to his patients about the virus at this stage?

A. I didn't form any view. That has never crossed my mind, I am afraid.

Q. Okay. Thank you.

A. One would need to also look at what information was available at the time in a slightly wider community, not just in a narrow research community as Dr Forbes was involved in, but what information was known to the whole of the haematologists and what was available to the public.

Q. Yes. I'm just struck by this, you say:

"He wanted me to use my skills to help his patients find out if they knew about the existence of the virus

...""

I'm just suggesting that raises the question of whether Dr Forbes had discussed it with his patients, but you don't have a view about that?

A. I don't know to what extent it had been discussed with patients but when the project started, patients had not been tested, nor had they been informed, to the best of my knowledge, and it wasn't until a little later into the project that a decision was made by Drs Forbes and Gordon Lowe that the patients should be told -- they should be tested.

Q. I'm really talking about the stage before that, Dr Wilkie, the stage whether the patients even knew that there was such a virus, and potentially transmitted by blood products that they had been taking?

A. I had no evidence and it didn't come up in discussions. I mean, there were a lot of things that the patients knew about, and they knew about which treatments worked better and the problems of certain treatments. They were also -- although they came from the east end of Glasgow or the west coast of Glasgow, they were also very wise, the majority. Although their educations -- well, some of them -- many of them -- were poor, they were knowledgeable. A lot of the information they got from the Haemophilia Society, may I say, the severe

haemophiliacs.

Q. Could we just pass on to paragraph 56 your statement. You say:

"I accepted Dr Forbes' offer and generally working for three days with the kidney patients and two days with the haemophilia patients. A small research project was set up to establish what did patients know about the genetics of haemophilia, what did patients and their families know about infections and haemophilia and what could be done about any infections and what treatments did the patients think were available."

Just to be absolutely clear, who funded this project in the end? It was the Scottish ...?

A. Home and Health Department.

Q. -- Department.

A. The initial project, and then there was an additional project for me from the Haemophilia Society.

Q. Yes.

A. At the end of the project.

Q. It was funded by the Scottish Home and Health Department but I think you said it was administered by --

A. Ivana Markova.

Q. Yes. Is that at Stirling University, Stirling?

A. My understanding for this is that Stirling University was very good administratively, so that the grant

holding went there.

Q. So who drafted the proposal?

A. Charles, Ivana and I.

Q. Thank you. Just reading on in paragraph 5, you talk about:

"Dr Forbes was a very ethical man with far-reaching ideas ... at that time there was very little information about the mortality rates of haemophilia patients. Dr Forbes wanted to improve this situation so started compiling data. Also working in the department at this time were Dr Gordon Lowe, Sister Ishbel McDougall and a registrar, Dr Madhok."

Just passing on to the next paragraph, paragraph 6 you say:

"Not long after I started working for Dr Forbes, a letter was sent by the haemophilia department and signed by me, to all the patients asking whether they would like to speak to me about issues relating to haemophilia."

Do you have an approximate date for that, Dr Wilkie?

A. I have no dates for it again. I'm sorry.

Q. That's fine.

A. It's very bad practice, I have to say, and it's something I would criticise research students that I have. You must always date things but at that time we

were learning.

Q. Just reading on:

"The letter was in very general terms, inviting patients and their families to make an appointment to speak to me about haemophilia, its treatment and any concerns they may have."

Approximately how many patients would that letter have gone to?

A. There were approximately 216 patients with haemophilia registered in the unit at the time, approximately. And the letter went to the great majority of patients. We eliminated -- there were some people who lived in Orkney for example, and people who are very frail because they were older, these would be mild haemophiliacs. We didn't involve them. So it was about 200 we sent letters to and after the first interim report we had interviewed about 115.

Q. Yes.

A. The intention was to have two interviews quite close together but because of the infirmity of the patients, we did one very long interview followed by a questionnaire.

Q. Yes. What was the date of the interim report?

A. I have no date, I'm sorry. It's appalling.

Q. Yes --

A. I gave it to you but it has no date on it.
Q. Okay. Just broadly, how long did it take before --
A. I would have thought it would be some time, 1985/1986. It would be about that time.
Q. So between the time that you started and 1985/1986, you saw approximately 115 of these patients?
A. Yes, some of that included either a parent or partner or a sib or a child; seldom children.
Q. Would you be able to say how many of that 115 were patients?
A. About 100 of them, I think.
Q. 100? Thank you.
A. And these were all severities, not simply -- because there were relatively few severe haemophiliacs.
Q. Yes. Just reading on in your statement at paragraph 5, you say:

"This letter was sent around the time when there were lots of lurid headlines in the press about HIV and AIDS. The newspapers reported cases of haemophiliacs being infected with HIV through blood products. There was a general feeling of fear and panic in relation to HIV and AIDS as so little was known about the virus."

Just to clarify, was the general feeling of fear and panic just amongst people with haemophilia or was it in the public generally?

A. Oh, the public generally. Totally. And also amongst staff, not the staff of the haemophilia unit but the staff in the hospital, staff in care homes, staff on general wards in the hospital. Not peculiarly GRI but other places.

Q. How did that fear and panic manifest itself in those people?

A. Well, one patient was in a care home and he was allocated his own china. The blood products -- if a sample was going at that time to the laboratory, if it was a sample for somebody who was HIV positive, it went in a special box which would identify to those who were wise, including porters, that this was a patient who was HIV positive.

Patients weren't able to get the telephone, one of these mobile phones that come up to your bed, until the last patient had used it and then it had to be properly cleaned. Ambulance drivers were concerned about carrying patients who were HIV positive. I'm not talking peculiarly about haemophilia patients. I mean, it was throughout the caring professions, healthcare professions as well as the general public.

Q. Yes.

A. There was never a day when the press didn't have something. And it wasn't just the tabloids, it was also

the broadsheets.

Q. Yes, thank you. The next sentence says:

"As a consequence, the general attitude to haemophiliacs at this time was diabolical both among hospital workers and the general public."

Could you just expand a little bit about the general attitude to haemophiliacs being diabolical?

A. Unlike other people who may have tragically acquired HIV, haemophilia patients were known generally to have haemophilia, particularly severe patients. It was known by the GP, it was known in the community that they lived in, it was known by friends, it was known by clubs that they belonged to. It was known by the family and the family's wider friends.

Suddenly they perceived that they had become something that was not desirable. Instead of being able to continue to live their lives, they became more isolated. And it was tragic because this was a time when the treatments for haemophilia had improved the quality of life and they were now back again -- receding backwards to a time before, and people -- I mean, the gay community were well supported. There was nothing quite the same for HIV positive haemophilia patients.

Q. Yes. Thank you. Just reading on in that paragraph:

"Many of the patients I saw were from the east side

of Glasgow and hadn't been able to go to school for much of their young lives due to their condition. They had no qualifications so couldn't get good jobs, manual labour was not possible due to their haemophilia. Many of the patients relied on benefits so life was a struggle. Most of the patients I saw who had severe haemophilia are now dead."

A. The reason I know that is that for some years the Haemophilia Society had an obituary at the back of it, and I saw these patients, because I'm a member of the Haemophilia Society. I saw the names but I don't know about all of them at all.

Q. Yes. Thank you. Just moving on to next paragraph, you say:

"Almost all of the 20 or so patients I wrote to agreed to meet me."

A. These must be the patients who were HIV positive.

Q. Oh, right, okay. So we have gone through testing and these are people who have been identified as being positive. Is that --

A. These would be the severe haemophilia patients, I think.

Q. Right.

A. In fact, in a study nobody declined to come and speak, nobody at all.

Q. Yes. So --

A. I think it says something.
Q. I think in the previous paragraph you wrote to or a letter was sent by the haemophilia department to 200, and this is you specifically writing -- this is a separate letter, is it?
A. No, no, the same letter but then an arrangement was being made to meet them.
Q. Yes. So these 20 patients are people with severe haemophilia?
A. Yes.
Q. Thank you.

You say:

"Glasgow was ahead of its time in taking me on as a counsellor. I think GRI was the first haemophilia unit to employ such a person. My role as a counsellor gradually took over from my role as a researcher. I met the patients both individually and with their partners. I would discuss the implications of testing for HIV with each of the patients. I would discuss the implications of being tested and there being a positive result and the implications of not taking a test."

Could you just expand a little bit more. The interviews you are talking about here, is this pre-testing --
A. No, this is the research interview.

Q. Yes.
A. This is the research interview.
Q. Right. So is this after testing then?
A. No, before testing.
Q. This is before testing?
A. Yes.
Q. Right, I see. So could you just expand a little bit on how an interview like that would go, Dr Wilkie?
A. Right. There was a schedule, which I sent in actually, and one would ask them first of all how haemophilia had affected them in their life, what were their fears, and it is interesting the findings of the research but also what they said to you, because part of it was that the more severe the patient, the less they were concerned about HIV and AIDS, the more several affected they were.

They were more concerned about the control of pain, the fact that money was a problem, that they had no work and so on. I mean, these were all the issues that they were concerned about. One needs to remember that this was at a time when there were very few patients with florid AIDS. So that hadn't yet reached the headlines but this is how the severe haemophiliacs approached things.

They were also quite -- what's the word? -- accepting. They took what life -- most dignified

people. It was a privilege to work with them. But they took life on the chin and they assumed that if there was anything nasty in the blood, they would have it because of the amount of blood they had used -- blood products. I'm using that in a general sense.

One would discuss the implications if they were tested, the implications for their partner, or partners, and that was a big area. Easier when they were in a stable relationship. And it was also tricky because some of these men were really very disabled and I am afraid I assumed that sexual activity was negligible. And to keep their dignity, one did not probe down that line at all, or not very much. But with the younger men, who were not in a stable relationship, actually what emerged -- I'm jumping slightly -- was that this made it more difficult for them and they went on one-night stands much more, rather than getting involved in a stable relationship when they would have to tell somebody that they were HIV positive.

Q. You are talking about a time after there has been a test?

A. Yes.

Q. And I'm just concentrating on interviews --

A. I appreciate that. It was my brain going down one line, sorry.

Q. No, that's fine. But is it your recollection that you saw 20 patients with severe haemophilia before they had been tested?
A. Yes, yes.
Q. Yes. Thank you.
In the next sentence you say:
"The majority assumed they were HIV positive."
A. Yes.
Q. So this is before they have had a test?
A. Before they had confirmation. Yes, before they had had a test with confirmation.
Q. Yes.
A. Yes.
Q. Yes. Well, which is it? Confirmation ...?
A. Before they had had a test. They assumed that they would be positive because they had received so many blood products.
Q. Yes.
A. That was the assumption.
Q. Yes. I mean, can you remember what Dr Forbes told you about what testing was going on at this stage?
A. No, I can't remember.
Q. Okay. You can't remember --
A. In terms of testing the patients?
Q. Yes.

A. I would know -- once I collected this information, I fed this back to Dr Forbes -- that these patients had been seen, this is what they knew and then there was a discussion about testing, that this patient was happy to be tested, that patient wasn't.

Q. I see.

A. There were one or two who didn't want immediately to be tested.

Q. Yes. So part of your job was to find out whether the patients wanted to have a test?

A. Yes, yes, but that was part of giving them all the information about what the implications of being tested were.

Q. Yes. If we exclude the first two patients that have tested with the kits from America, when you started this project, had any of Dr Forbes' other patients been tested?

A. No, no.

Q. Thank you. Just reading on in paragraph 7, you say:

"One patient didn't want to know."

A. That's correct.

Q. And so --

A. Not immediately. I mean, he came round to it eventually but it was some time later and he came of his own volition, nine months later.

Q. Yes. So if we imagine an interview with a patient who didn't want to know then, you would simply feedback to Dr Forbes, "This patient doesn't want to be tested"?
A. And that would go in the notes. So nobody would speak to him about it.
Q. Right. Within this paragraph, I think we move to the post-test interviews because in the next sentence you say:

"Often I was the one who told them."

Are you meaning there that often you were the person who told the patients that they had tested positive for the virus?
A. Yes.
Q. Yes, okay. So perhaps you could just explain to us how a post-test interview would go, distinguishing it from a pre-test interview?
A. Well, this would be done in the clinic rather than in the counselling room, and I should say that counselling was often done in the renal unit because I had a very nice room in the renal unit, and the geography was very easy. But it would be done in the clinic and I would attend and I would say, "We are here today", or Dr Forbes would say, "We are here today to look at the results". I mean, there would be other things they were looking at but they were here today to look at the

results of the HTLV-III test. And the patients usually said, "Oh, I know, doctor, that I will be positive", and one said, "Yes", and then one went on to talk about the implications.

Q. Was that always with Dr Forbes that you performed this exercise?

A. I really don't have any recollection of doing that with Dr Lowe but I may have done on some occasions but it was nearly always with Dr Forbes.

Q. Yes. Dr Wilkie, just doing the best you can, can you hazard an estimate of how many patients you personally delivered results to?

A. It's very difficult because I don't know the answer but also because I must emphasise, these patients knew in their heart of hearts. I think we are applying the knowledge of what should happen now in 2011. These men knew that they were at high risk because of blood products they had received. They had read all the information.

Q. Yes.

A. I'm sorry, I don't know. I'm not being difficult. I just don't remember. One feels a fool when you don't remember.

Q. You just have to tell us what you can remember, Dr Wilkie, but are we talking more than five people?

A. No idea, I'm sorry.
Q. But at least one person?
A. Oh, yes.
Q. Thank you. Then just reading on --
A. Can I just say something about this? Even if they had been told by one particular clinician, there is a lot of academic evidence that people are often stunned even if they had suspected that this was the result, and what they needed afterwards was somebody to go over it again and say gently, "Yes, the results are positive and these are the implications".
Q. Yes. So on some of these occasions you think possibly the patients had already been told by the doctors but as part of the process you were being asked to tell the patients --
A. I found myself in a position to follow it up.
Q. And tell the patients again? Can I just ask you a little bit about the academic evidence that you referred to? Can you give us any references for that?
A. It comes from the genetic world. I haven't got them here off the top of my head but I can certainly send you them very quickly. There are lots of references about getting bad information -- and in cancer studies as well -- well documented.
Q. And what's the conclusion of these studies, Dr Wilkie?

A. That one needs to often repeat information that's given when one is receiving bad information. I'm using "bad" in inverted commas.
Q. Yes. Please correct me if I am wrong, but I imagine that's because the patient, the first time, has difficulty accepting the information or --
A. In taking it all in. In genetics we discovered, in the project that I was doing and working with clinicians, that if you gave all the information in a hour's interview with a patient and perhaps their next of kin, you could see that they glazed over, and what one needed to do was write them a letter immediately afterwards saying, "Dear Mr So and So, we saw you yesterday and this is what we discussed," so that they had an aide-memoire. That became the way that the Clinical Genetics Society recommended for all genetic interviews. It's very important. It's just one example of people understanding. That was in the 1980s, when I understood that. It is now being taken on board by other specialities, a long time later.
Q. So, as well as the academic evidence, you have personal experience of this phenomenon?
A. Yes.
Q. And the practice of following up with a letter after an interview, was that something that was followed --

A. We didn't do that because of confidentiality. But I did inform them that there were different issues discussed, like insurance.

Q. Yes, thank you. If we go back to paragraph 7 and keep reading there -- and I think the context is a post result interview -- you say you would discuss the implications of a positive HIV test, including information about the sexual transmission of HIV. Insurance was also discussed and indeed you tried to persuade the government to be an underwriter.

You say:

"Confidentiality and who should know about the positive status was also discussed. As was how to tell existing and new partners. I don't remember there being very much treatment available if the result was positive."

A. I tried to persuade the government to be an underwriter. I spoke at an actuarial conference and tried to persuade the government to underwrite, so that people who were severe haemophiliacs could get an insurance policy at an upgraded -- I mean, they would be loaded but the government would underwrite it. But they didn't take it on board. I tried.

Q. Yes. In terms of treatment, you say that you don't remember there being very much treatment available and

you say:

"I think some patients were prescribed AZT."

Our information is that that wouldn't have been available until about 1987.

A. Yes, in 1987. And there was one patient who died in 1987 that I was very familiar with and he had been treated with AZT.

Q. So does that make it likely that at these initial post-test interviews that you did there weren't really --

A. There wasn't much to offer.

Q. Right, thank you. And you say:

"There was not much information at that time, so I got help from the Terence Higgins Trust, as well as the gay community in Edinburgh."

Could you just briefly tell us what help you got from the Terence Higgins Trust and the gay community?

A. I got information about the latest treatments and the extent of the problem in the gay community and how they were reacting to safe sex. That was what I got from both communities.

Q. Yes. Thank you. Just thinking about the post-test interview again -- and again it may seem like an obvious question, Dr Wilkie, but how did patients react to the news that they had tested positive?

A. Life had been cruel to them and it wasn't -- I have worked also with cancer patients more recently. It wasn't like getting a terrible diagnosis of a rapidly developing carcinoma in a child, let's say, which would be sudden; they took it -- that's what they would have expected, they said. You know, "This is what has happened to us."

Q. Were there any relatives present at these --

A. Sometimes they brought a wife or a girlfriend, sometimes.

Q. And again, Dr Wilkie, how do you remember the relatives reacting to the news of a positive test?

A. Wives were -- other halves, wives, were concerned, concerned about the implications for looking after them, and at that time although one knew how HIV was transmitted, for the wife, who was often the housekeeper, the home maker -- domestic chores: what did they need to do, how careful did they need to be.

I think in some of the articles that we wrote we had evidence that a mother went round after her son and poured lysol, quite a strong disinfectant, every time he went to the toilet. She had big rubber gloves on and she was cleaning it and popping it down.

So there was that as well. So one was able to discuss with them what are reasonable ways of dealing

with things and that, apart from intercourse and blood, the likelihood of it being transmitted in normal domestic living was negligible.

Q. Yes. Thank you.

A. We also discussed the heat treatment, or the possible heat treatment, of blood products and blood donations and I remember giving an example of the pasteurisation of milk.

Q. So you remember explaining to patients how blood had been inactivated by heat treatment?

A. Yes.

Q. Thank you. To return to this question of the patients absorbing the information, did you get the impression that these specific patients that you had interviews with were able to absorb this information at the first meeting?

A. Yes, because it wasn't out of the blue for the majority of them. Also, they did have the opportunity -- I was around. The hospital switchboard had my telephone number and if patients wanted to contact me -- I lived in Edinburgh all this time. If the patients wanted to contact me, they asked the hospital switchboard if I wasn't -- they contacted me sometimes at the weekend, not infrequently out-of-hours, and I would then speak to them. So I was available to talk to them.

Q. Yes. Thank you.
A. To listen actually. I think that was the important thing.
Q. Thank you. To move on to paragraph 8 now, you say there:

"I was also involved in counselling the patients with regard to their sex lives. The issue was quite sensitive as people with haemophilia may not be sexually active because of their disability and might not want to disclose this. We talked about the risk of transfer of the HIV virus through semen and the importance of using a condom. If the patients didn't want to be tested, I advised them it was better to assume they might be HIV positive and always wear a condom."

A. That's the whole lot of patients now? We are not talking about peculiarly about the severe haemophiliacs: the totality of the patients.
Q. Yes, thank you. Then, reading on, paragraph 9:

"I tried to persuade the haemophilia unit to provide condoms."

And you wrote to Richard Branson and asked him for a sample:

"He sent a large suitcase full of condoms. I wanted them to be in the haemophilia treatment room, where the patients could help themselves, but they were hidden

away in a cupboard. This reflects an attitude in the clinical medical world at that time. The attitude towards prevention of infection has now changed."

Could you explain what you mean by hiding the condoms away relating to an attitude at that time?

A. The haemophilia clinic room had a whole lot of dockets with swabs and needles and syringes for patients who were on home treatment and they would come in and help themselves. I wanted condoms to be put in one of these dockets. An arrangement was made that patients -- remember, these are east end of Glasgow, mainly, men -- could go to the family planning clinic on a Friday afternoon and pick up condoms there, having seen somebody. In no way were they going to do that and I wouldn't have even asked them to do it. That was not on.

The family planning clinic at that time was in the basement of the hospital and the haemophilia unit was on the first floor and some of these men had considerable mobility problems, so I asked the family planning clinic if I could have a supply of condoms to put in the unit: "No, not unless the patient appeared in person."

That was not on. So I then wrote -- Richard Branson was doing a publicity stunt and I then wrote to him and he sent this suitcase of what I call 57 varieties and we

put them in -- I suggested they go in a docket but that wasn't acceptable and they were put actually in the bottom of a cupboard, which was very difficult for the patients to get into. I was very angry but I managed to change it eventually.

Q. Which doctor didn't want the condoms to be on such general display?

A. There was a feeling that people would steal them but they didn't steal the needles. They were unlikely to steal them. And even if they did take more than they needed, it didn't matter. It was a general attitude.

Q. Yes. What was that attitude, Dr Wilkie?

A. For a haematologist to discuss sexual matters was not -- they weren't trained to do it. It was difficult.

Q. Yes.

A. And it became -- it was a wider issue. It is difficult to discuss unless you are trained to do so and able to do so. It's very difficult.

Q. Yes. So do I take it that some of the doctors were embarrassed to address this subject?

A. Yes.

Q. Thank you.

A. And possibly not just the doctors. Other staff as well.

Q. What other staff are you thinking about?

A. Well, there was the nursing staff who were not

comfortable either because that had not been their relationship with the patients.

Q. Yes, thank you. Just to move on to paragraph 10, you say:

"I tried to be available to help the patients as much as possible. They could write to me or phone me at any time via the hospital switchboard. I tried to be as positive as possible and give the families glimmers of hope. I believed that because HIV was a worldwide problem, commercial companies would be working very hard to produce drugs to treat the infection. The Terence Higgins Trust was making huge efforts to raise the profile of HIV and AIDS. Consequently, the HIV positive patients from the gay community were obtaining good treatment in the best hospitals in London. In Scotland the haemophilia community was not necessarily getting the best treatment."

You did touch on this earlier but could you expand a little bit about what you mean by the haemophilia community not getting the best treatment?

A. Well, it was to do with being -- I don't know the level of severity of their HIV and how near approaching they were to AIDS, and some of them did develop fully blown AIDS while I was there, but the gay community in London had a much better documentation of how severe people

were and how ill they were and what sort of treatments were available. That information didn't appear to be so widely available to the haemophilia population in Glasgow. I would imagine that would be true throughout the country. We are working with two different groups of people and the gay community and the doctors who worked with them were extremely vocal and powerful. In fact I would suggest that it's that that has changed the patient movement that has developed so strongly since the 1980s.

Q. We have heard that before, Dr Wilkie.

Just reading on in that paragraph -- this is over the page at the top of page 5:

"Patients tended to put on a brave face and tended to minimise the significance of the problems they faced."

Why do you think that was?

A. Because that's what they had always done. This is particularly the severely affected haemophilia patients. They had always done that. Okay, there would be one or two who moaned but they were exceptionally brave and dignified people. It's not particularly true of the more mildly affected patients with haemophilia, who tended -- and we discovered this in our study -- to be more like the worried well that come into GP surgeries.

They were concerned that they would get HIV where their chances were minimal or negligible.

Q. Yes, thank you. Just moving on to paragraph 11, you say:

"At this time compensation was an issue. Patients and their families were struggling financially."

And you would:

"... refer them to the Haemophilia Society to get the Society to lobby for them."

You say:

"I was angry at the government's attitude to compensation for infected haemophiliacs which was along the lines of, 'It's not as if they were fit to begin with so they shouldn't get compensation'. After hearing that I wrote a strongly worded letter to the Guardian and it was published the next day."

Do you remember the date of your letter to the Guardian?

A. No, and I have tried to get it but I haven't succeeded.

Q. Before we have a look at that, could you perhaps expand a bit on why you were angry about the government's attitude?

A. Because --

THE CHAIRMAN: Mr Gardiner, remember this Inquiry is not dealing with compensation. There is argumentation in

that letter that I frankly do not want to become part of the proceedings of the Inquiry. I think that Dr Wilkie's use of this as a staging post is important but I am not prepared to allow any impression to be conveyed that I'm changing my mind about the scope of my obligations.

MR GARDINER: Yes, thank you, sir.

Well, perhaps, Dr Wilkie, you could help us with the question of how families managed at that time with the loss of earnings, which a patient would normally be earning but for the illness.

A. We had to refer them to social work departments but then not all patients wanted to go to the social work department because of confidentiality. They were referred to the Haemophilia Society but then the need for money wasn't really so acute -- I mean, it was acute but they had already been needing money because of their haemophilia.

Q. Yes, thank you.

THE CHAIRMAN: I think it's quite important. I think Mr Gardiner may have leapt forward to assume that these were people who had jobs and had to give them up because of HIV, but that's not the position?

A. No, there were very few in that category. There were some but there were very few.

THE CHAIRMAN: Yes, thank you. Most of these people just didn't have work at all because of their haemophilia.

A. They possibly had never worked because of their severe haemophilia. Some of them did but I wasn't seeing them at a time when they had become seriously ill because of HIV. I must make that clear.

THE CHAIRMAN: Yes, thank you.

A. Except for one patient.

MR GARDINER: If we just move on to paragraph 12, you say:

"I don't remember whether patients were warned of any risks before being given blood products. I doubt that any patient receiving blood products at that time had received such information. It was a very busy haemophilia unit and most people working in the unit were dealing with the day-to-day care issues and not considering wider implications."

You are speculating to a certain extent here, Dr Wilkie. Do you accept that?

A. Yes.

Q. Perhaps you could explain to us the basis of your doubts that patients had received this information.

A. Well, most patients at that time didn't receive any information about the risks of procedures. It wasn't part of the culture of the medical or nursing professions.

I mean, if one went for a hip replacement, one wasn't necessarily told that one was going to get a particular synthetic product put in one that might disintegrate in four years' time. This information just wasn't used. It's recently that giving information and giving consent has come into being. There was also an assumption, and still is, that if somebody sticks out their arm, they are expecting the needle to be put in and that's an implication that they are happy to have that done.

Q. Yes.

A. So I mean, that culture was there at that time.

Q. Yes. Justed reading on, you say:

"A general assumption not peculiar to GRI nor to haemophilia units was that patients would not really understand what the risks were even if they had been explained to them."

A. That's certainly true of all medical units, not haemophilia units. At that time you don't understand, you know -- it's still true in some areas.

Q. But, Dr Wilkie, of course, you are expressing a personal opinion here.

A. I'm looking at it from a General Medical Council point of view, where I had helped to write the paper on consent and from a previous fitness-to-practise

panellist. It's a bit more than that.

Q. Yes.

A. I could give you a lot of references.

Q. Yes, I understand. I want to focus on the assumption in this paragraph here, by which I assume you mean an assumption amongst the doctors. Is that right?

A. Yes, yes.

Q. So an assumption amongst doctors that patients would not really understand what was being explained to them?

A. Hm-mm.

Q. Can you explain to us the basis of your view about that general assumption at that time?

A. Because the profession itself -- the professionals in the wider sense of the word -- didn't quite know what the risks were themselves. There was such uncertainty about them and that means it's even more difficult to explain it to patients. Doctors at that time were paternalistic. There is a very good book written by J Katz, an American, who is both a doctor and a lawyer. It's about uncertainty, judgments under uncertainty. If in fact one has been paternalistic and then one has to say, "I'm not really very sure," that shows the doctor, the healthcare professional, in a weaker position. That's where I'm coming from.

Q. That's a general statement but focusing specifically on

Glasgow Royal Infirmary at this time, was that your personal experience, that there was a general assumption amongst the doctors that patients would not understand?

A. That some patients would not understand.

THE CHAIRMAN: Mr Gardiner, time?

MR GARDINER: Yes, indeed.

THE CHAIRMAN: The second half of the paragraph, I think, changes context sufficiently to break.

Dr Wilkie, was it an aspect of this concern of doctors that if they communicated to patients their own uncertainty and lack of knowledge, that would have an adverse effect on the relationship?

A. Precisely.

THE CHAIRMAN: Yes.

A. Precisely because they had been paternalistic and kindly and it shows their vulnerability, yes.

THE CHAIRMAN: So they are human too, are they?

A. Absolutely.

THE CHAIRMAN: We will have a break.

(11.02 am)

(Short break)

(11.27 am)

THE CHAIRMAN: Right? Yes?

MR GARDINER: Thank you, sir.

Dr Wilkie, I think you should have in front of you

a bit of paper which has "Health in Scotland" on the front of it. I'm very grateful to the Scottish Government representatives who have been busy researching the question of when your grant was awarded for this work.

THE CHAIRMAN: I'm grateful too, very efficient.

MR GARDINER: If we look at page 81. Unfortunately this isn't in courtbook. We can just look from the paper copies at the moment. Page 81 at the top, "Research projects", we see:

"Projects approved during 1985 with support from Exchequer funds."

Then if we go to page 85, just over the page, half way down we see:

"Professor I Markova."

Do you see that, Dr Wilkie?

A. Yes, I have it.

Q. "Dr DC Forbes, department of psychology, University of Stirling. Coping strategies of haemophilia patients who are at risk of AIDS."

So that's your study, isn't it?

A. Yes.

Q. So it does looks as though the award was made in 1985?

A. That would appear so but I was already working in Glasgow Royal at that time.

THE CHAIRMAN: Could we work back from the date of the award, because there would be a period of assessment of what you submitted?

A. Oh, yes.

THE CHAIRMAN: Does that involve discussion with people, interviews and so on, or is it just a paper exercise?

A. To the best of my knowledge it was a paper exercise.

THE CHAIRMAN: Then before that you need the period of working up your submission for the grant?

A. Yes, but I was already there in the hospital working.

THE CHAIRMAN: I'm trying to get back to the beginning slowly. Let's see if we can put a timeframe on it, Dr Wilkie.

A. I thought it was earlier than that. That was my impression. But I may have been working without being paid formally by this grant.

THE CHAIRMAN: I just have the impression from university work that sometimes it takes quite a considerable period of time between the thought that there should be a project and the realisation of that in money terms.

A. And the money actually coming, yes. I have been a researcher all my working life and the work starts and the money follows. If you are lucky.

THE CHAIRMAN: If you are lucky. But you don't have any feeling now for how long that process might have taken

in this case?
A. My impression is that I was already working before the money came.
THE CHAIRMAN: Yes.
A. I'm really sorry. I can't help anymore.
THE CHAIRMAN: No.
MR GARDINER: So already working on this project before the money came?
A. Yes.
Q. Doing the best you can, Dr Wilkie, how long do you think you were working on it?
A. I really don't know. I'm sorry, I would like to help but I really don't know. My impression was, from what I have seen in the volume of work I produced, it would have been very difficult to have produced it all if the funding only started in 1985. I must have been working beforehand.
Q. But maybe not as much as a year. Would that be fair?
A. I have no idea. I really don't know.
Q. It could be a year then?
A. It could be.
Q. All right. Just to try to focus in a little bit on the date, I would like to look at a couple of documents, which you probably haven't seen before, Dr Wilkie. The first one is SNF0010255. If you see at the head of

that bit of paper:

"Note of meeting of haemophilia directors and SNBTS representatives on 29 November 1984 in St Andrew's House."

We see those present and the second in the list is Dr Forbes. So Dr Forbes was present there. If you go down to paragraph 4, we see the report from Dr Forbes:

"Dr Forbes described the findings relating to HTLV-III antibody seroconversion in a comparative study of haemophilia patients in Glasgow and Denmark. This study would shortly be published in the Lancet."

Sir, we have considered that in the preliminary report. So if could we have a look at that, which is LIT0012478. This is our preliminary report, Dr Wilkie. It was produced before the hearings started. If you look at paragraph 8.105, there is a description of this meeting and it says --

THE CHAIRMAN: We are not there, Mr Gardiner.

A. I haven't got it yet.

THE CHAIRMAN: This is chapter 7.

MR DI ROLLO: You said 8.112.

MR GARDINER: 8.112. Try that. Paragraph 8.105.

There we go – page 32 of LIT0012479.

So, Dr Wilkie, could you look at paragraph 8.105, where we have a description of this meeting:

"At that meeting, outbreaks in three centres were discussed. Dr Ludlam explained that 16 haemophilia patients treated exclusively with SNBTS Factor VIII had developed antibodies to HTLV-III."

Then the next line is what we are interested in:

"Dr Forbes described the findings relating to HTLV-III antibody seroconversion in a comparative study of haemophilia patients in Glasgow and Denmark. The Glasgow research was subsequently included in an article published in the Lancet on 22 December 1984. It was a study by Melbye, Frobel and others of HTLV-III antibody in 77 Scottish haemophiliacs and 22 Danish haemophiliacs."

If we just look at the footnote there, which is at 161, we will see the name of the article. If we could go to that article, which is DHF0026016, at page 4. It will come up on the screen in a second.

Page 4 is a description of the study. If we could go to page 5 in the right-hand column -- just move up a little bit -- we see the paragraph that starts:

"In Scotland 11 (18 per cent) of 62 Haemophilia A patients and 1 (7 per cent) of 15 Haemophilia B patients were HTLV-III positive (tables 1 and 3)."

So it's a long-winded way of saying, Dr Wilkie, that it looks like there were 12 people with haemophilia who

had tested positive at that time and this is what Dr Forbes is reporting at the meeting. So we see therefore that by at least 29 November 1984, Dr Forbes had 12 patients under his care who had tested positive for the virus.

THE CHAIRMAN: Could we go back to the beginning, just to get the context? Back to the description of what was done, so that Dr Wilkie can see anything that might be important to her.

The summary doesn't tell us very much in the way of detail, Dr Wilkie, and if we go down after the introduction to the materials and methods, what we see is that the Danish exercise was in April 1984. Can we go on and see whether there is anything about the Glasgow data obtained, taken from patients between December 1983 and July 1984 so we have a timeframe in the description of the method that might help.

MR GARDINER: It's possible that that testing is retrospective, sir.

THE CHAIRMAN: I'm sure it has to be retrospective since they have to exist but perhaps it gives a help to Dr Wilkie. I don't know whether it will.

MR GARDINER: Indeed.

THE CHAIRMAN: Rather than the date of publication.

MR GARDINER: Indeed. Thank you, sir.

So the purpose of this, Dr Wilkie, is to try to see if it helps at all to jog your memory about dates. It certainly looks as though by November 1984 Dr Forbes has patients who have tested positive and it seems that your or award funding was in 1985. Does that help at all?

A. No, it doesn't help because the funding often comes retrospectively. And as I have already explained, I was already working in Glasgow Royal with adult polycystic kidney disease patients and my feeling has been all along that I was working with haemophilia patients earlier than 1985, and I'm really sorry I can't help any more.

THE CHAIRMAN: Professor James suggests to me that the smartest people get grants for work they have already done but not published.

A. I know that.

MR GARDINER: Given that you appear to have been working at the hospital in 1984, do you have any recollection of 77 patients being tested?

A. Well, if I was working and doing the work that I have already mentioned, I must have been seeing these patients then.

Q. Okay.

A. I mean, I'm really sorry I have no record and that there

are no records available. I'm really sorry.

Q. Please don't apologise, Dr Wilkie. We are just trying to use the documents to focus in on the timeframe.

A. I appreciate that.

Q. Right. Could we go back to your statement, please, at page 5 of PEN0161297. Just before the break we were about half way down paragraph 12. We are talking about the general assumption and after that you say:

"Most patients suspected that the products were not absolutely pure. I would look at patients' records to see what blood products they had received over the years. Some had received only Scottish product but others had received American or Austrian product or porcine Factor VIII. Those patients who had travelled were most likely to have received the most commercial product. Because blood was donated as a gift in the UK but often paid for in the USA, there was an awareness that US blood and blood products might not be as pure as Scottish blood. It was generally known that some of the American donors were drug addicts or not in the best of health."

This, I assume, was information that you picked up from interviews with the patients that you have told us about?

A. It was information that was available through Richard

Titmuss's book, "The Gift Relationship". We talked about the gifts in the UK blood transfusion population. People gave blood for free and in the US population they were paid. And people who were more likely or most likely to go were people who needed the money, drug users or people who were just out of prison, people who may not have been in the best of health.

Q. Yes. So you are not talking here about information that patients have given you?

A. No.

Q. Thank you. Just to move on to paragraph 13, you say:

"The HIV virus had a huge impact on the haemophilia population. Before the emergence of the virus, people with haemophilia were beginning to live a more normal life. They were able to obtain better rates of insurance than previously. Patients were beginning to feel that the condition had lost some of its earlier stigma and they felt more able tell people, including their employers, that they suffered from the condition. The arrival of the HIV virus changed all that. Patients no longer felt able to divulge that they were suffering from haemophilia. Partly because of sometimes hysterical press coverage, there was an assumption that if you were a haemophiliac, you were likely to have AIDS."

In your experience, did patients keep their diagnosis from friends and family?

A. Some of them did.

Q. Thank you. Just reading on:

"Patients were unwilling to go to their GPs even for minor ailments as they feared that the local GP, receptionist, practice nurse et cetera, might not always treat their personal information as confidential. Another consequence was the reduction in surgical procedures carried out on people with haemophilia. Before the discovery of the HIV virus there were more and more joint replacements being carried out. This stopped as the surgery was very bloody and there were very few surgeons willing to undertake such surgery."

A. This was at the early stages.

Q. Yes. Dr Wilkie, what's your basis for saying that there was less surgery. Did you have personal experience?

A. Sorry --

Q. What was your basis for coming to that conclusion?

A. Well, that two or thee of the patients who would have liked to have either a knee or a hip replacement didn't get it at the time, simply that.

Q. Yes. So it was your impression that the reason for that was just as you say here, that surgeons were unwilling to undertake the surgery?

A. They didn't know enough about it. They needed to get a team working with them in theatre, who were willing to cooperate. As joint surgery, as I have said, is a very bloody, messy business and there was this fear at the beginning. I'm sure that changed but this project was not concerned with what happened later.

Q. Yes. Thank you. Paragraph 14, you say:

"There was a lot of fear surrounding HIV and AIDS. Generally those were mild haemophilia who had received very little product and had the lowest risk were the most scared of contracting the virus. As some of the patients became ill from AIDS, the hospital didn't have a policy for dealing with them. The medical profession and other healthcare professionals had received no training in dealing with AIDS patient."

You say:

"I visited one patient in a general ward in hospital who had to have some molars extract. He was in a separate room from the ward and all personnel entering the room were covered from head to toe in protective clothing. Everyone in the hospital knew that this patient had some serious infectious disease. It was grim for these men. The haemophilia unit was better but the general wards were characteristic of hospitals at that time."

"At that time"; what year are we talking about here?

A. Sorry, in the middle of the study, in the middle 1980s. I'm really sorry I don't know the precise date. I would love to be able to help more.

Q. That's fine.

Yes. Moving on to the next paragraph, you give a description of one young man that you used to see who died within nine months of taking up your post:

"He knew he was seriously ill and he wanted to die at home. He was a huge Celtic fan and wanted to watch a football match on television at home. A bed was made up for him in the living room but before the end of the match he had lost consciousness. His parents panicked and phoned for an ambulance. What the ambulance arrived, the parents told the ambulance men that their son had AIDS. The ambulance men then refused to take him. Another ambulance was called and the ambulance men insisted that it was NHS policy to transfer the patient to the nearest hospital. The man's parents wanted him to be taken to GRI but the ambulance men said they couldn't and took him to a nearby hospital instead. He was resuscitated while in hospital and died there two days later. At the end of their lives these patients were treated like 'dirty patients'."

Again, we are talking about the mid 1980s here, are

we? You are nodding?
A. Yes.
Q. Thank you.
A. Sorry.
Q. You give more examples of that kind of treatment in paragraph 16 and paragraph 17. Perhaps you could just expand a little bit, Dr Wilkie. You say that:

"Patients were treated like 'dirty patients'."

What do you mean by that?
A. Well, there was a -- first of all, can we go back to the previous paragraph?
Q. Previous page, thank you, 1302.
A. It was the patient who died first. The ambulance wouldn't take him and then there was a great fuss and the family were told that he would be taken at the end of a day so that the ambulance was already dirty and then it would be "sterilised". It would be scrubbed out and cleaned. Often, when HIV positive patients were seen by a dentist, the dentist was dressed like a man from the moon, which wasn't appropriate and was unnecessary. So it was that. And I think there was a problem with the young man who died, in the parents being able to see him afterwards. Because I think he was whisked away and wrapped up in a body bag.
Q. Yes. Thank you.

If we go back to paragraph 16, I think there we have a description of a young man that you saw who was 17 years old. You explain how the surgical team was very apprehensive about treating him and that nobody wanted to touch him. In fact, his bedside table was left out of his reach. He was only given a plastic cup with a dribble of water.

A. He hadn't been given any breakfast because it was the time when airport meals were being introduced and they didn't think they could give him one of these, and they didn't know what to do about it. But there was also a further problem with this young man, in that they forgot, in the ward where he was, that the longer that they kept him there waiting to go to theatre, he was likely to need treatment and his treatment went all haywire. His treatment for haemophilia went a little haywire too. He was treated almost like -- and I don't know how lepers are treated, but to use a common phrase -- a leper.

Q. Again, we are talking here about the mid 1980s, are we?

A. Yes.

Q. Then if we move on to paragraph 17, you tell us about a family with two brothers who were positive and how their mother became obsessive about hygiene, pouring a great deal of antiseptic down the toilet. I think you

told us something about that earlier today?

A. Yes, the interesting thing about this lady was that the younger child, the younger boy, was still at the Sick Children's Hospital, treated there, and they had introduced at Sick Children -- somebody had decided that all mothers of haemophilia boys should be seen by a psychiatrist. This lady was shown by the psychiatrist to have a serious mental disorder. Now, she didn't. She had a normal reaction to an abnormal situation. And that didn't help the situation either because in fact the family coped very well in the circumstances.

Q. Yes. Thank you.

Perhaps we can just have a look at the research paper that you produced at the end of your study, which is PEN0120998. Do you have a hard copy of that with you, Dr Wilkie?

A. Did I get it given back to me? Just one moment.

(Pause)

Yes, I do, thank you.

Q. Thank you. Could we just have a look at page 1 to see the background here? So we see that that confirms that in July 1985 Dr Forbes and Professor Markova were awarded a grant to investigate how patients with haemophilia cope with information and knowledge about the Acquired Immune Deficiency Syndrome. You say:

"Early in this study, it became very clear that there was a need to clarify what counselling was needed, what specialist information was required in counselling and who should give the counselling. It was not that there was an unwillingness to offer counselling, it was that it was not known what should be offered. It had also become clear that there was a need for support for family members and partners of those who are HIV antibody positive. Glasgow Royal Infirmary is an adult hospital. From the time that a young haemophiliac arrives at the hospital around the age of 15, he is treated as an adult on his own and parents gradually become less involved in hospital visits. While parents and also partners may be well-known to unit staff, routine care of patients does not generally necessitate their active involvement. As HIV can be sexually transmitted, it has very considerable significance for the sexual partner of those who are HIV antibody positive. AIDS, as an incurable disease, has very great significance for family, friends and loved ones. These new problems raised very many questions about the need for counselling, the sort of help and support required and who could give it and the specialist information that was required. It seemed important to investigate these questions so that the pest possible service can be

offered to haemophilia patients and their families. In November 1986 an application for a grant in support of this work was made to the Haemophilia Society and was warded."

Do we see there a general description of the background to your work?

A. Yes.

Q. Yes. If we go over to page 2, we have a description of your method of investigation, talking about initial interviews. Then if we go to the bottom of the page, the heading "Sexual contact", you say:

"As an adult hospital, it had been the pattern to inform the patient about his condition, including the presence of HIV on his own. For this study, the issue of sexual transmission to a sexual partner was first discussed with the patient and an appointment then offered for partners."

Is that your recollection of what happened?

A. Yes.

Q. If we go over the page to page 3, at the bottom of the page we have demographic data. You say:

"There are 35 HIV antibody-positive patients in the West of Scotland. In January 1987 25 of these patients were attending the haemophilia unit of Glasgow Royal Infirmary. The remainder of these HIV

antibody positive patients are under the age of 15 and therefore still attending The Royal Hospital for Sick Children, Yorkhill, Glasgow."

Did you have any involvement with Yorkhill?

A. A very little, yes. We gave seminars there.

Q. Yes.

A. I went to see one young man before he transferred to the Royal.

Q. Yes, thank you.

A. The age when they transferred was variable depending on the maturity of the person concerned.

Q. Thank you. If we go over the page to page 4, we see that you have set out the age range of seropositive haemophiliac patients attending Glasgow Royal Infirmary. Table 2, there is information about sexual partners.

If we go over the page to page 5, there is information about domicile and employment. I think, as we go through your paper, Dr Wilkie, we see an analysis of all of the different information about this patient group. Is that right?

A. Yes.

Q. If we go to page 9, section 4. This is headed "Coming to terms with the diagnosis". Just to pick up at the bottom of the page, we see three lines up from the bottom of the page:

"Ten patients had informed their parents of the diagnosis but had been reluctant to get involved in further discussion."

So this is a description of the younger patients that you were dealing with. Is that right?

A. Yes.

Q. Then at page 10, I think the context here is that you are describing reactions to stressful information. You say in the middle of the page, the sentence that begins:

"It must be remembered that at this stage all Glasgow Royal Infirmary patients were asymptomatic. Public education campaign with its great media publicity was still to come. Also at this time, the figures that were available for developing ARC, AIDS-Related Conditions, like symptoms or AIDS for those who were seropositive, appeared relatively small."

What period would you say you are talking about here?

A. Well, I would have said about 1985 but I'm now getting confused about the dates. I do believe that the study, the work with the patients, started before the money for the grant came. It could not have been anything else.

Q. You say:

"The public education campaign with its great media publicity was still to come."

What are you referring to there?

A. The pictures that came out from the Department of Health; the big picture of a condom. I don't know when that came. There was a lot of public education. Much of it was inappropriate in my opinion.

Q. Yes. Thank you. If we could go to page 16 now, please, here you are talking about how the parents of children or young adults who had been infected came to terms with the diagnosis. You say:

"The majority of parents learned of the diagnosis from their son after his visit to the hospital, when he had been told that he was HIV positive. There were exceptions to this when the young person had been diagnosed at the children's hospital, where parents had been informed by medical staff. Most parents reported that the information given them by their son was very scant, 'I have this AIDS virus but there are no problems'."

Is that what you were told by the parents you interviewed?

A. By the parents interviewed and by the young people.

Q. Yes, thank you. If we could just turn over the page --

A. Can I just say it is quite difficult with these young men because they are becoming adults and wanting to behave like an adult. It was a tricky time.

Q. Indeed. Could we just go over the page to page 17? You talk about the reaction of some of the patients. Five lines down, the sentence that begins "most patients", if you see that:

"Most patients expressed some degree of anger. This anger was not aimed at the staff of the unit, not really at anyone in particular. There was a general feeling that the introduction of genetically engineered factor was clearly too slow and perhaps would have prevented the tragedy happening. Some parents felt cheated. Their expectation of the new system of treatment prophylactically were of a normal life for their son. Parents thought that the stigma had gone out haemophilia until AIDS. Fathers seemed particularly angry about the association through HIV infection of their son with homosexuality."

Is that a description of your experience of these --

A. I think the second word in that paragraph should be "parents expressed".

Q. Yes, thank you.

A. Because this is all about parents.

Q. Is that your recollection of what parents told you at that time?

A. Yes.

Q. Thank you. Could we go to page 22 now, please? This is

under the heading of "Treatment" and you say:

"Patients are now asking explicitly about the treatments that are available for the symptoms of AIDS. For example, when is it appropriate to start AZT and is AZT available for anyone who needs it? In asking these questions, some patients are also seeking an explanation of the symptoms of AIDS and also reassurance that they are not at the moment suffering from problems that would require such treatment. Many patients have raised the question of the control of infection and what they can do to prevent infection. There is an opportunity here for a discussion about healthy living, including such topics as what we eat, the amount of exercise we take and the amount of sleep we have however simple this may sound ..."

Dr Wilkie, at this stage, are these interviews with patients who have had the diagnosis for some time?

A. Yes.

Q. Yes. So how long would you say?

A. I don't know the distance in time and it would be variable. It would vary from patient to patient. I mean, some people didn't ask about anything but others did and it would have depended on what they needed.

Q. Yes, I understand. Just at the bottom of that paragraph, you say:

"Most patients have asked what will happen should they become ill with HIV infections and in particular in which hospital will they be cared for. There is clearly a preference for their own hospital, with which they are familiar."

A. This was, I think, at the time to do with where the ambulance took them. If we go back to the young chap who died, the nearest hospital was not Glasgow Royal Infirmary, and I think patients may have known about this and were concerned that they wanted to be where they were known. It's part of continuity of care, that these patients felt very strongly about.

Q. These are the kinds of things that you discussed with these patients at that time?

A. Yes.

Q. Thank you. Then the next paragraph, which is headed "Looking for symptoms":

"Most patients continue to be anxious about the appearance of possible symptoms of AIDS, for example, is a cold or an eye infection the beginning of what one patient refers to as 'big trouble'? From a few patients who are very well informed about the symptoms of AIDS there have been several questions about neurological symptoms and considerable concern expressed about how they may be affected."

Dr Wilkie, how did you deal with those sorts of questions?

A. I listened to the patient. If I knew the answer, I would give them the answer but if I didn't, I would say that I would need to discuss it with Charles Forbes or Gordon Lowe and come back to them, because I didn't know the answers to everything.

Q. Yes. So you would get the information from the doctors and then --

A. Go back.

Q. -- pass it op the patients?

A. Yes, and it would have been recorded in their notes too.

Q. Yes. Are these notes that you kept yourself?

A. No, no, these would be the hospital notes.

Q. So your meeting to get information from the doctors would be recorded?

A. Yes, yes -- no, no, my information to the patient would be recorded. That sort of information, that they were concerned about this or if they were ill, they wanted to be treated in GRI. That would be recorded.

Q. In terms of discussing symptoms and progress noses, were there occasions when you would refer the patient back to their doctor?

A. Yes.

Q. Yes, thank you.

A. Or the nurse. I mean, whatever was appropriate.
Q. Yes, thank you. If we could go to page 25, part 6, the heading is:

"Terminal HIV infection", and I think here what you do on this page and then the subsequent pages is really to describe one particular patient who had haemophilia and who developed symptoms of HIV infection, and you give a description of the illness and then eventually his death. That's right, isn't it?

Could you explain why you have done that here, Dr Wilkie?

A. Well, first of all it was done with the family's consent. It was done to help other patients, to have it recorded so other patients could be helped, but perhaps more importantly, it was done to help the staff; that these are the issues that face these patients and what can one learn and what could one do differently or better in the future. That is why it was done.
Q. Yes. I see, if we go to page 29, under the heading of "Speed of onset and progress of illness", you say:

"I would like to comment on the speed at which the patient became ill and died. This speed made it difficult to prepare the patient, the family and staff for what was about to happen."

Was that information used for future counselling and

treatment?

A. It's well-known that often patients, particularly in genetic disease and with cancer and other serious diseases, know the symptoms themselves, are more aware before there is a clinical diagnosis, perhaps when they are asymptomatic, and this had clearly happened in this case. Simply, in a departmental seminar, it was discussed so that people knew and that was part of the role that we played in the project.

Q. Yes, thank you. If we go to page 42, the end of your paper, we see that that's dated December 1987.

Did it take you a long time to prepare and produce the report? Was there a big gap between finishing your counselling work and producing it?

A. These sort of reports are partly written as one goes along. One has the data. There had been quite a substantial interim report. So, I mean, of course, there were additional things to put in but it had -- no, is the answer, not really. It was done when you are working. You get used to it as a researcher.

Q. Yes. Thank you.

We touched on the anger that was expressed by the parents. Without wanting to suggest anything to you particularly, Dr Wilkie, doing the best you can, can you remember if there was any anger from the patients or the

parents about the way in which their results had been communicated to them?

A. I never heard that. The anger was about why. Why does this happen? What could have been done to prevent it?

Q. Thank you.

A. What will happen in the future? No, I never heard anything.

Q. Thank you. Putting your research paper to one side and just asking you a question on a completely different topic. I don't know if you will know anything about this or not but going back to December 1984, were you aware of a meeting which took place in Edinburgh, when people with haemophilia were told that some of them had been diagnosed with HTLV-III virus?

A. I'm vaguely aware now that you remind me but ...

Q. Vaguely aware?

A. Vaguely.

Q. Do you have any recollection of patients or parents having letters written to them inviting them to such a meeting?

A. No.

Q. I'm sorry?

A. No, I beg your pardon, no.

Q. Thank you. Just bear with me. (Pause)

I have no more questions, sir.

Thank you very much, Dr Wilkie.

THE CHAIRMAN: Mr Di Rollo?

MR DI ROLLO: Thank you, sir.

Questions by MR DI ROLLO

MR DI ROLLO: Just one point of clarification I would like to ask you, Dr Wilkie. Just give me a moment.

A. Sorry, I find it quite difficult to hear you.

Q. That's because I haven't switched my microphone on, sorry about that.

Dr Wilkie, what I wanted to ask you is at the end of paragraph 3 of your statement you refer to -- perhaps I can have that put up on the screen.

Just over the page there, page 2. Thank you.

I think the context of this is Dr Forbes having anonymously tested a couple of patients, he has discovered that there is a positive finding and, as you indicated in your statement:

"He was very concerned about the results of the tests and I think he stopped testing for ethical reasons."

Do you see that?

A. Yes.

Q. What I wanted is for you to tell us what those ethical reasons would have been?

A. Dr Forbes and I had worked together with Ivana Markova

on many different areas and particularly on genetics, and we had had innumerable conversations. So while there was no strict guidelines at the time -- I mean, I have used the words with a little E, not a capital E, that he would realise, I suspect, that you needed to inform people first because. That's what I would have been saying to him for the last eight or nine years because of the work I had done in genetics.

Q. Can you just explain what the thinking is about this? Just spell it out for me, please?

A. Right. You don't inform people about something for which there is no treatment -- and I'm coming from the genetics side.

Q. All right. I understand that?

A. No treatment where the prognosis may be not very great. You don't test them and inform them that they have this particular problem unless you have their permission, and that was a finding that we had done in the work that we did -- not Charles and I but I did, in Edinburgh from 1972 to 1977, well publicised in all academic journals, but not yet adopted by the General Medical Council, may I say.

Q. Maybe not, but the ethical reasons you were considering at that time were that you would not test someone without their knowledge?

A. Their permission.
Q. Their permission?
A. Their permission, yes, and their understanding of the implications: If they were tested, what would this be.
Q. It was that consideration which caused him, is your understanding, to pause at that point, before going any further?
A. That's what I think, and getting in touch. That's my recollection.
Q. The only other matter I want to ask you was concerning an answer you gave about patients would suspect that products were not absolutely pure. That's at a later stage of your statement, Dr Wilkie. It's at paragraph 12. Perhaps we could just put that up, just to give the context of that as well. It's the sentence:

"Most patients suspected that the products were not absolutely pure."

I think the context of your evidence was that you were referring there to severe haemophiliacs?
A. Yes.
Q. Not to those who were suffering from mild and moderate haemophilia?
A. Not moderate or mild, yes.
Q. And the question really I want to ask you is: do you know where moderate and mild haemophiliacs, and perhaps

those severe haemophiliacs who were not members of the Haemophilia Society, would get their information?

A. The press.

Q. Right.

A. That was one area, but patients who are severely affected had possibly had to have different types of treatments. Some treatments may not have worked with them. They were realists. They had picked up other infections, they were aware, that may have come from blood. It's not documented, I know, but these men were really practical people. It was no surprise to them that there was now yet another problem with blood products.

Q. Maybe you can't really help me with this, but I'm just trying to see whether or not mild and moderate haemophiliacs, or indeed those that are not members of the Haemophilia Society, may not be as well informed as the severe haemophiliacs that you were dealing with. Is that reasonable or not?

A. Yes, possibly, because the milder ones would not necessarily become members of the Haemophilia Society.

Q. All right. Thank you for that. I have no further questions.

THE CHAIRMAN: Can I ask you one question about the same sentence? You say that the products were not absolutely

pure. What are you thinking of at that point?
A. I was coming from the perspective that all medicines have a risk, and this could be seen in terms of a medicine, and the patients knew that.
THE CHAIRMAN: It carries the risk of infection or something like that?
A. Yes.
THE CHAIRMAN: "Absolutely pure" may have a different meaning in the rest of the Inquiry, Dr Wilkie.
A. I'm sorry, I beg your pardon.
THE CHAIRMAN: I just want to make sure that I limited it to what you intended to cover.
MR DI ROLLO: Thank you, sir.
THE CHAIRMAN: Mr Anderson?
MR ANDERSON: I have no questions.
MR SHELDON: Nor I, sir.

Further questions by MR GARDINER

MR GARDINER: I wonder if I might ask one final question arising from Mr Di Rollo's question about ethics.
THE CHAIRMAN: Yes, certainly.
MR GARDINER: Dr Wilkie, from an ethical point of view, I would like to pose a hypothetical question to you, and we are talking now about the era 1984/1985. At that time what should you do if you happen to know the results of a test and the patient doesn't know and nor

has the patient consented to the test? Would you like me to repeat the question.

A. No, you don't need to repeat the question.

You find out from the patient what they know and what their reservations would be about testing. You need to explore that first.

Q. Yes.

A. Then you have to be honest and tell them that they have been tested.

Q. Whatever their reservations?

A. No, depending on their reservations. Their reservations may be things that can be resolved.

Q. Yes. Could you tease that out a bit? Could you explain a bit more about that?

A. Well, if in fact somebody is concerned that their wife or their girlfriend wouldn't love them any more and that was a reason for not knowing -- and that could well be a reason -- then you would need to reassure them that that was unlikely to be the case and that would they like to bring in the wife or the girlfriend and discuss this together. So one explored further down that line.

Q. Would that then allow the clinician to pass over the information about the result?

A. Yes, hopefully, hopefully.

Q. Yes.

A. Hopefully.
Q. What would be a situation where the clinician, after further investigation, would not be able to pass over the result?
A. All patients in the haemophilia unit by, I think it was, 1985 -- but I'm not sure -- were treated in the same way, regardless of whether they were HIV positive or otherwise, in the sense that gloves were worn to take blood, and that was done throughout; it was good practice. So one would just have to keep going until the opportunity arose again and try again to go back to the patient.
Q. Does that mean then that, whatever the reservations the patient has -- and, remember, the patient doesn't know that a test has been done -- ultimately the ethically correct way to behave is to pass over the result to the patient?
A. At the time there was nothing written. I wrote, subsequently, with other colleagues, ethical guidelines for dealing with this. At that time there was nothing written about ethical guidelines of working. It was work in progress throughout the country and throughout, in fact, the developed world, about how you inform people and what you do and that one shouldn't be testing without the patient's permission. That's consent, and

understood consent. So those were the guidelines that eventually came in and were accepted by different organisations, including the GMC.

Q. So is it not possible then to answer the hypothetical question that I have put to you because there weren't guidelines. Is that what you are saying?

A. Well, there weren't guidelines at the time. We were working in a very fluid situation. In fact the situation didn't arise for us in Glasgow Royal.

Q. Yes. So are you saying that it's not possible for you to say at the moment what someone should have done in that hypothetical situation at that time?

A. Well, what I would say is they should -- but this is not based on any evidence at all -- they would eventually need to tell the patient but one would do that having explored the issues over and over again with them.

Q. Yes, and that, even if the patient is expressing very strong reservations about wanting to be told the result --

A. Not wanting --

Q. -- not wanting to be told the result, your view is that a clinician would have to ultimately pass on that information?

A. No, keep exploring until the patient agreed. That's what I'm saying. And then the results would need to be

given. But it would only come up if in fact it would affect their treatment and that might not happen for a long time. But you must explore first. I don't think I'm answering the question for you and I don't quite know how to.

Q. Hypothetically again -- we are talking hypothetically -- at this time -- I'm asking you to imagine a patient who the clinician who knows the results goes back to and explores their reservations about knowing a result and the patient continues to have reservations and is adamant that they do not want to know the result. Are you able to tell us what the correct ethical thing to do for the clinician was in that hypothetical situation?

A. In 1984/1985/1986? No, because there was nothing -- there were no guidelines at that time.

THE CHAIRMAN: So if you had a mild haemophiliac patient who was known to be sexually active and had been tested and found to be positive, one would do nothing until treatment was required in his case?

A. No, one would have done exactly the same as one did for all the others. One would be going through the process of discussing -- I mean, if they had been tested without their consent, you mean?

THE CHAIRMAN: Yes, the same hypothesis.

A. One would go through all the process of finding out what

it was that was making them reluctant to know the answer.

THE CHAIRMAN: But, of course, in that case the knowledge that the young man is sexually active would carry with it the implication that not telling him --

A. But all patients with haemophilia were recommended at that time, whether they be mild, moderate or severe, to take full precautions and in fact were also recommended not to have children over this period, not to plan children over this period.

THE CHAIRMAN: I was just trying to pin it down, Mr Gardiner, but I think I have got the answer that --

MR GARDINER: Yes, that was very helpful, sir.

Thank you very much, Dr Wilkie.

THE CHAIRMAN: Dr Wilkie, thank you very much indeed. It's very helpful.

A. Thank you.

THE CHAIRMAN: Now, ladies and gentlemen, the closed session starts at 1.30 and, apart from other requests, there was a telephone on again this morning and, as before, I would ask you all to make sure that all electronic communication devices, to make sure that it's as comprehensive as possible, are off during the closed session.

(12.31 pm)

(The short adjournment)

(1.30 pm)

MARK

Questions by MS PATRICK

THE CHAIRMAN: Good afternoon. I think that Ms Patrick will tell you who all the people are who are here at the beginning but I can start. I am Lord Penrose and sitting beside me here is Professor James, who is the chief medical adviser to the Inquiry, and you may get a question from up here but otherwise it will all be from your right and straight ahead.

Yes, Ms Patrick?

MS PATRICK: Thank you.

Mark, I'll carry on telling you who is in the room with you just now.

A. Yes.

Q. So you have heard from Lord Penrose and he is sitting to your left on the bench with his medical adviser, Professor James.

A. Yes.

Q. Beneath them and closest to you are, firstly, the two stenographers, who are typing everything that's said today for the record of this afternoon's proceedings.

A. Yes.

Q. Then seated next to them is Maria McCann, who is the secretary to the Inquiry, and then seated next to her is

Neil MacFarlane, who is the documents manager, and as you are aware, we may be referring to parts of your medical records.

A. Yes.

Q. He will be responsible for ensuring that these medical records are shown to everybody here on the screens.

A. Okay.

Q. Okay? I'm directly opposite you and seated next to me is Laura Dunlop, the senior counsel to the Inquiry, and behind her is GregorMair, who I think you have met with already.

A. Right.

Q. Yes? Along to the right we have the lawyers for the different parties to the Inquiry. Closest to me we have the lawyers for the patients, relatives and Haemophilia Society, I think, the lawyers who have been representing you. We have Simon Di Rollo, Laura-Anne Van der Westhuizen and Lynn Fraser. I think you have met them.

A. Yes.

Q. In the middle we have Rory Anderson and the solicitor for the Central Legal Office who are representing the health boards and the Blood Transfusion Service.

A. Right.

Q. Finally, closest to you is the advocate for the Scottish Executive, David Sheldon with a solicitor sitting behind

him.
A. Right.
Q. Also, further to your right in the public seating area is your father and your social support worker.
A. Yes.
Q. Margaret is sitting next to you and you have obviously met her on a few occasions.
A. Yes.
Q. Some time ago you helpfully provided the Inquiry with a witness statement.
A. Yes.
Q. Each of these documents have a number and the number for this is WIT0040015. As we go through this afternoon, I'm going to refer to parts of that witness statement and when I do, these parts will appear on the screen, so everybody can see what I'm referring to but at the same time I will be reading them to you and you should recognise it since it's from your witness statement.
A. Right.
Q. You tell us in paragraph 1 that you are 41 years old. Is that still the case?
A. Yes, it is.
Q. You were employed as a cabinet maker?
A. Yes, and then several years later I was running my own business.

Q. Sorry, I didn't catch the end of that.
A. And several years after my training, I was running my own business.
Q. Right. Where was that?
A. In [redacted].
Q. And what sort of work did you do?
A. Cabinet making and finishing joinery.
Q. Great. Did you enjoy that?
A. Very much so.
Q. Great. It's quite skilled work. So was it something you had been interested in for a while?
A. It was the -- when I left school, you would go to the job centre and the jobs were for secretaries and cleaners and the only job was a YTS cabinet maker, so that's the one I applied for.
Q. Good. You obviously proved quite good at it if you were able to set up your own business and run that?
A. It was one of -- the final year at school was when the teachers' strikes were on. So apart from higher art and O-grade woodwork, that was all I managed on that year.
Q. And then you tell us that you were medically retired in 1997?
A. Yes.
Q. Yes. You also tell us there that you are registered blind?

A. Yes.
Q. Are you able to see anything at all?
A. I have awareness on the left-hand side. I have -- I am conscious of things moving on the left-hand.
Q. Right.But nothing on the right?
A. I can't read. I don't recognise people.
Q. Okay. Thank you.
You tell us in paragraph 2 of your statement that you have Haemophilia A?
A. Yes.
Q. That your clotting factor is 2.2, which is borderline severe?
A. That's correct.
Q. And you have contracted HIV and Hepatitis C from your treatment with blood products?
A. Yes.
Q. In paragraph 3 you tell us about when you were first diagnosed with haemophilia and that was when you were 11 months old?
A. Yes.
Q. Yes. You tell us there that you fell over and split your lip?
A. To be honest, I don't remember. It's what my parents have reminded me of.
Q. Have told you. You were living in [redacted] at the time?

A. Yes.
Q. In fact, in your medical records we have the letter that was written by the doctors after you were initially diagnosed with haemophilia?
A. Yes.
Q. So what I would like to do is refer to that and I'll tell you what it says.
It's WIT0040240. This is dated August 1970, when you were admitted to hospital for, it appears, two nights, and it says that ten days previously you had had a cut in your mouth. It was possible to stop the bleeding but four days ago it started bleeding again and it bled on and off until the time of admission.
A. Yes.
Q. I think from what your parents have told you, initially the doctors maybe thought they were overreacting to the bleed?
A. Yes.
Q. Yes. Because you have noted that the GP told your parents that a teaspoon of blood on a white sheet looked worse than it was.
A. Yes.
Q. But obviously they persisted and you were admitted to hospital.
A. My father became quite upset. Well, both my parents

1 became quite upset when I became lethargic and I believe
2 my hands and feet were going blue.
3 Q. It is noted that by the time you were admitted to
4 hospital you were very pale indeed and at that point it
5 was found that you had a Factor VIII deficiency?
6 A. Yes.
7 Q. The conclusion was -- and this is written at the bottom
8 of the page -- that at that time you had mild
9 Haemophilia A?
10 A. That's because they gave me a blood transfusion.
11 Q. Yes. I think that's right. They gave you a blood
12 transfusion and then I think your Factor VIII assay was
13 measured to be 56 per cent?
14 A. So I was a mild haemophiliac.
15 Q. Well, that's what they are saying at that time but we
16 can see from the records that it became quite soon after
17 that apparent that you weren't mild, that you were more
18 severe than that?
19 A. I believe that was when we moved from [redacted]
20 down to [redacted], where I was reassessed at Edinburgh
21 Infirmary, and from the blood tests it was found that
22 I was borderline severe with the 2.2 per cent.
23 THE CHAIRMAN: I think, Mark, that the 56 per cent was after
24 you had had the infusion of blood and some fresh-frozen
25 plasma. So it was bumped up at that point.

A. Yes.
MS PATRICK: Yes. If we go over to the next page, we will see that at that time you were given 700 mls of blood and 200 mls of fresh-frozen plasma, and then you were given more blood. So you had about a litre in all.
A. Right.
Q. So you touched there on the fact that you then moved with your family to [redacted]?
A. Yes.
Q. That was in about 1972 or 1973?
A. Yes, that's about right.
Q. What prompted that move from [redacted] to [redacted]?
A. My father's job was -- that's where my dad's job took him.
Q. Yes. You believe that you had some treatment at [redacted] Hospital?
A. Yes. But over the six or seven years we were there I had very little treatment because I was only considered a mild haemophiliac.
Q. Yes. Sorry, if you go back to the statement at WIT0040015, paragraph 4, and over the page. Then you tell us also that when you were ten years old you moved from [redacted] to [redacted]?
A. Yes.
Q. We actually have a letter from around this time, which

details what treatments you had received before you moved to the [redacted]?

A. Right.

Q. Which I will refer to you. It's WIT0040243. This is a letter from a paediatrician, consultant paediatrician in [redacted], to Dr Parker, consultant haematologist at the Royal Infirmary, Edinburgh. It says in the first paragraph that this paediatrician has just seen you and you are newly arrived in the area. In paragraph 2 it recounts your admission to hospital in [redacted], that we have already heard about, and then it gives further details of treatment that you have received since that time. It says that you were given cryoprecipitate at the age of two and a half years for a bitten tongue. You received cryo at about seven years old for a bleed in your right elbow, secondary to trauma, and at eight years old for a bleed in your right knee, and at nine years old for another bleed in the right knee.

So, as you say, you didn't receive very many treatments when you lived in [redacted]?

A. No.

Q. It was noted at that time, in the third paragraph, that your right knee was warm and slightly swollen and you were unable to flex or extend it fully and that there was wasting of some of the muscles. I think you mention

that, that you did have problems with your knee?

A. The right knee was starting to give problems by the time we moved from [redacted], yes.

Q. But assuming that you had mild haemophilia, you didn't look for more treatment than the treatment that you received?

A. Well, no.

Q. Okay. Going back to your statement, you tell us in paragraph 5 that at the time you moved to [redacted], your haemophilia was reassessed at Edinburgh Royal Infirmary and the doctor dealing with this there was DrToolis, a locum consultant, and he initiated a full set of blood tests and then informed you that your haemophilia was classified as moderately severe?

A. Yes.

Q. Yes. There is a letter from DrToolis, which is WIT0040234. This is dated November 1979. On the first page this narrates what he has been told in the letter that we have looked at. At the bottom it says:

"I have checked his Factor VIII and IX levels."

He has also taken the liberty of checking Factor VIII levels in your mother and your sister. If we look over the page, there is a PS and this gives the results of the tests that he performed on you and what he says is:

"This patient's Factor VIII level was greatly reduced at 2.2 per cent, confirming that he does in fact have moderately severe haemophilia."

So it was at this time that it was confirmed to you that your haemophilia was moderately severe?

A. Yes.

Q. It goes on to mention further investigations on your mother to see if she is a carrier of haemophilia?

A. Hm-mm, yes.

Q. Returning to paragraph 5 of your statement, you tell us that while you were living in [redacted], you were mainly treated at [redacted] Hospital?

A. That's correct.

Q. And it was mainly by Dr Alison Thomson, consultant paediatrician?

A. Yes, that's right.

Q. You tell us that you were treated with cryoprecipitate for any bleeds you had.

A. Yes, which was a lot more regular.

Q. We can see that from the medical records. I wonder if I could refer to WIT0040248. Because it appears that Dr Thomson was very diligent in updating Edinburgh Royal Infirmary about the bleeds you had and the treatment you had before you went a clinic appointments there. This is a letter dated August 1980 and in this letter she is

noting the treatment that you have received since she last wrote at the beginning of June. So it effectively details the treatments you have received between 5 June 1980 and the date of this letter, 4 August. So it's for a two-month period.

It records that on 8 June you received 12 packs of cryoprecipitate for a bleed into your right knee. On 30 June you woke with a stiff right knee following a fairly strenuous weekend and you had a moderate sized bleed, and you received 12 packs of cryoprecipitate on day one and nine packs the following day.

Moving into July, you received 12 packs of cryoprecipitate, having stubbed your toe on the door frame, and then about a week later you had a moderate bleed into your right knee for which you received 12 packs of cryoprecipitate. On 31 July, following a slip downstairs, you had marked swelling and bruising around your right ankle and you were treated with nine units of cryoprecipitate. Then on 4 August you had a stiff swollen right knee and on examination had a moderate bleed and received 12 bags of cryoprecipitate and then a further nine bags.

So in that two-month period, you received treatment on six separate occasions. So obviously the amount of treatment you received, as you say, dramatically

increased?
A. Yes.
THE CHAIRMAN: Had you had a fairly active summer? Is that what's it's all about?
A. I don't think I was any more active. I don't remember being any more active but it did seem to be that I was rushed off to [redacted] Hospital.
THE CHAIRMAN: Quite a lot.
A. Now they knew what was wrong with me, it was not a case of just rest and relax, it was off to the hospital for assessment.
THE CHAIRMAN: So you think this is a proper appreciation of the haemophilia that's causing --
A. Yes, my hatred for needles grew dramatically.
THE CHAIRMAN: Who was administering the cryoprecipitate at this time?
A. The staff --
THE CHAIRMAN: The staff.
A. -- in the [redacted] Hospital. Who they were, I don't remember.
THE CHAIRMAN: You don't remember.
MS PATRICK: So you attended [redacted] Hospital in [redacted] for that treatment.
A. Yes.
Q. And went for regular clinic appointments at Edinburgh

Royal Infirmary every three months?

A. Yes.

Q. You tell us that you were advised not to use gardening tools including scythes, and we can see in a letter, WIT0040249.

A. It is not actually a scythe, it's a much smaller implement called a bagging hook.

Q. A bagging hook, right. Because you were obviously out --

A. I used to help my parents. Their house had a wood and lawns and stuff like that and I wanted to help.

Q. Yes.

A. I was -- I certainly enjoyed being in -- down in [redacted]. On [redacted] there were few trees. It was different countryside, it was ideal ground for a young -- you know, a young guy to be charging around, enjoying himself.

Q. Absolutely, which is what young guys generally like doing?

A. Well, yes.

Q. In this letter it's noted that you have been helping your parents cutting nettles with the bagging hook and you were chopping logs as well --

A. Yes.

Q. -- with a full sized axe, and it was suggested to you

that this might not be such a good idea?
A. Yes, I was fairly strictly advised to stop doing manual tasks.
Q. Yes, but you were obviously trying to live as normal a life as possible, despite your haemophilia?
A. Well, yes.
Q. If we could return to your statement, paragraph 6, you tell us that when you were about 12 years old, your mother was taught how to give you home treatment of Factor VIII?
A. Yes.
Q. Had you had treatment with Factor VIII before that?
A. I honestly don't know.
Q. Okay. Your mother was giving you Factor VIII in response to bleeds?
A. Yes.
Q. And only occasionally prophylactically to deal with severe bleeds?
A. Yes. To -- after a severe bleed, the idea is to keep the factor levels up to stop it recurring.
Q. Yes. Then you tell us that when you were about 14 years old you began to treat yourself with Factor VIII?
A. Yes.
Q. And how did you find that?
A. I suppose it's easier to do it yourself rather than sit

there and let somebody else stick needles in. It doesn't make it hurt any less but you are concentrating on what you are doing. And it also meant by the time I was 14, you are starting to grow up, you are stretching out for independence and doing your own thing.

Q. Yes. Did you and your mother keep records of the treatment which you gave yourself?

A. Yes, we had to write -- I believe my mother wrote the medical notes, treatment sheets.

Q. What happened to these treatment sheets?

A. They would have been sent back to -- I don't know whether it was the [redacted] Hospital or whether it was sent back to Edinburgh Infirmary.

Q. Right. I would like to refer to WIT0040435, which is a record of treatment that you received between March 1984 and June 1984. What we have in front of us here is a record of treatment which you received between 25 March 1984 -- if we scroll down -- and 17 June --

A. Is that from Edinburgh Royal Infirmary?

Q. It is, yes.

A. Was that when I was kept in? I stayed -- I seem to remember staying in the [redacted] Hospital on one or two occasions but then, when I got to 14, I certainly

remember being kept in hospital in Edinburgh because the knee was becoming quite problematic.

Q. Yes. This shows that you received treatment every day from 25 March to 1 April and it was in relation to your right knee?

A. Yes.

Q. Yes. So it does have an "H" in a column in the middle and I'm not sure if that means that you received that treatment at home but it could be "hospital" too?

A. Yes.

Q. But it shows that you received batch number 90 between 25 March 1984 and 27 April 1984 for treatment of a bleed in your right knee and then elbows, left foot.

Were you or your parents ever told about any risks associated with the use of blood products?

A. Yes, we were informed that there were risks but it was emphasised that I was being treated with blood from Edinburgh, so I wasn't going to be treated with commercial Factor VIII and I was to only receive what the Infirmary provided, nothing else.

Q. Right. So you mentioned there that you were told about risks, some risks?

A. Yes.

Q. What were the risks that you were told about?

A. That blood products did contain the possibility, because

it comes from a selection of people who have donated blood -- there was a risk of various infections and from -- of course, from 1983/1984 HIV had emerged.

Q. Right. So did you know from that time that there was a risk of that from blood products?

A. Yes, I suppose my greatest concern at that time was Hepatitis A, Hepatitis B and -- what was it called? -- non-A non-B hepatitis.

Q. Had these all been mentioned to you at your clinic appointments?

A. Yes. But they did emphasise the whole point of being treated with the local -- the Edinburgh factor; it was the safest, which reduced the risks.

Q. Right. So am I right in thinking you thought there were more risks associated with commercial factor products?

A. Well, yes.

Q. You thought, because you were receiving only -- you have said, Edinburgh factor -- that that was safer and carried less risk than the commercial product?

A. Yes, I seem to have memories, the stuff was produced -- I think the place is called Ellen's Glen. So it was produced locally. And that was emphasised to a high degree. We used to go down to [redacted] to stay with my grandparents and we were given letters so that if I had any difficulties down south, I was to go to hospital and

hand the letter over to make sure I wasn't given any other type of Factor VIII.

Q. Right. So did you take Factor VIII with you?

A. Yes.

Q. Can you remember if you were ever advised specifically of a risk of HIV from the blood products or HTLV-III, as it was known in the early days?

A. Yes, it was mentioned. It was pointed out there was a risk but, "Providing you stick to the Factor VIII we are providing, the risk is very low".

Q. Right. So did you feel reassured by that?

A. Very much so.

Q. Returning to your statement, paragraph seven, you tell us that soon after starting high school in August 1981, you started having severe problems with your right knee?

A. Yes.

Q. What were these problems?

A. Regular bleeds. The joint -- the problem is it -- if you have bleeds, you have to rest, and resting just weakens things. So you lose muscle strength and naturally, after days or weeks of doing nothing, you go out and you still want to run around and climb the trees and ride the bicycle, and that's exactly what you shouldn't be doing but try telling that to a young man.

Q. I want to ask you, how did your haemophilia affect your

time, firstly in primary school?

A. The only thing I remember was moving to [redacted], starting primary in [redacted], the biggest problem I had was my accent, trying to understand what a lot of people were talking about. For weeks I struggled to understand what people were saying and you are surrounded by a group of youngsters who, when it's announced that you have a bleeding disorder, their idea is to push you around, shove you about and ask why you are not bleeding.

Q. Right.

A. I would have to say I did not enjoy primary school in [redacted]. The change to high school continued not quite to the same extent. When you start at a new school, everyone is in the same situation but it was pointed out that I was classified as being rather weak and feeble. I wasn't allowed to go for games. So I used to be sent off to the library. And for certainly the first year, there was an element of being pushed around and bullied. That was overcome by -- at registration it was decided that I couldn't beat anyone in a fight. So to my horror, it was announced several minutes later that I was fighting another schoolfriend at 1 o'clock behind the games hall. If you disagree, you get teased to a greater extent, so with a shrug of

the shoulders, I said, "Yes, no problem, I'll see him there". Expecting nothing to happen, I was even more horrified when, with a selection of apparent friends, I was herded round the back of the games hall to fight half of [redacted] School there.

The guy that had been challenged to the fight was also there. Neither of us -- I had known the youngster since primary school and neither of us actually wanted the fight, but to do with keeping your social status correct, you -- the fight started. And the fight was rather feeble to start with. We were just pushing each other around, which gets the crowd shouting and shouting derisory comments about you: "Are you happier holding hands? Just run around skipping." So the guy I'm challenged to decides he has had enough and strides forward and you have a moment of horror when you get punched in the face. Staggering backwards, you have got the -- what's the term? -- fight or flight, and before I knew what I had done, I flattened him. And I believe I broke his nose. And you stand there in horror, his white teeshirt is streaked with blood, everyone is clapping and cheering and I'm picked up and carried out from behind the games hall by a crowd of clapping and cheering youngsters. The difference was I was never bullied again.

My credibility at [redacted] School went up dramatically.

Q. By breaking a nose?

A. Well, the teacher that turned up and caught me went off and checked things and he said that that lad had been taken off to the nurse and may have to go to hospital as it's looking like you have broken his nose.

Q. Right. But you feel that all that stemmed from being singled out due to your haemophilia?

A. Yes. I was very much classified as weak and feeble.

Q. Right. Did you miss a lot of time at school due to bleeds?

A. Yes.

Q. Did that affect your school work?

A. Yes. Before -- I ended up in hospital for -- on and off and they actually said, before I was supposed to be sitting O-grades, that, "You have missed so many classes you don't actually have to sit the exams or even the prelims". I said I might as well sit the prelims which I did and failed everything quite spectacularly. So once again they said, "You do not have to sit your exams". Again, I think, as a bit of a wake-up call, I did spend the next weeks and months concentrating and I sat my O-grades and passed everything apart from French.

Q. Well done. So what qualifications did you have when you left school?
A. I had, I think, five O-grades, it may have been six, because in fifth year I got O-grade woodwork and higher art, but again, with teachers' strikes school turned into a shambles. A lot of classes were shut down and we were actually to go off and entertain ourselves.
Q. Okay. So you may not have had as many qualifications as you would have liked but it wasn't all due to haemophilia?
A. No.
Q. It was due to teachers' strikes at the time?
A. Yes, a connection of things.
Q. Yes. In paragraph 8 of your statement you tell us that when you were about 13 or 14 years old, you recall your first feeling of despair when you heard talk of the spread of HIV?
A. There was a television programme concerning this horrific virus that was going to wipe out a quarter of the world's population. And as a family we watched it on television. I don't know whether it was Panorama or something along those lines. The programme was basically about homosexuals and drug addicts. They then mentioned there is another category of people who have received blood products and the people at highest risk

arehaemophiliacs. The sudden awareness that I had almost stopped breathing, and as they continued, I simply had to get out of the house.

Q. Yes. You think that you had a panic attack?

A. I suppose, yes, that may well have been. Yes, it was -- I had to get away. It was like I didn't want to hear it.

Q. No. And had you heard of HIV before that, before you heard of it being linked there to people with haemophilia?

A. No, not -- not really that I remember. I think there was a risk but I think that was more to do with commercial Factor VIII and -- from America.

Q. Right. Then you say also that there were occasional discussions at the haemophilia clinic about HIV and your mother was usually with you when these occurred.

A. Yes.

Q. What were these discussions?

A. It was usually comments after you would turn up. There would be discussion about -- most of the discussion was about the right knee, which continued to give problems. Again, other joints and bruises were examined and discussed and it was usually discussed at the end of meetings about the possibly of other infections, as I said, from hepatitis to HIV was certainly -- there was

certainly mention of HIV.

Q. Yes.

A. But again they emphasised sticking with local Factor VIII was the safest approach. "Do not use commercial Factor VIII."

Q. Yes. You say there, as you have said already, that you were told that blood was safe for Scottish people and therefore you felt safe?

A. Yes.

Q. You say you always relied on and trusted the doctors, as you felt that they were there to help you?

A. To a very great extent.

Q. Yes. The Inquiry is aware that in December 1984 there was a meeting at Edinburgh Royal Infirmary of people with haemophilia and doctors concerning the HIV virus and I wonder if you have any recollection of you or your parents being asked to go to such a meeting at that time?

A. There were occasionally letters that would come through, with details of about, you know, haemophilia and treatments and stuff like that, but again, with my dad working in [redacted], it seemed a long way. It was [redacted] miles to drive back through. In the majority of cases we didn't go.

Q. No. So you don't know if your parents went to a meeting

at Edinburgh Royal Infirmary around that time?
A. No, I don't know.
Q. Okay. You tell us in paragraph 9 that when you were 17 years old you passed your driving test and from then onwards you went on your own to your clinic appointments?
A. Yes.
Q. Without your parents?
A. Yes.
Q. You say that when you attended for the three-monthly clinic appointments, the doctors would want to discuss your blood test results?
A. Again, that was usually towards the end of the meeting, so, once again joints, difficulties and problem with movement were discussed. I don't think they were overly enthusiastic about the fact I was training for joinery and cabinet making, again as a haemophiliac. They were emphasising that I should be doing an office job rather than a manual job. And one of the other problems had been I had failed my first driving test.

The job that I had applied for, the gentleman held the job for me until I passed my driving test. Unfortunately I failed it. So he pointed out that, "I will only hold the job for the next couple of weeks. So if you cannot provide yourself with transport, I will

give the job to somebody else." The result of that being a trip through to [redacted] the following Saturday and I ended up buying a motorbike. In fact my father bought the motorbike for me, which again the hospital were not happy about.

Q. No. Okay. When you say that the doctors would want to discuss your blood test results, what did they say to you? Can you remember what they said about that time?

A. Again, conversations often using technical terms that for me didn't really mean anything, and they would say -- one of the statements I remember is, "Do you want to know the results of your tests?"

My general response that I remember saying on numerous occasions was, "Tell me if there is anything wrong". Again, what does red blood cells, white blood cells and other technical details mean when you are 17/18 years old? You are relying on the doctors, which you have trusted and relied on for all these years. You automatically assume they are on your side and they will tell you -- surely it is their job to tell you if anything is amiss or wrong.

Q. So when they mentioned blood test results, what results did you think the test was of?

A. Well, as I said, red blood cells, white blood cells and other details. Again, I knew they would be testing for

different things, like hepatitis and HIV, but once again you are relying on the fact that -- I assumed that if anything was wrong, they would tell me, that it wasn't a matter of actually having to ask for specific things. I assumed, as people I trusted, they would tell me if anything was actually amiss.

Q. Now you know had been tested for the HIV virus but were you aware at this time that you had been?

A. Yes, I knew I was tested, yes.

Q. So when you went to the meetings, your clinic appointments in 1986, you knew by then that you had been tested for the virus?

A. Well, I knew because I was receiving blood products I knew that despite there being safe blood products, there was still a small percentage of infection. So blood products was -- you know, the blood tests, I assumed was to keep an eye on my blood test results, to see if I had caught anything.

Q. Right, okay. Did you speak to other patients when you went to these appointments?

A. No, funnily enough, I do recall when I was younger -- I think quite a lot younger -- when we were having cryoprecipitate, the porter would bring the treatment round and there would be a group of haemophiliacs, our names would be called out, we would be given the bags of

cryoprecipitate and it was a case of all giving ourselves, you know -- it almost turned into a race to try and get the needle in and give yourself the cryo as fast as possible.

Q. Okay.

A. And thinking back, it gradually became fewer and fewer people. So you would turn up and there wouldn't be other people to talk to. But again, you don't suspect anything is going on or anything is amiss, you just think the place is, you know -- other people are away doing other things.

Q. Right. So were you aware that other patients with haemophilia in Edinburgh had been infected with HIV?

A. I knew there would have been a risk but I didn't know -- no, I didn't know.

Q. Right. Okay. So you tell us that you said to the doctors, "Tell me if there is anything wrong."

A. Yes.

Q. And the doctor would then close the file and say, "See you in three months."

A. Yes.

Q. You tell us that when you were 19 years old you moved to [redacted]?

A. Yes.

Q. Was this to do with your carpentry work?

A. My -- the workshop that I was using in [redacted] was being closed for -- it was demolished and a block of flats was put in there. So I was sharing a workshop with a selection of other people and one of them had set up -- had moved his business to [redacted] and he offered me space in his workshop.

Q. So you started working there?

A. Yes.

Q. And was that when you set up your business?

A. Now, I think I may have set up my business already in [redacted] because the reason I set up my business was on an enterprise allowance scheme by the government, where they paid you £40 to boost your income for a year, and so I had started my own business on the enterprise allowance scheme.

Q. Right. But while you lived in [redacted] you continued to attend the Haemophilia Centre at Edinburgh Royal Infirmary?

A. Yes.

Q. I would like to refer you to part of your records, WIT0040708. These are clinical notes of an appointment at Edinburgh Royal Infirmary on 20 March 1989. I think you have seen these or they have been referred to you before because you mention them in your statement and say you are aware of the notes that

have been made here. So what I'll do is I'll read you what it says. If we go over the page, we can see that they are notes made by B Auger. Was that a doctor at the clinic?

A. Yes, anything on the notes would be written by the doctor.

Q. I think we have heard of a Bernadette Auger. Does that ring any bells?

A. Not really, no.

Q. But if we go back to the first page of these notes, 0708, it says:

"Seen in centre."

It's 20 March 1989:

"Bleeds approx once/fortnight. Bleed in left elbow since yesterday. Bleed left ankle recently. No jt [*joint*] causing patient problems at present. Feels well in himself."

I think it then talks about the results of examining you in relation to the bleed in the left elbow and notes there is swelling in the posterior part of it and you are reluctant to move the elbow. In the forearm there is some swelling. Then over the page:

"No tenderness.Few small nodes, both axillae. No other nodes."

Then underneath that there is a paragraph and it

reads:

"Aware we have been doing HIV tests."

Then a star and in block capitals:

"DOES NOT WANT TO KNOW THE RESULT. Consents to continuation of HIV testing. I have told him that if he ever wants to discuss his HIV results, he can contact one of the doctors in the centre and arrange to see them at any time. I have advised him to assume that he is at risk of passing on HIV infection and therefore should use protection for intercourse and be especially careful with the disposal of needles and blood spillages."

It then goes on to say that you enquired about possible loans for a house purchase:

"I said that a bank/insurance company would probably want to know his HIV result but that we would never disclose this information to anyone including his GP. I advised him to contact the Haemophilia Society for the most recent information on loans, etc."

Then it finishes by saying:

For Factor VIII, five bottles now and home treatment X 20 bottles.

This obviously doesn't accord with what you have told us, which is that you said to the doctors, "Tell me if there is anything wrong"?

A. Well, yes. I knew I was being tested for HIV but

I would have expected a doctor to have actually informed me if there is anything wrong. So when they say, "Do you want to know the results of your tests," I was expecting it to be a whole list of information that, as a cabinet maker and joiner didn't really mean very much to me. So again, knowing that HIV was a risk, I would have automatically assumed, for the medical practitioners that I trusted and relied on, they would tell me if anything as monumentally wrong as being infected with HIV -- I would be automatically informed.

So, as I say, my assumption is the blood test results would be red blood cells, white blood cells and the levels of what is in my blood, not a virus.

Q. Right. What about the advice --

A. The other thing, as was pointed there, about looking at buying a house. If I had any inkling of what was wrong with me, why would I be buying a house? So does that not indicate that I had no idea that anything was wrong with me? If I'm discussing the possibility of buying a house or a flat, if I was HIV positive, knowing that HIV in those days was classified as a fatal condition, that if you have HIV you will be dead in three or five years; if I suspected I had HIV, why on earth would I be looking at buying a flat or a house?

Q. Yes. Do you think from this note that the doctors and

social workers at the hospital may have thought that you didn't want to know the results of the test?

A. But why should I -- should they not tell me? If something is seriously wrong with a patient, is it not their job as a trained practitioner to help and assist the patient? So if there is something wrong -- if you went to see a GP and the doctor found you had cancer or something -- "We won't tell him just now. We don't want to spoil the weekend." You wouldn't consider that fair, would you?

On that basis I would have assumed if they knew I was HIV positive but they deliberately did not tell me and as I have subsequently discovered, they didn't tell me but they were publishing it in the Lancet from 1985, I believe. So they are telling the rest of the world and the medical fraternity but they don't have the manners or conscience to tell the actual victim who is infected.

Q. Right. I wonder if we could turn to paragraph 12 of your statement, which deals with when you actually did find out that you had acquired the HIV virus, and this was at a clinic appointment with DrLudlam in 1991. You tell us that you would have been 21 years old then and you hadn't seen --

A. I think was that in January?

Q. If you bear with me, January 1991?
A. Was I 20 or 21?
Q. We have redacted your date of birth from your statement and your medical records so you were either 20 or 21 at this time.
A. Yes.
Q. Right. You tell us that you had been having regular bleeds in your right knee?
A. Yes, that was becoming a serious problem. For years it became what's classed as a target joint.
Q. And what does becoming a target joint mean?
A. It means it bleeds regularly. You actually don't have to do very much and it will bleed. It's a weak link.
Q. Right. So your knee and other bleeds were discussed at this appointment and then you say -- this is over at page WIT0040018:

"There was an awkward pause and then DrLudlam said to me, 'It has come to my attention that you were one of the few unfortunates to be infected with HIV. You have been infected for a number of years and you will be dead within a year.' I was absolutely stunned. I was aware that there was a risk of contracting HIV but had been told that blood products from Ellen's Glen were the safest you could get. The nurses at the haemophiliacentre had said this and had also discussed

safe sexual intercourse with me.DrLudlam informed me that I was entitled to an ex gratia payment to help me through the last few months of my life."

A. Yes.

Q. "He said to qualify for this payment, all I had to do was 'sign here and here'."

A. I believe it was three lots of documents I had to sign and I believe I received counselling and there was other discussions. Again, you are in a stunned condition. Your world has just been smashed to pieces and I do remember wanting to be out of the hospital as soon as possible.

Q. So that was your immediate reaction, just to get away?

A. Yes.

Q. You say there was no one else present at this meeting "other than me and DrLudlam."

A. As far as I remember, yes. There were other people that came in and out.

Q. Yes. I wonder if I could refer to you the clinical note of the appointment, which is WIT0040706. This is dated 15 January 1991 and it reads:

"We have at last managed to persuade [you] to come for review. Has not had many bleeds recently except with his left elbow - continues bleed today..."

Maybe?

PROFESSOR JAMES: "Active".

MS PATRICK: "Active". Thank you.

"Gen health good. O/E [*on examination]* looks reasonably well."

Then scrolling down, at the bottom of the entry, having detailed what has been found on examination:

"I have told him of his HIV status. He had not really suspected that he might be positive and he was therefore quite taken aback. Does not wish to tell anyone at present.To see Mrs Brown today. Review 1/52 [*one week*]."

Do you remember if you saw Mrs Brown?

A. I would think so, yes. As I said, I saw a number of people but I do remember my priority was to get out the building, but, as is written, I was stunned. Yes, I was because I did not suspect. I was living what I thought was a normal life, you know? Dealing with haemophilia and running my own business and, you know, living what I thought was a normal life, as I could manage.

Q. You were still at [redacted] at this point, were you?

A. I was, yes.

Q. It will be very difficult for you to remember, I appreciate this, being given such news at the time but did DrLudlam tell you how long you had been infected with the virus for?

A. No. No, he didn't.
Q. Was it explained to you how you had been infected with the virus?
A. No -- well, through the Factor VIII -- well, that was what was -- I don't know whether that was specifically mentioned but it was -- I think that was what was assumed.
Q. Do you remember if DrLudlam asked you if he could do further tests on your blood as part of monitoring of the virus?
A. Yes. On the whole I agreed to, you know, any tests. So, yes, I would imagine I did.
Q. Right. Do you remember if you gave a blood sample at that appointment?
A. I can't remember.
Q. No.
A. If not, it would have been a week later. I know the -- it used to amaze me how much blood they were taking. So, you know, I used to say it was an armful.
Q. So at every appointment --
A. They used to take a lot, yes.
Q. You think you may have seen Mrs Brown, who we assume to be Geraldine Brown, the social worker in the department?
A. Yes, I certainly saw her on a good few occasions.
Q. Yes. Did you also see Dr Alison Richardson on a few

occasions as well?
A. I don't think -- I think -- when I was seeing her, I think she said she had been watching me on paper for 13 years before she actually met me. So I don't think I saw her at that stage.
Q. No, but later on?
A. Yes. Again, when speaking with her, she comments about, "There has been a lot of people watching you with a lot of interest". So I actually took that as a compliment, again from the medical fraternity, that they were taking a lot of interest in trying to help me.
Q. Yes. Could we return to your statement, to paragraph 13. This is something that you have already touched on, that when you obtained your medical records, you found out that you had been infected with HIV in 1984, although you were part of an AIDS study from 1983?
A. Yes.
Q. When did you recover your medical records?
A. Oh, again, I don't know. It was -- what's that? -- probably about seven years ago.
Q. Right.
A. Six or seven years ago.
Q. You refer to a report confirming your HIV positive status. The reference for that is WIT0040436. It is dated 18 January 1988.

From what you have said in your statement, is it right to say that you didn't consent to being part of this study?

A. Certainly not, not at 13/14 years old and I can't imagine if my parents had been asked, they would have agreed either.

Q. Going back to your statement, to paragraph 15, you say that you were going through a General Medical Council Inquiry. What was that about?

A. Now, what year was this?

Q. It said there a few years ago. It's in relation to Professor Ludlam mentioning having two files on you and one being a personal file?

A. Yes, I was -- I knew what my status was and I -- at that stage I assumed I was simply one of the unfortunates. Now, there was a couple that I had known [redacted] and [redacted], and I had known them for -- well, it's over 20 years.

I remember [redacted] giving me fishing lessons when I was about 12 or 13 years old. So I had known him quite some time and he was a character that, as another haemophiliac, I knew and trusted. He got in touch with me and was fairly surprised that I was still alive and came round, and I actually did not believe for quite some time what he was telling me. So on numerous visits

they came back round to the house and were putting paperwork in front of me, and that proved that it was published in the Lancet and that I had been used for scientific research.

Q. So the GMC reference there is in relation to that?

A. That's why [redacted] and [redacted] were wanting to go after Ludlam through the GMC.

Q. Right. Do you know what the outcome of that was?

A. No case.

Q. No case. Okay.

A. Well, with the GMC you don't -- the final report you don't get. They keep that. You don't get told what the final bit is.

Q. Thank you.

A. Or in fact it might be the final statement -- the final statementLudlam put in is not let out to the public.

Q. Thank you.

Sir, I wonder if that might be an appropriate point --

THE CHAIRMAN: Yes, certainly --

MS PATRICK: -- to take a break.

THE CHAIRMAN: We will have a short break at that time. The stenographer will have to have a break or her hands will seize up.

A. Oh, right.

(2.47 pm)

(Short break)

(3.10 pm)

THE CHAIRMAN: Yes, Ms Patrick?

MS PATRICK: Thank you.

Mark, I just want to revert briefly to one point we were talking about before the break and I just really have one more question for you about it. I referred you to an entry in your medical records, where it was stated that you did not wish to know the result of any HIV tests.

The Inquiry is aware that that's not the only entry that refers to HIV tests and saying that you don't wish to know the result. Is it possible that the doctors got that impression, even though your memory about that is different?

A. The -- they said, "Do you want to know the results of the tests?" and my response every time was a clear. "Tell me if there is anything wrong."

Q. Okay. Right. Thank you very much.

Reverting to the appointment where DrLudlam told you that you had HIV, you tell us that your immediate reaction was that you wanted to get away from the hospital as quickly as possible?

A. Yes.

Q. What did you do after that appointment? Can you remember?
A. No.
Q. No. Who did you tell about your HIV diagnosis?
A. Nobody.
Q. And why not?
A. Because of the social stigma in those days involving HIV, plus the fact that, as a self-employed cabinet maker and finishing joining I was running my own business. In those days, the adverts -- not adverts but programmes on the television were gravestones falling down, and if you shake hands with somebody who is HIV positive, a quarter of the population will be dead. And so I stopped buying newspapers, I stopped socialising, I basically stopped doing things.
Q. If we look at paragraph 17 of your statement, you say that although you were initially referred to the Western General Hospital in Edinburgh, you refused to attend.
A. Well, as they were telling me that I had been ill for some time, I assumed that there was no point in going to another hospital and meeting a whole lot of other people as I had been infected for a number of years, as is quoted. So I was assuming the life expectancy was about three to five years, so what's the point in seeing a whole lot of doctors when you are going to be dead in

a few months?

Q. And you tell us in paragraph 18 that you received money from the Macfarlane Trust?

A. Yes.

Q. And used it to buy the biggest and fastest motorcycle you could find and you rode it like a lunatic?

A. Yes.

Q. Yes. In paragraph 19 another concern you obviously had was in relation to taking medication and how your housemates at the time might react to that?

A. Again, from the fact that HIV was considered very contagious, you only had to shake hands with somebody for the infection to be passed on. I, I suppose, subconsciously made the decision to not only not tell anyone but to remove any evidence.

I do recall being sent information which I would put it in the car, drive out into the middle of the countryside, read through everything I possibly could and then, the paranoia was to the extent I would then shred it and burn it so there was no evidence. And it was the same when they suggested medication and again, would it cure it? No. So what's the point? And I refused everything.

I told nobody. I didn't tell my parents. And for what was it, eight years, I effectively lived a lie.

I carried on the same cheerful cabinet maker, finishing joiner, carried on my own work, I certainly spent 18 months of, you know, relaxation and leisure. That is when I was charging around on the motorbike. The money has gone, it's back to work. And so for the next years I just carried on working and again, you know, living a lie. I carried on as though everything was perfectly all right until you shut the front door and then it's back to utter despair and the end of the world, and that went on for years.

Q. The words you use in paragraph 19 are that you had huge levels of stress and it was a mixture of frustration, anger and despair?

A. Well, again, that was one of the reasons that the motorbike was a good way of letting off -- effectively letting off steam. The other reason -- well, the other thing that was noted is from going out with groups of other friends riding motorcycles, I was not one of the most nimble riders until I bought the big fast Suzuki and four months later I was in the top three. Again, you do not care, it doesn't matter.

Q. You tell us back in paragraph 17 that the only treatment you took was strong antibiotics for knee infections. What was that antibiotic, can you remember?

A. No.

Q. Was it Septrin?
A. It could well have been. It was once every other day and the only thing I recall is that it upset my digestive system spectacularly. And again, sharing a workshop with three or four other colleagues, it's something that you really want to be avoiding. So you would be in the middle of assembling or building something and you would know that your stomach is just about to protest very vigorously. So it would be a very quickly go out, start the bike up, make some excuse about having to go off and see MrSo and So about getting measurements and whisk off back home, charge into the house and my digestive system would explode.
Q. Right.
A. Which again, I want to try and avoid doing. It gave serious problems with working in people's houses. You get some raised eyebrows and people shaking their heads when you are disappearing off to the toilet half a dozen times.
Q. So you took that treatment for a while and you thought that was for knee infections?
A. Well, it was -- they said because your immune system is -- dropping, you should be taking something to try and, you know, give you some support. Again, I was refusing all medication. Again, from the point of view

of -- I didn't want to be carrying piles of medication around. Again, with sharing a flat, anyone finding a packet of medication saying, "What's this?" Plus the fact the -- I believe it was AZT, which was something like six or eight tablets three times a day, and you try doing that discreetly when you are sharing a house. So I refused it.

Q. Okay. You tell us in paragraph 20 that in about 1993 you were a lodger in someone's house?

A. Yes.

Q. Was this in [redacted].

A. No, it was the small village about seven or eight miles away.

Q. Right. You say there had been a programme on the television about people with haemophilia having AIDS?

A. Yes, which -- I didn't watch it.

Q. But the couple you were lodging with said they wanted to have a chat with you about it?

A. They came round immediately when the programme finished and I was in my room. Again a feeling of suspicion when they knocked on the door, they were good friends -- they still are good friends -- but they knocked on the door instead of just tapping on the door and walking in, which was what their usual procedure was, and you know straight away from people's response if something -- if

all is not well, and the pair of them were standing there saying we have just watched this programme and they have stated that all haemophiliacs have AIDS. A very awkward moment.

So expecting to go scarlet in the face and start stuttering, I took a deep breath and simply pointed out that the media are trying to horrify people. "Don't believe everything you hear. Bear in mind the details they are talking about are from England. I have received blood products from Scotland and that is considered considerably safer. There are a number of haemophiliacs infected but the numbers are much less. So you must not believe everything you hear or see on the television or radio."

To which he obviously relaxed and plonked himself down on the seat but his partner was more persistent and straightforwardly pointed out, "You haven't answered the question: do you have AIDS?"

Now, at the time my awareness was I was HIV positive. So I said, "No, I don't have AIDS at the moment. I'll let you know if I do."

Now, again I don't know whether my status was AIDS or whether it was simply HIV at that stage, but it was my justification for being, not lying but being vague with the truth. I was brought up that you don't -- I am

not a good liar.

Q. Then you tell us in 1995 or 1996 about going back to visit?

A. Yes, I went round to their cottage, knocked on the door, the lady answered the door and again knowing straight away something is amiss, she looks left to right and whisks me into the house straight away, and hisses at me, "You are not going to believe what's happening in this village. There is a couple further up the road and it has turned out they have got AIDS." And I am afraid I burst out laughing. And she was obviously taken aback about that and said, "What's the problem? Why are you laughing?" and I said, "You have to appreciate it can be all over the place". And she said, "Well, we are so paranoid about it, we don't let our little boy play in the garden" -- their garden was on the opposite side of the road and four gardens down from where this couple apparently stayed. And she was very much paranoid about HIV. So the relief that I hadn't told them was immense, which again I think was part of the reason that I was probably too light-hearted about things.

Q. Right.

A. And as -- I have never told them. They still don't know.

Q. Right. In paragraph 23, you got into trouble with the

hospitals for not attending appointments?
A. Yes.
Q. And you avoided your parents as the conversation often headed in the direction of HIV and you didn't want to disclose that to them?
A. No, no, I mean -- it was -- as I have said, a feeling of shame, you know. HIV was a condition that was very generally categorised for homosexuals and drug addicts. It was a condition which had an element of disgrace about it. So to say there was any plan, that the joy I had with motorbikes and the reason that I was so adventurous and, to be honest, irresponsible with it, was because the thought in the background was if I have a serious accident, as one of my friends took me to one side and said, "You have got to calm yourself down, you are going to kill yourself". I would have actually seen that more as a bonus than a minus because if I had died in a motorcycle accident, it may have turned out that no one would ever know what happened.
Q. Yes. You tell us that some years later in about 1997 -- this is paragraph 24 -- you were told that you had acquired Hepatitis C and this was whilst attending an appointment at the Western General Hospital, Edinburgh?
A. Yes.
Q. And you believe that this was the first time it was made

clear to you that you had Hepatitis C?

A. Well, part of the problem was Hepatitis C had been referred to as "non-A non-B".

Now, again, running through -- from what I remember, the doctors would rattle through a selection of medical conditions and they would use technical terms and at the end of the day I knew how to build furniture. I was not qualified with medical terminology or what things actually stood for.

Again, as I have said, I trusted and relied on these people to a very great extent, relying on the fact that if anything was wrong or amiss, they would simply tell me. Surely that's what their job is, that's what they are there to do. And I believe that with medical training, when a doctor qualifies in those days, they had undertaken to help patients.

Now, infecting somebody with HIV and not telling them, do you class that as helpful?

Q. Looking at this paragraph in relation to finding out that you had Hepatitis C, you say that there had been discussions about the risks of hepatitis and the possibility that you might have had it?

A. Well, yes.

Q. Yes. You have been made aware that there is a note in your medical records dated 15 December 1993 by

Janet Andrews stating that she had a long discussion with you about Hepatitis C and she also gave you an information sheet on Hepatitis C but you can't recall that?

A. No, I mean, as I said, there were discussions about different medical matters, things like that. My greatest concern from the medical point of view -- again I knew there were risks because you are receiving blood products and there are risks, but I automatically assumed -- I suppose "ignorance" is the way it is phrased -- that they would tell me when things were wrong, not ask me if I wanted to know what results were.

So I did know there were risks and, yes -- so being told, "Do you want information?" I would automatically have assumed that the information was to keep an eye on whether anything happened, not that I had it already.

Q. Right. I wonder if we could, please, look at WIT0040262. It is the letter relevant to that note and it's a letter dated 16 December 1993 by Janet Andrews,Clinical Assistant to DrLudlam. It notes that she saw you for review at the haemophiliacentre on 15 December 1993. You are feeling very well at present:

"has a good appetite and no specific symptoms."

It notes in the second paragraph the problem you were telling us about in relation to Septrin causing

diarrhoea, and the fact that you had stopped it over a month ago, which would mean you stopped it in about November 1993, when your supply ran out. The third paragraph says that there were no abnormal findings on examination. In particular, no lymphadenopathy or hepatosplenomegaly.

A. Do you know what these things are?

Q. Lymphadenopathy is swollen lymph nodes?

A. Right.

PROFESSOR JAMES: And hepatosplenomegaly is enlargement of the liver and the spleen. And they might go with HIV/AIDS or they might go with Hepatitis C.

A. Hm-mm. But as I say, if they are using technical terms like that, if they said HIV or hepatitis, I would understand but when you use more technical terms, again from a -- you know, that was not my -- that was not -- didn't provide a great deal of understanding for me.

THE CHAIRMAN: I think that's the point, isn't it, Mark, that if that was the way you were addressed, it really wouldn't tell you very much.

A. Yes. They are using technical terms, which is, you know -- goes straight over the head.

THE CHAIRMAN: Yes.

MS PATRICK: The fourth paragraph of this letter reads:

"I took the opportunity to discuss Hepatitis C with

[your name is blanked out]. Our investigations have demonstrated that he is Hepatitis C antibody positive but his liver function tests are normal. Our policy is to invite patients who have Hepatitis C to a joint liver clinic run with Dr Peter Hayes, Consultant Hepatologist. I have invited [your name again] to attend and he will let me know whether he wishes to do so. He is aware that we would prefer to see him monthly but because of the travelling involved, he will contact us when he is next in Edinburgh."

But you don't remember these discussions with you in 1993?

A. I remember discussions about things but again, I wouldn't be able to tell you what date it was.

Q. Right.

THE CHAIRMAN: Can we look to the top? To whom is this addressed?

MS PATRICK: Unfortunately it has been redacted but I assume it's the GP.

THE CHAIRMAN: Yes. But if we look at the very bottom. It says the top copy was not sent to the GP. It's rather odd if it was a letter intended for the GP and wasn't sent.

A. The reason it was not sent to the GP was the GP was a family friend.

THE CHAIRMAN: So you prevented it from being sent?
A. It was -- well, yes, basically, yes. There was discussion and I knew who the GP -- the GP was the same as my parents and knowing that they socialised, I appreciated that it's very easy to make a comment, and they would only have to ask, "Oh, and how is he at the moment?"So ...
MS PATRICK: I think also, Mark, the medical records show that there was a spell when you weren't actually registered with a GP.
A. Yes.
Q. Because you were so worried about your confidentiality. So that may have been during this period, when you didn't in fact have a GP?
A. Yes.
PROFESSOR JAMES: But they would still write this letter for your records, as if there was a GP. And it's made clear here that it was not sent, which was your wish. But they have kept it in your records so it is known what was going on at the time kind of thing. That's kind of normal behaviour --
A. Yes.
PROFESSOR JAMES: -- from them.
A. Yes.
PROFESSOR JAMES: Yes.

MS PATRICK: The positive test results for Hepatitis C virus are WIT0040437, dated 26 March 1992 -- we don't need to look at them -- and WIT0040438, dated 30 March 1992.

A. With Hepatitis C, to start with, it was called "non-A non-B". So it's difficult -- do you class it as the same thing?

PROFESSOR JAMES: Yes. Yes, you do.

MS PATRICK: Okay.

PROFESSOR JAMES: It changed its name in about 1990.

A. Yes.

MS PATRICK: Moving on in your statement, paragraph 25, you tell us about an accident at work in December 1995 when you were machining wood and you machined the ends off two of your fingers.

A. Yes.

Q. You tell us about being taken to hospital by a man working in the same workshop -- or in another workshop?

A. It was actually another workshop. The workshop I was working in I was there on my own, and the first reaction -- I mean, it happened in a -- just in a second. You don't -- to start with -- the occasional cut or injury is, you know, it's not unusual and so my first reaction was to grab hold of it, get something to wrap round my hand. My first reaction was to put the

kettle on and make myself a cup of coffee but then the glance under the towel indicated that it was actually a lot worse. So I very carefully went round, switched everything off in the workshop, switched the lights off, picked my car keys up and put them in my pocket, went out the workshop, locked the door, went across the road to where there was a guy who made glass swans and spoke to his wife. Unfortunately the wife was a district nurse, who very enthusiastically got me in the house and insisted that she had a look.

Knowing what was wrong with me, it didn't go very well because I basically had to say no, which she got quite offended by.

THE CHAIRMAN: Were you concerned about the risks from your blood.

A. Exactly. And I didn't want to be telling her that, knowing that she wouldn't be putting gloves on. She would be looking at the wound to see what was going on. Plus the fact I did appreciate that the wound was a lot worse than the impression that I gave. I believe I said I have got a cut, which was not the case at all. I had actually machined the backs of two of my fingers.

It wasn't actually bleeding too badly but that was because in my haste I had just folded the hands over and had sealed it off with the towel wrapped round the hand.

So the guy said he would give me a lift across in his Land Rover and it turned out the battery was flat. So he said, "Well, have a cup of tea and in half an hour, the battery will have charged".

Luckily, for whatever reason, I had put the car keys in my pocket. So I gave him the car keys and he drove me to the [redacted] Hospital immediately. With a whole lot of fuss about what I would do about the car. I said, "You have got it for 24 hours. You can do what you want with it". And went into the cottage hospital.

They were all very nonchalant until the towel was removed and the result was a stream of blood over the metal table dripping onto the floor. The doctor takes a step back with, "My goodness, my gosh, get this guy to hospital". Straight away I'm put in an ambulance and whisked through to [redacted] and from [redacted] taken to [redacted].

Q. Where you say you had surgery under a local anaesthetic?

A. Yes, I wanted a general anaesthetic because as soon as the doctor examined it, I very nearly passed out from the sheer pain and they wouldn't give me anything. They wouldn't give me any painkillers or anything and in the ambulance travelling at some considerable speed with all the lights and sirens going, the other -- the other ambulance gentleman was pushing me around and keeping me awake and conscious, and all I wanted to do was go to

sleep, which I have subsequently found out they are determined not to let you sleep.

Q. Right. Was this an accident or do you think this was the start of your eyesight beginning to fail?

A. I would imagine it was the beginning of -- yes, it was. I had used these machines for years and, yes, you get scratches and things like that but nothing along those lines. So it's the beginning of the co-ordination and skill starting to fail.

Q. Right. I would like to refer to a document, WIT0040267, which is a letter from Dr Dennis of the HaemophiliaCentre, dated 5 January 1996. This records that you attended the Haemophilia Centre on 29 December 1995 to collect home treatment. You had been seen at -- I think this may be another hospital on 9 December 1995 with an injury to your left hand. You had caught your middle and ring fingers in a machine and had amputated the ends of both fingers.

A. Well, the fingers were amputated at [redacted] Hospital in [redacted]. The fingers were still there but so badly damaged the Australian surgeons -- there were two surgeons that I spoke to. And they very enthusiastically said, "We can put it back together again but it will almost -- one of them will almost certainly remain off at a funny angle and I would put money on the fact that you will be

back in a year to have it removed."

So I said just, "Tidy it up. Remove what you have to and tidy it up." They told me that I wouldn't be able to work for a good few weeks but as it turned out I think I was back to work within three days.

Q. Yes, you tell us you went back to work more or less straight away.

I think you are given extra Factor VIII for when the sutures are removed?

A. Yes.

Q. You are advised to continue with Factor VIII daily. In the last paragraph it notes that when you were seen at the orthopaedic clinic in December, you were noted to have a rash affecting your trunk and forearms?

A. Right.

Q. You had been treating this initially with an antifungal cream but unfortunately the cream ran out and the antifungal cream had caused a dramatic improvement. So you were given a further prescription for Canesten cream to be used three times a day. How long had you had that rash for, can you remember?

A. No.

Q. No.

THE CHAIRMAN: You say you went back to work. Did you go back to machining wood?

A. Well, yes. Back to the workshop but the other problem at that time was, when I had set-up my business, work seemed a lot -- well, not easier but more financially a better option, and I remember finishing -- on numerous occasions I would finish a major job, a big job in somebody's house. You get final payment and then I wouldn't -- you go on holiday for a week and then come back and do it. But as the months and years went by, people actually started to haggle. So when you would turn up and look at the job and give a quote, somebody would say, "We can actually get it done cheaper. So if you can -- unless you can lower the price, we will get somebody else to do it."

So financially it was becoming more of an issue. And when I machined my fingers off, I was actually restoring three cottages at the time, which meant I was staying there rent free but I was working at the same time. So at some stages I would have been working probably close to 18 hours a day. So you know, going to work in the morning, coming back at teatime and then working in the evening, which again was the reason for having to continue work after machining my fingers off. If you don't get the job done, if you do not get the cottages finished, you get thrown out. So you have to do it.

THE CHAIRMAN: So you must have been fairly tired at this stage.

A. It would have been doing me a fair amount of damage. Plus the fact I'm still dealing with the stress and anguish of what's going on. Again, with the financial difficulties, I would have to sell my fabulous motorbike and a selection of other things. So it was very much a case of trying to raise money in different directions. You are working very hard and again finding somewhere where you could stay over the winter, effectively free, was a very good option but for the fact that I was having to work to do it.

THE CHAIRMAN: Ms Patrick had asked you whether you thought this might be the beginning of eyesight problems but I would be very surprised if your eyes were operating properly after 18 hours a day handling timber and machining it. You would be pretty tired.

A. Yes, I certainly remember being tired and the other thing was, of course, staying in a cottage, these were -- even further north, up in [redacted], which was where I was staying at one stage and -- what was it? -- [redacted], and that was where I was working and yet I was still running the workshop in [redacted] but travelling further up north.

So my travelling time was up quite dramatically,

which again was more cost but it did mean I was staying somewhere for free, but these places did not have central heating. It would be a log burning stove. So not only that but you are having to collect timber as well as bringing in fragments and offcuts of material that you have been working with. So it's all work, it's all manual stuff to keep yourself warm.

THE CHAIRMAN: Yes, I can imagine you didn't take your heavy equipment to the cottage, your spindle moulder is something you would leave --

A. Yes, when I would finish a day at the workshop, anything that needed to be machined, plus the fact that the gentleman that I was working for, he actually had a workshop himself. So -- well, I did not have a key but I knew where he kept his keys. So I had access to his workshop and storage place. So for doing up his cottages I would get the materials and stuff from his place.

THE CHAIRMAN: What was the machine you were using when you damaged your hand?

A. A surface planer.

THE CHAIRMAN: Oh, yes.

A. A big thing. I think it was capable of planing timber of 18 inches across, it may have been two feet. It was a big thing.Three-bladed surface planer.

THE CHAIRMAN: And you were feeding it by hand.
A. No, it has got power -- a --
THE CHAIRMAN: Yes, it has a power feeder.
A. And you have metal covers that you slide across to cover the blade and when you are running small bits across -- I mean, I remember doing it. I was finishing a wardrobe and I built the wardrobe and all I was doing was making the little cornices for the top, and so the little lengths of wood or -- well, long lengths of thin wood, I was finishing off to make sure they were the right thickness. Because initially, when I put them in situ they stuck out too far. So I was running them over the machine and the only conclusion that I had, I'm holding it with two fingers, the blade -- there is only a very small amount of blade because most of it is covered with the metal cover, and on the other side there was a cover on that side as well. So I must have just clipped it as I cleared the bit and it machined the backs badly out of one and just a fair amount out the other one.

So the -- when it was repaired -- and my fingerprints are now on the back of my hand. Because they cut out what they could and folded it over.

THE CHAIRMAN: Yes, thank you.
MS PATRICK: I would like to refer you to another letter which touches on some of the difficulties that you have

just referred to, which is WIT0040270. It's a letter dated July 1996 from J Hanley to Mrs Brown. It reads:

"I took the opportunity to have a long chat with [you] when he appeared at the Haemophilia Centre the other day. He remains very well with no HIV-related problems. We discussed a number of issues. His financial situation remains difficult for him. I think he is on a fairly low income and still gets some money from the Macfarlane Trust as well as mobility allowance."

So were you receiving an income from the Macfarlane Trust?

A. I used to get a monthly payment, which was something like £80.

Q. Right.

A. A month.

Q. And also mobility allowance. Was that in relation to your right knee problems?

A. Mobility allowance? Yes, quite possibly.

Q. Quite possibly, right.

A. I know it wasn't a huge amount of money. I do recall, before everything went wrong financially I was -- I was not quite in a muddle but dawdling.

Q. I think he is wondering here if you are entitled to further benefits of any kind and I think you are keen to

come and discuss this further with Geraldine Brown?

A. Yes.

Q. It also reads:

"We also discussed at some length [your] feelings of social isolation. As you know, he has not confided his HIV status to any family members or friends. He is very concerned about the possibility of social stigma… where he lives. He feels that if it became known locally that he was HIV positive, he would not be able to remain living there."

A. I wouldn't be able to run a business in the Highlands of Scotland if people had known that, particularly after the experience with the neighbours in [redacted].

Q. Of course, which you told us about.

A. Yes.

Q. It says:

"This seems to be the main reason why he is reluctant to register with a GP or divulge his HIV status to Social Security. He did say, however, he has been thinking recently that he would like to meet with other HIV positive individuals. I suggested that we could put him in contact with Edinburgh based support groups or individuals."

It was left that you would think about that and it would be discussed further. Did you ever do that, get

in touch with other individuals or join any support groups?

A. No.

Q. Fairly soon after the accident you have told us about, your eyesight started to deteriorate?

A. Yes, the first indication was I started having problems reading the tape measure at work.

Q. Yes. I think you tell us in paragraph 26, which is WIT0040021, that you went to an optician at that time and were informed that you would need very weak prescription spectacles?

A. Yes, I went through to [redacted] to -- I think it was to pick up materials or something or, you know, some piece of machinery and it seemed an ideal opportunity and I went and got my eyes tested and they said, "You need mild reading glasses". I didn't do anything about it at that precise time as they cheerfully told me it would cost me £280 for three pairs of glasses and I would get three pairs of tinted spectacles at the same time. Again, in my financial situation I was not that enthusiastic and so I paid the £16 and left.

Q. Right. You then say in paragraph 27 that within two weeks of this you were referred to the eye pavillion of Edinburgh Royal Infirmary as you knew that there was something seriously wrong with your sight?

A. Yes.
Q. What had happened to it by then?
A. I found I just couldn't work, I couldn't see what I was doing. There were serious problems with driving and things like that and I ended up scaring myself quite seriously, again with taking the motorbike out, and discovering -- well, rumbling along on a road I knew very well, I discovered the sudden alarm when you find, by clipping part of a bush on the right-hand side, that you are driving along on a motorbike on the wrong side of the road.

So trying to rapidly correct it put me up the verge on the other side and the trouble I have with my eyesight is -- or what limited sight I have, if I look at something, I can't see it. So again I tried to concentrate on what I was seeing and that was absolutely hopeless. So for the following two miles I was all over the road, all over the place and terrified myself.

Q. In what period of time did this deterioration occur to that level?
A. It was quick.
Q. It was quick.
A. I mean, within weeks. I think from -- first, I think, problems, it would only have been, you know, literally -- well, probably only a week or two.

Q. I would like to refer to a letter WIT0040273. This is a letter from Dr Hanley to Dr Mumford, Consultant Neurologist at the Western General Hospital in August 1996. It says:

"Dear Dr Mumford, thank you for seeing [you] at such short notice."

How you have coped very well over the years with problems associated with haemophilia and you have a degree of arthropathy, particularly affecting your knees and elbows. In the second paragraph, it states that you became infected with HIV in 1984 from a contaminated Factor VIII infusion and that you also have chronic Hepatitis C, which probably dates from the 1970s.

In the third paragraph he writes that you have not had any HIV related problems previously. Your CD4 count has declined relatively slowly over the past 12 years and has been around 50 cells per millimetre cubed for the past year, and that you have been reluctant to have any therapy in view of your lack of symptoms in the past.

You have never received antiretrovirals and you have declined prophylaxis treatment for pneumocystis pneumonia, which can be one of the symptoms of HIV.

It then goes on to recount your problems with your

eyes and states that your recent problems started five or six weeks ago. You noticed a gradual deterioration in your eyesight to the extent that you were having difficulty reading. You attended the Haemophilia Centre as you were worried about these symptoms and you were admitted for investigation. You were reviewed by DrDhillon, Consultant Opthalmologist, who confirmed a reduction in visual acuity, and there was no evidence of retinitis. You underwent both a CT and an MRI scan and initially the CT report was normal but the MRI scan revealed a left parieto occipital white matter lesion 4 centimetres by 3 centimetres. And in retrospect this was also visible on the CT scan. The radiological appearances, as in what was shown on these scans, were strongly suggestive of PML, Progressive Multifocal Leukoencephalopathy.

Going over to the next page, it discusses a lumbar puncture being performed and samples sent and says in summary, they think that you have progressive visual impairments and the scan is suggestive of PML and they would be grateful for Dr Mumford's opinion as to whether they can be certain about this diagnosis?

A. But from the lumbar puncture, they did not get the results they expected.

Q. No. I think they were looking for the JC virus and

I think that it didn't confirm the JC virus, the lumbar puncture, but the diagnosis of PML remained.

A. Yes.

Q. Yes.

A. This was disputed by my GP at the time.

Q. Yes. You mention that. Just to finish this letter, the second last paragraph reads:

"The situation is further complicated by the fact that [you] have always been extremely concerned about confidentiality to the extent that you have not confided [your] HIV infection to any members of [your] family.[You] are now coming to terms with [your] new situation and may decide to tell [your] parents in the near future. Because of [your] worries about confidentiality, [you] have not registered with a GP."

So when you were diagnosed with PML, what were you told about PML at that time?

A. That PML is a fatal condition. From when it starts you have problems with your eyesight, you will eventually -- in a fairly short time it will get -- it gets dramatically worse. So from your sight failing, you will go blind. They were rather vague and only under pressure did they give a full rundown, which I remember being fairly appalled by, and the result was that I would go -- my sight would go completely, so I would

end up deaf, dumb, blind, incontinent and infirm. And the end result is I would be a vegetable and it would only be my heart and lungs that would be working and it would be matter of whichever failed first. All this is likely to occur within three months and you are fairly well advanced already.

Q. Right. Were you told that the PML was linked to your HIV?

A. Yes.

Q. Yes?

A. Yes, it's to do with -- it's one of these things that can be in your circulation or in your blood -- in your blood anyway but your immune system naturally keeps it at bay. Now, my immune system is so devastated that all these things come rearing up and cause all the damage.

Q. Yes. I would like to refer to you another letter, WIT0040275, which is a letter from Robin Grant, Consultant Neurologist, dated October 1996, to Dr Hanley. He goes over the deterioration in your eyesight and what the examination has shown and the MRI scan. At the bottom of the first page he states:

"I think that the time course and the MRI scan appearances would be entirely consistent with the diagnosis of PML. He is well aware of this condition and knows that there is a spontaneous remission rate in

a small percentage of people even who have HIV and there is no particularly effective treatment of this condition."

So were you told that, that there was a small remission rate?

A. No, no. I was told it was fatal.

Q. You do not remember being told that:

After being told there is no particularly effective treatment of this condition,“He does not wish to be tried on medication that will give him side effects and would rather have a good quality of life rather than extended survival with significant disability."

A. Yes.

Q. "I am not sure that there is anything to be gained by a further LP ..."

Lumbar puncture maybe?

A. I actually refused. From the lumbar puncture, I was very uncomfortable afterwards. It was done in the old infirmary and then my mother chauffeured me back to their place, which is [redacted] miles away. I was -- I think I was a horrible grey colour and in a fair amount of pain.

Q. So it goes on to say:

"it seems likely that the condition will continue to very gradually deteriorate over the next few months. In

my opinion, if he did wish to try something, it may be worthwhile trying to improve his immunity perhaps with triple therapy but he is quite certain just now that he doesn't wish to try this."

A. Yes.

Q. I think it mentions someone else:

"... as you know has been tried on this condition, not with any clear success and it has always been at the cost of side effects."

So were you warned about the risk of side effects?

A. Yes, there was mention of various types of side effect, yes.

Q. Right. So at this time you understood that this condition would continue to deteriorate and that really it was a condition that was going to prove fatal to you?

A. Yes.

Q. Yes. So how did you feel at this time?

A. I wanted it all over.

Q. Yes.

A. I had been -- they had been telling me for years that "You are very ill, you are dying," "You are very ill, you are dying." Well, get on with it. You know? I suppose that the anger, the frustration and the rage has faded away. You are now in such a medical mess that to die would have actually been pretty much a relief.

Q. Yes.
A. Again, the difficulty was the fact that, as I've said, I didn't want my parents to know.
Q. No.
A. And, you know, it would be difficult to explain and it was actually pointed out by a social worker, who ended up -- she ended up getting quite upset about it because she said, you know, "What respect are your parents going to have if I tell them because you didn't have the confidence, the manners or, you know -- to tell them what had been going on?" Which -- I mean, I remember both of us getting really quite upset about it.
Q. So did you have anybody with you at this point, when you were finding out about this, that you had PML?
A. Yes, I seem to remember there were two -- when they gave me -- after a whole lot of tests, I ended up seeing two doctors and a nurse and the -- they ran through -- they wouldn't tell me -- they wouldn't in detail tell me what was wrong. They were saying "It's very serious, it's very serious", and I pressurised them into saying what was going to happen and their response was, "It's not good, it's not good. You are very ill."
So, making a fuss, I said, "Then, tell me what's going to happen. As a patient, I'm basically insisting that you tell me what's going to happen." And so under

duress, one of the doctors ran through the full rundown, which must have taken a minute or so, of a horrific outcome. And the thing I remember about that, again, with my -- huge -- I have a good sense of humour, which is generally sarcastic, and there is a long silence when he has finished his tirade, and he said, "How do you feel about that? Is there any comment?" And I carefully straightened myself up in the seat and said:

"Well, it's a bit of a bummer."

And the nurse burst out laughing and had to leave the room and the doctors sat up and looked at each other. Again, my sense of humour may well have been one of the things that has kept me alive.

Q. It's very important, a sense of humour.

Going back to paragraph 28 of your statement, you tell us that you were also told that you suffered a series of strokes causing paralysis down your right side.

A. Down the right-hand side of my body, yes.

Q. Did this happen relatively soon after you found out that you had PML?

A. Yes, I only remember -- I remember one or two -- I don't know quite how they are phrased -- seizures.

Q. Yes.

A. Generally it seemed to be happening while I was asleep

but I remember one very horrific one, being woken up late at night, and it was a feeling of being squashed to the floor and I know I lost consciousness. The use of the right-hand side, the arm was then not controllable but I was having difficulty with it. It tended to go off and do its own thing, and in no time at all it was -- I was losing the use of it and shortly afterwards -- the right leg still worked but not very controllably but the right arm ended up completely floppy and useless.

Q. Right. You mentioned seizures there. If I could refer to you WIT0040277, which is a letter from C Stirling, a Haematology Registrar, to, presumably your GP, although I think you still didn't have a GP at that time, but it will have been for the records.

This tells us that you were admitted just before Christmas on 19 December 1996 for about four nights. There was a query whether one of the diagnoses was epileptic seizures. It was recorded that you were admitted having attended the Haemophilia Clinic and been found to have expressive dysphasia. As it points out, you were very independent, so it was unclear as to whether this had developed over a few hours or whether it had developed over days. So the first major concern was that you had had an intracranial bleed, but

initially you weren't that keen to have Factor VIII treatment but then you did receive some Factor VIII.

Then it goes on to say at the bottom that your expressive dysphasia had recovered by about 80 per cent, and in view of your history of acute sudden deterioration and recovery, Dr Grant, who is the neurologist, I think, queried whether this was some form of seizure but felt that the clinical story was consistent with this being part of your PML.

A. I certainly used to have muscle spasms on the right-hand side. Again, often with no warning. It would tighten up from the -- quite often from the groin and I would end up having a series of severe muscle spasms, and the arm would straighten out and go off in its own direction and straighten out and twitch uncontrollably, which is actually -- well, it's frightening because you just knock things over and flap things out the way.

Q. So was that found to be seizures?

A. I think that would be the technical term, yes.

Q. Right.

A. And again, depending on how severe it is, a really severe one you can't control but if you felt it coming, I discovered that if I kind of bent myself -- doubled myself over and controlled my breathing, you can limit the -- how fierce it is.

Q. Right. At this time, going back to this letter, you were commenced on sodium valproate, which is an anti-convulsant. Do you remember that?

A. I don't remember that particular drug. I know I did take several things to try and stop the spasms and I do know that on several occasions I bit my tongue.

Now, again, I don't know whether I bit right through it or whether it was just nipped on the edge but I certainly remember having -- there were one or two occasions up north, where I know I lost consciousness and you wake up and you have got the strong taste of blood and you know -- and things hurt because you have obviously bumped into stuff and ...

Q. Right. It was noted here that you had refused antiretroviral treatment despite your CD4 count being very low?

A. Yes.

Q. That eventually you informed your parents of your admission to hospital and agreed to DrLudlam speaking to them regarding risk of contact with body fluids. And they were still not informed then of your HIV status in accordance with your wishes. But DrLudlam was insistent that they be told that you were hepatitis positive and that they should protect themselves. And you were aware of that.

A. I would have to say I don't remember that.
Q. Right. You tell us in paragraph 29 that in January 1997 you moved back to supported accommodation in [redacted]?
A. Yes.
Q. So you had had to stop your work and move to [redacted]. Was that because you could get the support that you needed there?
A. It was because I was doing myself a whole lot of harm living up north. I had ended up having a seizure or a fit or a spasm on a train and had ended up in hospital with a selection of, I think, it was malnutrition and hypothermia and stuff like that, and it was -- it was pointed out that any possibility of medical assistance would mean I would have to be in [redacted]. They initially wanted me to go into a home, which I refused flatly, and it was then suggested that SATA(?), I think they were called at the time, would try and find accommodation for me, and I think I refused several of their properties until finally they got me a small flat in [redacted].
Q. Right. How about self-caring? How were you able manage on your own at that point?
A. Again, from my motorcycling knowledge, I knew that you could get jeans with padded knees. So I got a pair of them so I could move around the flat on my knees because

I had lost the use of the -- I couldn't use the arm. So I was having to move -- I couldn't use crutches either. So I was having to move around on my knees in the flat, which was very small. So it was actually not much of a problem to get about. They were fairly enthusiastic for me to get home help. And again, it was my first experiences with home helps. It didn't go down very well.

Q. And why was that?

A. I think I developed -- I wanted to do things on my own. I didn't want other people telling me what to do and providing food that I didn't like and didn't want.

Q. The medical records show that in February 1997 you registered with a GP?

A. [redacted].

Q. I'm not sure because it is redacted from the record that I have. But the letter of referral to the GP is WIT0040281. I think you had previously been seeing this GP for homeopathic therapy because that's mentioned in the letter:

"I appreciate that you have seen him previously for homeopathic therapy. He seems to be receiving much support in his flat from the Social Work Department."

A. Yes, in those days, the organisation used to come round Monday, Wednesday and Friday and they had what was

referred to as an out-of-hours service.

Q. It's noted in the letter that you still haven't told your parents about your underlying viral condition:

"... although it is difficult to conceive of them not having considered this possibility. As you may know, we have been trying to encourage him to tell them for some time. He tells me today that he has asked them to visit him tonight when he will explain his situation to them. He has given his agreement to us speaking with them thereafter. He has also indicated that his parents should make decisions for him if he is not capable to do so himself."

DrLudlam notes:

"His vision continues to fail and he now has progressive weakness of his right arm and leg. He can still manage around his flat with holding onto the furniture."

You have an alarm in your house, which you wear around your neck in case of a problem at that point. He says he has discussed with you longer term care arrangements when you cannot manage in your flat and he thought that you should be taking one issue at a time and telling your parents is the most important thing at that point.

You tell us in paragraph 29 of your statement that

you did tell your parents and your sister about your diagnosis on 19 February 1997. And how was that?

A. We had a -- they came round, we had a meal and after the meal we sat down and I brought it up as the conversation. Obviously a very difficult topic to broach and on completing the outcome, my sister burst into tears and flung her arms around me and Mum and Dad were suitably shocked and stunned.

Q. Because at this point you are having to tell them both about HIV and PML?

A. Yes.

Q. Yes. So your parents became very much involved with your care?

A. Yes. Yes, my Dad had been speaking to one of the doctors at the Haemophilia Unit and I know he had started to get a bit irritated because he said that he was assuming the doctor was being decidedly vague about things. And so after I told them, Dad phoned the doctor up, who was apparently quite relieved that I had finally let things out.

Q. Yes, and so you carried on with the help from your family and the help from the Social Work Department?

A. Yes.

Q. Then you tell us, over the page in paragraph 30, that you learned, after discussion with your support worker

at the time, that treatment for HIV had moved on. So you decided to give it a try.

A. Yes.

Q. So you started treatment initially with AZT. Is that right? Zidovudine?

A. Again, with help reading any of the paperwork, they gave me medication. Yes, they would have been telling me what it was but there would have been more discussion about side effects and reactions, which is what I would have been paying attention to. But the other reason that I agreed to start taking medication was the right arm started to respond. From being floppy and useless, I had managed to get a small amount of movement back in it.

Q. Did you notice that after you had started the treatment?

A. From what I remember, yes.

Q. Because the records show that you started taking Zidovudine and then Didanosine was added in and you were on these two medications. This was in 1997 and then Didanosine was changed to Lamivudine and it was thought that might be a better combination for you. Did you find any side effects? Did you have any side effects from taking these medications?

A. Again, things like stomach upsets and things along those lines but I don't remember anything more serious than

that.
Q. Yes. How did you find taking them?
A. I don't think there were any serious side effects.
Q. I think in November 1997 the reference for this, I don't propose to refer to it, is WIT0040302. Your treatment was changed to Stavudine, Didanosine and Nevirapine as your CD4 count had fallen to pre-treatment level and so it was thought that this might help more. Then there was a further change in your medication in January 1998, when Saquinavir was put in place of Nevirapine.
How were you during this period? You obviously noticed some improvement in your right arm?
A. Yes.
Q. Yes. How was your condition? Did your sight remain the same?
A. Yes.
Q. Yes. Physically, did your right arm continue to improve?
A. Yes, as far as I remember, things very gradually got better. A lot of it was to do with continuous exercise and, you know, encouraging it to work.
Q. Yes.
A. And again, from having -- in the past I had had problems with -- I had cut the circulation off in one arm and I had ended up with pins and needles in my fingers when

I was a youngster and the medical people had advised me to do a whole lot of exercises. So I remembered parts of this and this was what I was doing to try and get the right arm working.

Q. I noted in your medical records that at one point you asked for an exercise bicycle from the Haemophilia Society so that you could try and keep fit in your flat?

A. Yes.

Q. Could I refer to WIT0040313? This is a letter about having to stop your treatment due to grossly abnormal liver function test results. Do you remember that?

A. Not really, no.

Q. No. I'll read you the letter. It's dated July 1998, 6 July, and it's a letter from Janet Andrews, who is at the Western General Regional Infectious Diseases Unit.

THE CHAIRMAN: Ms Patrick, I'm becoming quite concerned that we have had the witness here for rather a long time.

MS PATRICK: Yes.

THE CHAIRMAN: And it's already clear to me, I think, that you have got some way to go.

MS PATRICK: Yes.

THE CHAIRMAN: I'm prepared to shortcut things. I would like you to give me a note of all the references to medical records that you have taken, rather in a shortcut way, and I can deal with that. I think there

are important things in the rest of the statement that I wouldn't want to rush.

Mark, are you --

A. No problem.

THE CHAIRMAN: -- happy to go on? We will go on because accommodating you is the most important thing but if feel at all unhappy, just tell Margaret and we will interrupt it.

MS PATRICK: I'll refer to letters but we don't need to look at them, so if I just provide the reference.

THE CHAIRMAN: I think you have missed one or two. If you just go over the references for when treatment was changed. I don't think you gave the initial references but don't do it just now.

MS PATRICK: We can do it after you have gone, Mark.

I think in July 1998, WIT0040313 shows that your liver function tests were grossly abnormal and so it was decided that it would be preferable to stop your antiretrovirals and monitor your liver function, but you knew then that there was a risk that your PML may progress because you were stopping the antiretrovirals. But that's what was done at that time, the treatment was stopped.

A further letter in September 1998, WIT0040318, showed that this had helped and that your liver function

tests had stabilised.

In June 1999, WIT0040324, a Neurovirology Clinic noted that you were feeling well and there was no deterioration over the last three months.

At some point did you start to become concerned about treatment for the Hepatitis C virus?

A. No.

Q. No? Do you remember that being discussed with you?

A. Yes, there was discussion about hepatitis.

Q. A letter dated 15 September 1999 -- we don't need to look at it, WIT0040328 -- notes that you enquired about two things: whether you should be on prophylactic Septrin -- and I think the concerns were that that would have the same side effects it had had before, these antibiotics?

A. Yes.

Q. Also that you were wondering about the possibility of treatment for Hepatitis C. I think the side effects were pointed out to you and the fact that Interferon and Ribavirin treatment didn't necessarily cure --

A. Yes, it wasn't guaranteed success.

Q. I think you were well aware of your genotype and the chances of success of treatment?

A. Yes, there was certainly discussion about these things and the end result was a decision not to.

Q. Yes. In 2003 you underwent knee replacement surgery?
A. Yes.
Q. This was due to all the bleeds you had had as a child presumably, and the fact that that became --
A. Well, as has been pointed out, I had had problems with my knee since I was ten years old and it got to the point where the knee was giving serious problems and bleeds, so I ended up taking stronger and stronger painkillers and ended up on morphine patches, which I didn't seem to get on with very well and I was often just sick.
Q. Yes. I think that when you were discussing the risks of that surgery, it was pointed out to you that the risks of your knee replacement surgery were greater due to the fact that you had HIV and your immune system was lower?
A. Yes.
Q. The reference for that is WIT0040349. How did your knee replacement surgery go? Did you have a good outcome from that?
A. Absolutely perfect, yes. Yes, I mean, very painful, several months of discomfort but, yes, the end result was fantastic.
Q. Good. In April 2004 you were referred to a plastic surgeon due to facial lipoatrophy, and this was changes in your facial appearance due to your HIV medication?

A. Yes.
Q. And what was the outcome of seeing the plastic surgeon?
A. I refused. What's the point? I can't see myself in a mirror. Who is going to be looking at you? I don't go out. I don't go out, I don't get about. The only people I'm seeing are friends and social workers and colleagues. So what's the point in having more medical procedures, as there is more risk?
Q. So you tell us in paragraph 37 that when you were 35 years old, you were diagnosed with bowel cancer?
A. Yes.
Q. The medical records show that -- this is getting technical -- that it was anal squamous carcinoma that you were diagnosed with at that time?
A. Right.
Q. And you then had to undergo chemotherapy and radiotherapy for five weeks?
A. Yes.
Q. Six days a week at the hospital?
A. Yes.
Q. Were you told that that was caused by your HIV?
A. Yes.
Q. Yes.
A. Yes, it was pointed out that I was unusually young but that was because of my HIV status and my lack of immune

response.
Q. Right. And what were the side effects of your chemotherapy and radiotherapy treatment?
A. Well, I didn't go bald, which was one of the things that they had warned me about, but I did lose a whole lot of body hair. There weren't really very much -- very many effects until the final week and that's when things became painful and, you know -- and I think by that stage I was on oramorph and other painkillers.
Q. Right. And you tell us that following that treatment you got the all clear and then a year later you were told that the cancer had recurred?
A. Yes, yes.
Q. And this time you had to have surgery?
A. There was surgery done to reassess it and then the professor came back and said, "It's come back and it's very angry. You have the option of a full colostomy or once again you can die screaming in the next few months."
Q. Right. And so you underwent a full colostomy in August 2008?
A. Yes.
Q. And how have you managed with that?
A. I think it is classified as surprisingly well. I subsequently discovered one of their greatest concerns

was after the chemo- and radiotherapy, they were not expecting the tissue to heal properly and there was a distinct possibility of wounds remaining open and, for whatever reason, everything healed, you know, very well. So, apart from having some impressive scars and the colostomy bag, it actually worked very well.

Q. Good. And one letter I would like to refer to you is WIT0040415, which is a letter from DrCatriona McLean, Consultant Clinical Oncologist, dated October 2008. She is referring to your good recovery from this surgery and that you have no ongoing problems and that the painful area in the lower end of the wound is slowly beginning to resolve. She states that you are really a remarkable man, given all your adversities, and that you had been telling her about your trip on a motorbike with your friends to Europe.

A. That was before a whole lot of the procedures.

Q. Yes. Was that after you were diagnosed with PML?

A. Yes.

Q. Yes.

A. Yes, I think it was after I had had the chemo- and radiotherapy but before the colostomy.

Q. And she describes you as being really quite inspirational.

A. Yes, I suppose trying to get on with things.

Q. The last letter I would like to refer to is WIT0040430, which is the most up-to-date review we have from Professor Leen, your consultant physician at the Western General Hospital. It really gives us the most up-to-date position of your discussions with him. It notes that your last CD4 count was 219 cells per millimetre cubed and your last HIV viral load was less than 40 copies. You are obviously still considering treatment, are you, for the Hepatitis C virus?

A. Yes, again from consultation with the professor. He basically advised me to hold back because there are other options on the way. And so he said, you know, "I'll see you every three to four months and discuss things but if nothing changes dramatically, I would advise to you hold on because there are other options, with other possibilities in the pipeline."

Q. Right. And how do you feel you are managing now?

A. The biggest problem at the moment is the arthritis. The knees -- I have had -- the right knee was replaced. I have had keyhole surgery on the left knee but the problem now is my ankles, again to do with arthritis, which I believe is aggravated by my HIV status, and I think -- I don't think the medication helps.

For ankles, their suggestion is to fuse it. That, for me, is a step back, not a step forward. So while

there is still a small amount of use with it and the pain is -- it is getting worse but currently controllable to some degree, I'm refusing.

Q. Right. And how do you spend your time?

A. I have a talking computer. I have had parts of the house altered so I can get upstairs and move around. There has been a lot of work again in the garden, removing steps, so I can get -- I can move right round the garden. So it's basically, you know, trying to get my own environment, where I know where things are. I have home helps every day of the week, which would -- which certainly make a difference. Again, whenever I have a bleed, that's me stationary for between two and four days. So, without a home help, I wouldn't be able to manage. And there is a fair degree of determination to stay in my own house.

Q. Yes.

A. Because I know again the other difficulty I have is knowing where things are, and one of the only problems, or one of the serious problems, I have with home helps is where they put the sharp knives.

Q. Right.

A. Because I can't see them.

Q. Right. You tell us in paragraph 41 of your statement that you have a mortgage, which was arranged through the

Macfarlane Trust.

A. Yes.

Q. And you say you would be unable to obtain life insurance?

A. Oh, yes.

Q. Have you ever tried to obtain life insurance?

A. No, I haven't.

Q. And you say you have never taken out a pension.

A. No.

Q. And you have found travel insurance to be all right?

A. It was more expensive after I had had the -- the first lot of treatment -- of the cancer treatment. The company that I dealt with before moved me on to another company because I had had a -- a serious medical procedure within 12 months.

Q. Okay.

A. And I think it's not considered exactly normal for somebody in my situation to go off to Europe on the back of a large capacity motorcycle.

Q. No.

A. But then I was with other friends, who were driving cars. So you, you know ...

Q. Yes. And you tell us at the very end of your statement that you have received both Skipton fund payments as well.

A. Yes.
Q. I would just like to ask you a couple more questions. The first is: how do you think that your infection with HIV has impacted on your family?
A. I think in the scheme of things it has probably helped my parents to some degree because they didn't know. I know the stress and concern would have been greatly increased over the years. Again, I think, if I had told them, they would have been very enthusiastic for me to start taking medication or antiretrovirals before I actually did, which in the scheme of things may not have been beneficial.

I do have a feeling of -- certainly a feeling of regret that I virtually didn't trust -- well, to try and not to tell your parents is very awkward and I know it upset them because my father, also being enthusiastic on motorcycles, was very aware, when I went past the house on my bike, of why I didn't stop and say hello and it was because there was the possibility of a conversation. You know, if he had asked me directly, I wouldn't have been able to deny it.

Q. Yes.
A. So, yes, it's unfortunate. I feel I have let them down to some degree and -- but they have been very helpful, once they have known.

Q. Yes. Finally, we have heard of the very significant impact that this has had on your life. Is there anything else that you would like to say about the impact of your infection with HIV on you?

A. I suppose the thing that I remember is how my world was smashed into a million pieces from one sentence, when Ludlam told me what the situation was; that was my world effectively over, plus the fact that the outcome of being -- you know, "You have been infected for a number of years, you will be dead within a few months" is a very difficult thing to live with and seems very harsh and unfair when you have worked very hard and made a lot of effort to achieve a lot of things that I was told I wouldn't be able to do.

So again I suppose it's the same situation. I mean, I'm in my 40s. I did not expect to get this far. Again whether I have helped myself by refusing medication and letting my body get on with things, it's difficult to say. The biggest problem I have at the moment again is my sight. I have tried to live a lot of my life very independent and the lack of sight very much takes that away. I'm relying on other people for everything from shopping to transport and that has got to be one of the hardest things for me to deal with, you know, to take that deep breath and allow other people. But it has --

it has very much brought out who my proper friends are and who is on my side.

Q. Thank you very much. I would like to thank you for going through all that with us. It has been very, very helpful. So thank you.

A. Right.

THE CHAIRMAN: Gentlemen, are you content?

MR DI ROLLO: Yes, sir.

THE CHAIRMAN: Mark, thank you very much.

A. Right.

THE CHAIRMAN: We will adjourn until tomorrow.

(4.48 pm)

(The Inquiry adjourned until 9.30 am the following day)