

Friday, 12 March 2021

(10.00 am)

SIR BRIAN LANGSTAFF: Good morning, Ms Phipps. Can you see and hear me?

THE WITNESS: I can see and hear you.

SIR BRIAN LANGSTAFF: Good. Sorry?

THE WITNESS: Can you see and hear me?

SIR BRIAN LANGSTAFF: Well, yes, I can. Now, are you at home?

THE WITNESS: I am.

SIR BRIAN LANGSTAFF: Are you there on your own?

THE WITNESS: I'm here -- well, my husband's out of earshot.

SIR BRIAN LANGSTAFF: Okay. You're talking to a room here which has got a total of -- let me just check -- eight/nine people in it, including myself, one of whom is Mary, who will take your affirmation in a moment or two. Another is Soumik, a name you will hear, whose job it is to make sure that you get the right paper in front of you at the right time, the right reference, the right document.

The audience to whom you are really talking is beyond this room. They are watching remotely because of obvious current circumstances, a mixture of either YouTube or Zoom and there are about 200 of those,

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Q. Your witness statement tells us that between 1991 and 1995 you worked on a programme run by the Wellcome Trust on PR for positive action to combat stigma and discrimination for communities affected with HIV and AIDS; is that right?

A. Yes.

Q. What was your role on that programme -- in that programme?

A. I was a consultant to the firm who were friends of mine who had successfully pitched to help with the programme and it was as much, in fact, it was probably more communication than PR. So my role was to write documents that might be used in communicating messages. I think I went to conferences with the programme. It was only a -- well, it was one of many clients that I was working for. The others were all in publishing. So it was -- you know, it was that sort of thing.

A lot of the -- sorry, a lot of the work was trying to get messages about HIV across in Africa. The only thing I did with any degree of success, I think, in the UK was trying to talk to the heterosexual male community because, at that time, it was very much not perceived as being an issue that the heterosexual male community perhaps got engaged with.

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probably. That's the sort of number we've had, between 200 and 300 over the last week or so and it will be about that number today, I would expect. So that's who you are talking to.

Now, Mary will ask you to affirm and then Ms Scott will ask you some questions.

SUSAN MARGARET PHIPPS, affirmed

Questions by MS SCOTT

MS SCOTT: Good morning, Ms Phipps. Can you see and hear me?

A. I can.

Q. You were a trustee of the Eileen Trust between 1993 and March 2017; is that correct?

A. That's right.

Q. Your background was in publishing particularly in magazines, and you'd undertaken roles in publishing both as a freelancer and on an employed basis; is that also correct?

A. Yes. It was only magazines and the vast majority was employed.

Q. You are currently deputy chair of the -- is it the Volunteer National Garden Scheme or the National Garden Scheme?

A. It's the National Garden Scheme. It's a health charity.

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Q. Did you come across or work with communities infected with HIV via blood or blood products through that work?

A. No, not at all.

Q. Can you tell us a bit about what you understood and learnt about the stigma and discrimination faced by people with HIV and AIDS during that period?

A. I think -- well, a lot but all through the -- well, not all but in the UK mostly through the prism of the gay society, because those were the people that -- there were gay people that I knew through that work, but I suppose just as anybody would have been aware at the time, the huge level of misinformation and fear and stigma and just horrendous stories that were swirling around something.

I mean, I think people were just very frightened and so it was a very easy time for bad stories to get credibility.

Q. Why were you drawn to the Eileen Trust?

A. It wasn't specifically the Eileen Trust. I had just gone freelance because I had small children so I was more -- I could be more flexible with my time and, I think by that time I was 37, so I had been working for 17 years and I think I just thought I wanted to do something apart from work and family that was maybe

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1 more useful, maybe I just thought it would be
 2 interesting to see if I could -- see if I had skills
 3 that could be used in a broader -- well, in
 4 a different world.

5 So I applied -- I sent my CV to something
 6 called the public appointments committee, or
 7 something, which I think still exists, which you could
 8 write to if you wanted to volunteer in any capacity
 9 and I think you just put down what you'd done and then
 10 they got in touch with you if they had roles or things
 11 that they thought you might be useful.

12 Q. When you applied or when you were interviewed -- well,
 13 were you interviewed for the Eileen Trust?

14 A. I don't -- I'm sure I didn't see anybody face-to-face.
 15 I think it was all done on the phone because I know
 16 that another position, which the people talked to me
 17 about which they didn't want me for, was just on the
 18 phone and I think the Eileen Trust -- I think it was
 19 just a phone call. I mean, I couldn't swear but --
 20 and I certainly don't think there was any kind of --
 21 much toing and froing and talking about it.

22 Q. When you first -- when you accepted the appointment,
 23 what did you know about people becoming infected with
 24 HIV through blood and blood products?

25 A. I think my perception was that it was a mistake that

5

1 it can have been going much before that and that was
 2 July.

3 Q. But did you have anything to do with the actual setup
 4 of the Eileen Trust and decisions made about how it's
 5 constituted, and so on?

6 A. Not about how it was constituted, no. But in the
 7 early days we made the decisions or had the
 8 discussions and made the decisions about payment
 9 levels or approach, that sort of thing.

10 Q. I'll come on to ask you some questions on payment
 11 levels later on this morning.

12 Is it right that the Reverend Tanner was
 13 already in place as the Chairman by the time you were
 14 appointed?

15 A. No, we voted for him -- well, the minutes of that
 16 first meeting say we chose the Chairman. I think it
 17 was probably a *fait accompli*.

18 Q. Was his expertise on the Macfarlane Trust a factor in
 19 that, can you recall, the fact that he was chair of
 20 the Macfarlane Trust?

21 A. The fact that we chose him?

22 Q. Yes.

23 A. I don't recall. No, I don't think -- well, except
 24 that it was probably a factor in why he was chosen to
 25 be a trustee because I think three of the trustees had

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1 was -- I probably at the time just assumed it was the
 2 National Health's fault. I certainly didn't know all
 3 the political background. I didn't know about the
 4 Macfarlane Trust and I don't think I thought massively
 5 about it. I understood that it had happened but
 6 I think my concern was, well, here we are, here's this
 7 Trust and now we're going forward to see what we can
 8 do.

9 Q. I think in your witness statement you have told us you
 10 didn't receive any induction to the Eileen Trust --

11 A. No.

12 Q. -- do you think that would have been helpful?

13 A. Yes, I think it would, yes, because -- well, yes,
 14 I think it would because, as time went on through
 15 fellow trustees [redacted] I learnt more, although
 16 yes, I think it would have been helpful but I don't
 17 know that it was a real impediment, perhaps. I don't
 18 know. Hard to say.

19 Q. By the time you were appointed, is it right that the
 20 Eileen Trust was already set up and running?

21 A. I was at the first meeting. I think -- reading the
 22 document, the first three founder trustees had to be
 23 something. I can't remember what it says but before
 24 the first meeting I had been appointed, because at the
 25 first meeting we chose the Chairman, so I don't think

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1 to be Macfarlane trustees, I think.

2 Q. Do you know why that was? Was an explanation ever
 3 given to you as to why there had to be so many
 4 Macfarlane trustees on the Eileen Trust?

5 A. I don't remember whether there was any explanation.
 6 I think they probably just thought it was convenient
 7 because they had access to people who could hit the
 8 ground running perhaps, and it had pros and cons
 9 probably.

10 Q. Was it your understanding that the Secretary of State
 11 had a power to approve or refuse the appointment of
 12 trustees?

13 A. Yes. Yes, I certainly -- my understanding, which may
 14 not have been quite right, was that I was appointed --
 15 I was one of the two trustees who was appointed by the
 16 Secretary of State and, since then, I think I've seen
 17 that one of the three Macfarlane Trusts had to be or
 18 was expected to be a Macfarlane trustee whom the
 19 Department had appointed. So that was another one
 20 that they were controlling or influencing the
 21 appointment of.

22 Q. So was it your understanding that they didn't have
 23 a power of approval or refusal over all of the
 24 trustees, just the ones that they were nominating?

25 A. Yes, and I think -- yes.

8

1 Q. We can see from the minutes that Dr Mayne and then
2 subsequently Dr Winter were trustees of the Eileen
3 Trust. Do you know why it was felt necessary to have
4 a medical trustee on the Eileen Trust Board?
5 A. I don't.
6 Q. Do you recall ever having to call on their expertise
7 in any capacity for decisions made?
8 A. I think more in the early days I remember there were
9 times when Dr Winter -- I don't remember before
10 Dr Winter, but when Dr Winter's experience was called
11 upon. As time went on, I think the reasons we were --
12 for which we were giving single grants were connected
13 with not directly medical things, it was much more
14 things going on in people's lives and needs that they
15 had as a result of the conditions they were living in.
16 Q. Do you recall there being any discussion during your
17 time at the Eileen Trust about having a user trustee
18 or someone from the infected or beneficiary community
19 on the Board without --
20 A. No -- sorry.
21 Q. Yes, sorry. No?
22 A. No, there wasn't and, actually, given that there was
23 some time where we seem to be -- we didn't have our
24 full capacity of trustees, I don't know why we
25 never -- I don't know why that was never considered.

9

1 Ann Hithersay, Martin Harvey then Susan Daniels?
2 A. Yes. Susan Daniels was there initially as an
3 independent financial adviser, and then as case
4 worker, and then as secretary.
5 Q. Was the role of the secretary to implement board
6 decisions and to run the Eileen Trust from an
7 operational perspective?
8 A. Yes.
9 Q. Is this also correct, that there was from the
10 inception of the Eileen Trust a social worker who was
11 initially Tudur Williams.
12 A. That's right.
13 Q. Subsequently Fran Dix?
14 A. Yes, if you have got the -- I couldn't swear to
15 everybody's names and the order in which they came.
16 Q. And then Claudette Allen?
17 A. Yes.
18 Q. Were they -- do you recall whether they were also
19 social workers for the Macfarlane Trust so were
20 dividing their time between the two organisations?
21 A. Yes, they were.
22 Q. What was their role, can you recall?
23 A. They communicated with the registrants. They were --
24 there was also a benefits adviser. They helped the
25 registrants with applications for grants, gave them

11

1 I don't know why.
2 Q. You were there for 27 years and Peter Stevens was
3 there for 17 years --
4 A. I think I was only there for 24 years.
5 Q. My maths, I beg your pardon. I think you are right,
6 24 years. What impact do you think the low turnover
7 of trustees had on the running of the Eileen Trust?
8 A. Well, I would say it was -- well, I think, actually,
9 I would say it was a good thing in that we got better,
10 and better, and better at running it. I think
11 circumstances changed but I think it was good
12 having -- I think it was good having consistency but
13 I do also think some change is a good idea. It was
14 good having a change of Chairman and I think that
15 certainly marked a change in our approach but maybe
16 that was circumstances as well. Whether it would have
17 been better if I hadn't been there so long, I don't
18 know. Hard to say.
19 Q. I'm going to ask you some questions about the staffing
20 arrangements at the Eileen Trust. So, is this right,
21 that there was always the position of a secretary who
22 was initially Commander Williams, then Martin Harvey
23 and then, latterly, Susan Daniels?
24 A. No, I think Ann Hithersay --
25 Q. And Ann Hithersay, yes. So Wing Commander Williams,

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1 advice. John Williams went to see -- well, I think
2 they probably all went to see them when people had
3 visits, that sort of thing.
4 Q. You've mentioned there was a benefits adviser.
5 A. Yes.
6 Q. Was that Jenny Jackson and then Carol Clisby?
7 A. I'm not good with names.
8 Q. And do you recall whether they were also dividing
9 their time between the Macfarlane Trust and the Eileen
10 Trust?
11 A. I think they all were. I think that one of the
12 reasons it was set up that way is that we were,
13 I think, always envisaged as going to be quite small,
14 and so wouldn't be able to justify having our own
15 full-time team, and this was felt to be a good
16 solution.
17 Q. And then we have heard evidence from Susan Daniels
18 that she, as you say, began doing casework around
19 about 2004 and then became the case worker in
20 February 2005.
21 A. Much earlier before that. She was the independent
22 financial adviser, because there's something in the
23 minutes of her and John Williams or -- no, and
24 Claudette going to see one of our registrants and
25 helping them, and I think that's -- I think that was

12

1 back in 2000, if not sooner; earlier.
 2 Q. I'm just going to take you now to the annual report
 3 from 31 March 1994 just to get a look at what was
 4 happening in the early days at the Macfarlane Trust.
 5 Soumik, can we go to EILN0000016_060.
 6 You can see on the first page there the annual
 7 report, 31 March 1994.
 8 Can we go to page 3 of that document, please.
 9 First paragraph sets out that the Government's
 10 established a scheme of payments, to make settlement
 11 payments for those that are infected and dependants,
 12 and then explains in the second paragraph how the
 13 Eileen Trust came to be set up.
 14 In the third paragraph, it's said:
 15 "It was known [this] group would be small, and
 16 hence that an organisation to administer the fund
 17 would be unlikely to be viable as a self-contained
 18 unit. [DoH] therefore invited the Macfarlane Trust to
 19 consider providing the administrative backing for the
 20 new fund. This would provide the advantage of staff
 21 already experienced with a similar condition and
 22 similar problems."
 23 Is that what you have been describing, in terms
 24 of the sharing of staff?
 25 A. Yes.

13

1 earlier years it was said more -- well, we couldn't do
 2 this in the Macfarlane Trust, but we in the Eileen
 3 Trust did do it because it was the right thing for us
 4 to do. And I think it was easier for me because
 5 I wasn't involved in the Macfarlane Trust. But I have
 6 to say, even the ones who were I don't think ever,
 7 ever we changed or made a decision that we wanted to
 8 make because we thought it would cause difficulties
 9 for the Macfarlane Trust.
 10 And I wouldn't say that -- I mean, it was an
 11 issue that comes up, and one sees it in the paperwork,
 12 but I wouldn't say it was a genuine factor.
 13 Q. And then moving down the page, I'm going to pick it up
 14 at the paragraph that starts, "At this stage, it was
 15 known that 46 people," so it's just above the second
 16 hole punch there:
 17 "At this stage, it was known that 46 people in
 18 England, Wales and Northern Ireland and 11 from
 19 Scotland had qualified for the scheme of settlement
 20 payments."
 21 That is referring, is it, to the Department of
 22 Health's scheme of capital payments to those that had
 23 been infected?
 24 A. Yes.
 25 Q. Then it says:

15

1 Q. Can we go, Soumik, on to the next page. First
 2 paragraph there:
 3 "In setting up the Eileen Trust, it had been
 4 acknowledged that the Eileen and Macfarlane Trusts in
 5 dealing with people whose situations and problems had
 6 much in common would be likely to pursue or develop
 7 broadly similar policies. Insofar as the ... two
 8 groups were the same, major differences in policy
 9 between the two Trusts could have created a sense of
 10 dissatisfaction in people being cared by one or the
 11 other."
 12 Just pausing there. We can see there that
 13 a policy objective, if I can put it that way, of
 14 having broadly similar policies to the
 15 Macfarlane Trust, is that something that you recall
 16 being aware of or the Trust following?
 17 A. I don't think we followed it. In some areas,
 18 I suppose when we thought we didn't want to reinvent
 19 the wheel, so admin-type problems, or when we were in
 20 the early days setting the initial levels, say, of reg
 21 pay, regular payments, we did follow the Macfarlane.
 22 But in terms of policies, absolutely not. And as time
 23 went on, there were more and more occasions where we
 24 would have conversations as a Trust, and it might be
 25 said -- and sometimes particularly perhaps in the

14

1 "Not -- "
 2 Sorry, were you going to say something?
 3 A. I was just -- no, I was going to pre-empt what you
 4 were probably going to say.
 5 Q. "Not all of these would be eligible for registration
 6 with the Trust, but allowing for applications still
 7 under validation with the Department, it was estimated
 8 that the eventual registration with the Trust would
 9 probably be between 50 and 60 and possibly, but most
 10 unlikely, as high as 100."
 11 So, again, just pausing there, what do we
 12 understand -- is it right that some people who
 13 received capital payments under the Government scheme
 14 of settlement payments were not eligible to be
 15 registrants of the Eileen Trust?
 16 A. Yes. If they were non-dependant relatives, they
 17 wouldn't have been eligible.
 18 Q. Do you ever recall having applications from such
 19 people and having to turn them down?
 20 A. Well, we didn't see the applications. We only sent
 21 letters to the people who were entitled to be -- is
 22 this right? We sent letters to the people who had --
 23 who we thought were going to be eligible. I don't
 24 know the answer to that question, except I know
 25 I didn't see any.

16

1 Q. Is it your recollection that the Department of Health
2 in fact told you who was eligible for the Eileen
3 Trust?
4 A. No, that can't be right because in the letter that we
5 write to them, I think we say they may not be
6 eligible. I'd have to look at the paperwork and see.
7 Q. But you don't recall --
8 A. I don't recall because I don't remember -- I'm doing
9 all this from what I've read since you gave me the
10 papers. I don't remember at the time us having
11 discussions ever about whether somebody was eligible
12 or whether -- yes, but we only started talking to the
13 registrants once they had said that they wanted to
14 come and register, which must be that the letter
15 they'd got was only because they were eligible.
16 So I think probably they were only written to
17 by us if they were eligible.
18 Q. And then it carries on:
19 "This uncertainty over the eventual number of
20 registrants continues. As of 31 March 1994, only 24
21 people had registered with the Trust, and the forecast
22 of eventual numbers was very little more reliable than
23 the initial estimates, though tending to retreat from
24 the upper limit. This clearly inhibits the ability to
25 forecast likely future expenditure. At this early

17

1 Q. And you say that you think that the figures from 2004
2 are probably more accurate.
3 A. In 2004?
4 Q. From the figures -- in your witness statement, you say
5 the figure from 2004 onwards are, you believe, more
6 accurate?
7 A. Yes.
8 Q. So we can see that there are total figures there from
9 2004: 28, and then dropping down to 21 in 2010.
10 And we can see on the left-hand side the number
11 of registrants increasing -- well, first of all,
12 decreasing and then increasing up through to 2018.
13 But by "registrants", do we understand that to
14 mean people who were themselves infected?
15 A. I think by the time we get to where the figures are
16 presented -- well, from 2010 onwards, I think the
17 infected intimates are included in there. And I think
18 the widows, and -- some of the widows I think were
19 included in that one as well.
20 Q. Is this right, that you were receiving new
21 registrants, new infected people and dependants on to
22 the scheme throughout the life of the scheme --
23 throughout the life of the Trust, sorry.
24 A. Yes. I think that was something that was certainly
25 not expected at the beginning and wasn't understood.

19

1 stage, it's not a serious problem, but it does mean
2 that decisions on expenditure must be pragmatic and,
3 to a degree, tentative."

4 Then:

5 "Fortunately, demands on the Trust have not
6 been excessive, and it has been possible to respond to
7 requests for help without fear that any undesirable
8 precedents have been established."

9 So just -- I was going to show you a table that
10 you produce in your witness statement just to have
11 a look at the numbers as we go through the Eileen
12 Trust years.

13 If we can turn then to WITN4682001, page --
14 just to see that that's your witness statement. If we
15 can turn to page 20 of that document, you produced
16 a table which you tell us is from the information from
17 the annual reports; is that right?

18 A. It is right, but I think that some of the figures --
19 for instance, the fact that in 1999 I haven't got any
20 widows and partners or dependant children, I think
21 that's wrong.

22 It was quite difficult pulling these out of the
23 annual reports and comparing like with like, but it's
24 certainly not an over-claim. I think there are some
25 rather obvious gaps.

18

1 You know, we had five people in the first five
2 years of the century, and even in 2015, there were
3 four possible people coming through to the Department
4 of Health. So it was -- you know, it was not going to
5 be something that was just going to be wound up.
6 Q. I'm going to ask you some questions now about the
7 policies on payments. First of all, I'm going to look
8 at regular payments.

9 Can we turn, please, to DHSC0002779_002. This
10 is the annual report from 31 March '95, so it's the
11 document that we've already looked at. Can we go,
12 please -- no, in fact, it's not the document we
13 already looked at.

14 Can we go to page 5 of that document, please.
15 So under "Regular payments" it says there:

16 "It was agreed that the cost of living directly
17 attributable to HIV is a considerable burden,
18 irrespective of health or means, and this is
19 recognised by payment on a continuous basis to anyone
20 with HIV who requests it. The extra burden to those
21 on lower incomes, particularly those living entirely
22 on benefits, is also considered as justifying a graded
23 addition to this basic payment; and the rapidly
24 escalating costs of advancing sickness is calling for
25 a further supplement over whatever basic or higher

20

1 payment is made."

2 So do we understand that from 1995, anyone who
3 was directly infected with HIV got a regular payment
4 from the Eileen Trust?

5 A. Well, I think they got it from 1993. I think the
6 first reg pay was paid out in August 1993 because --
7 well, that's what it says in the minutes. And I think
8 they were given three months back pay at the
9 beginning. And then in January 1994 -- sorry, yes, in
10 January 1994, we increased the amount of reg pay, and
11 we added on a sickness -- health-related supplement in
12 March 1994.

13 Q. Are we also to understand that the regular pay was
14 graded so there were effectively two bands: one that
15 everyone was entitled to, and one that you got if you
16 had lower income; for example, on benefits?

17 A. Yes, it went from 70 to 230 a month, plus 50 if you
18 have that.

19 Q. Then skipping the next paragraph, which deals with the
20 quantum, down to:

21 "Regular payments are made in some situations
22 to needy relatives of registered people who have died.
23 There is no set scheme for this and discretion is
24 applied according to the individual circumstances."

25 So again, are we to understand that regular

21

1 A. *(No audible response)*

2 Q. Then it is this paragraph I wanted to particularly
3 draw your attention to:

4 "There is one other consideration of which Sue
5 and Susan will not be aware. The [Macfarlane]
6 trustees spent a Saturday recently inspecting the
7 corporate navel. The day was kicked off by
8 a presentation by our solicitor from Berwin Leighton
9 Paisner, an ex-Charity Commission lawyer, who told us,
10 without reservation, that financial need is
11 an absolute prerequisite for any disbursement by
12 a charity. When it was put to her that anybody with
13 haemophilia, HIV and HCV by definition had financial
14 needs in connection with trying to preserve their
15 health, that the Man in the Street did not have, and
16 that such a person's health could deteriorate sharply
17 and without warning, she said that those were
18 insufficient to establish financial need or to justify
19 disbursement.

20 "This is quite tough, and goes against
21 everything that MFT, and, by extension, ET, have been
22 doing since inception. She acknowledged that, but
23 insisted that making disbursements without financial
24 need being established was, in effect, a breach of
25 trust."

23

1 payments could be made to relatives if they were
2 needy; that was the test, was it?

3 A. Yes. We had some widows -- and the children,
4 guardians of children or orphans got regular payments
5 as well.

6 Q. I'll come on in a moment to look at the payments to
7 relatives in a little bit more detail. We can see in
8 the next paragraph down there that there were 17
9 people, as of 31 March 1995, receiving regular
10 payments of some kind.

11 Can we have now, please, MACF0000051_057. I'm
12 just going to take you forward now to 2006. So this
13 is an email from Peter Stevens to, it looks like all
14 of the trustees, including yourself.

15 A. Yes.

16 Q. He talks in the first paragraph about looking at
17 figures, and the second paragraph talks about
18 categorising recipients of reg pay according to the
19 Macfarlane formula and a desire there to maintain
20 consistency and comparability across the
21 beneficiaries, without having to adopt precisely the
22 same formula as the Macfarlane Trust. So echoes what
23 you were saying earlier about the Eileen Trust going
24 its own way if it thought it was necessary; is that
25 how you read that?

22

1 So then picking up at the bottom of the next
2 paragraph where it's three lines up:

3 "So it seems to me that the automatic
4 presumption of financial need, on the grounds of the
5 infection alone, that we adopted in line with
6 Macfarlane at the outset, really is not applicable to
7 at least some of our registrants. In discussion,
8 I think after the lawyers departure, the Macfarlane
9 trustees agreed that anybody who is on income support
10 must, again by definition, be in financial need. So
11 in Macfarlane we only have 25 per cent of our
12 registrants to worry about. Reverting to the ET and
13 the attached table, this suggests that we are paying
14 reg pay to only three people who are not on income
15 support and might therefore not be in financial need."

16 Then missing out the next sentence:

17 "I offer as a suggestion that any increase to
18 reg pay should not be made to the first two pending
19 a review of how we are going to deal with the issue
20 and absent any evidence from Susan that either of them
21 is in fact in financial need."

22 Do you recall whether, after receiving this
23 information and this advice from lawyers via the
24 Macfarlane Trust that the test applied by the Eileen
25 Trust changed for reg pay?

24

1 A. What's the date of that?
 2 Q. November 2006.
 3 A. But it's early November, isn't it?
 4 Q. 13th.
 5 A. Yes, so then on 26 November there's another --
 6 a subsequent -- after this letter from Peter where he
 7 says that they then had got advice that both
 8 recipient -- both receipt of IS and earning a minimum
 9 wage were both indicators of financial need. So that
 10 meant that, from our point of view at the Eileen
 11 Trust, we only had one person who didn't qualify and
 12 she lived in [redacted] and didn't get reg pay. So
 13 we -- I haven't got the code for this document but
 14 Peter then says that we can break away from the MFT
 15 formula and he suggests that we put all of our reg pay
 16 up by 25 per cent.
 17 Q. I haven't got the -- of that either, so do we
 18 understand from what you're saying that the advice was
 19 taken on board --

20 (10.37 am)

21 (Connection lost: awaiting reconnection)

22 (10.57 am)

23 SIR BRIAN LANGSTAFF: I'm very sorry about that, both to
 24 you and to those who are listening remotely. For some
 25 reason we just lost all internet connectivity. I'm

25

1 needy).
 2 "So I am proposing that:
 3 "-- we simplify your structure and break away
 4 from the MFT formula by putting everyone on the same
 5 basic rate, to which we add supplements if they
 6 receive DLA and if they have families ...
 7 "-- we set the new rates at roughly 25 per cent
 8 above the current level for anybody who is not, as a
 9 result of the preceding paragraph, being
 10 're-classified' (who would get a higher uplift)."

11 Then he goes on to discuss what that means for
 12 individual cases, which I don't think we need to look
 13 at. So from November 2006 it's your understanding, is
 14 it, your recollection, that everybody was on same
 15 rates but with uplift, depending on their
 16 circumstances.

17 SIR BRIAN LANGSTAFF: Can I just make sure that when this
 18 is put out there, there is a redaction to the name
 19 which appears further on down the page.

20 MS SCOTT: Yes.

21 SIR BRIAN LANGSTAFF: Can I remind those who are watching
 22 that this document is subject to a restriction order
 23 which I made earlier. Thank you.

24 MS SCOTT: So that was the position from November 2006 was
 25 it?

27

1 glad to say we're now restored just magically as we
 2 disappeared. I hope it doesn't happen again but thank
 3 you for your patience. Ms Scott.

4 MS SCOTT: Just before we were cut off you were mentioning
 5 a document, which I have the reference for now, so we
 6 can put that up on screen, so that those that are
 7 listening can see it. It's EILN0000013_106.

8 This is an email dated 26 November from Peter
 9 Stevens to a number of trustees, including yourself,
 10 and if we look at the fourth paragraph down:

11 "The attached spreadsheet deals with all 19 who
 12 are receiving reg pay ..."

13 Then if we carry on down two paragraphs:

14 "We have been advised by Gillian Fletcher, the
 15 lawyer who addressed the MFT Awayday, that both
 16 receipt of IS and earning a minimum wage are
 17 reasonable indicators of the financial need which it
 18 is our duty to ensure is what we are meeting. In
 19 other words, on strict legal grounds there is only one
 20 recipient of regpay of whose financial need we not
 21 have evidence" --

22 SIR BRIAN LANGSTAFF: The "do" is missing.

23 MS SCOTT: Yes:

24 "... we [do] not have evidence (she is the
 25 Italian lady who has not hitherto appeared to be

26

1 A. Yes. He ends up by saying "I hope you will get back
 2 to me", and I haven't seen what comes out of that but
 3 my recollection of what was going on after that is
 4 that we went through with what we're saying now.
 5 I couldn't swear that it was 25 per cent but I can't
 6 imagine that we would have changed it.

7 Q. So the principle was that if you were infected or if
 8 you were a dependant you were eligible for the same
 9 level of payments?

10 A. Yes.

11 Q. Then can I move on now to the position for reg pay
 12 post-Archer Report. So in your witness statement, and
 13 we can see this reflected in the documents, you say
 14 that the aim of the Trust was to ensure that income
 15 for a single person was at £18,000 per annum and for
 16 someone living with a partner it was £30,000 per
 17 annum; is that right?

18 A. Yes, that was something that we decided in
 19 February 2010 that there should be minimum standards
 20 which we would expect people to have in terms of
 21 housing and transport, financial security, basically
 22 all those sort of major areas of expenditure and, as
 23 well as that, we would agree the minimum level of
 24 income as you've just said. So that meant that after
 25 Archer we still had some people on reg pay because

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1 Archer wasn't up there.
 2 **Q.** Again, the same question: those minimum levels of
 3 income applied equally, did it, to those that were
 4 infected and their needy relatives?
 5 **A.** Yes.
 6 **SIR BRIAN LANGSTAFF:** May I just ask whether that was the
 7 income per infected person, per registrant, or the
 8 household income?
 9 **A.** I don't know the answer but I know that when we
 10 assessed it we took into account income that they
 11 would have been getting from benefits and other
 12 sources. But I think it would have been the single
 13 person -- I think it would have been the household
 14 person, if they were with somebody, but the truth --
 15 actually, I don't know is the answer.
 16 **SIR BRIAN LANGSTAFF:** Thank you.
 17 **A.** I can't answer that.
 18 **MS SCOTT:** Sir, there is a documentary reference but
 19 I don't think that takes it any further.
 20 **SIR BRIAN LANGSTAFF:** It looks as though household income
 21 must be taken into account to justify the difference
 22 between a single person and a person with a partner
 23 because the latter says nothing about the partner's
 24 income.
 25 **A.** Yes, but I think we would -- you would be able to tell

29

1 should have a guideline for a minimum level of income
 2 that registrants should have, taking into account
 3 whether they were single, lived with a partner, had
 4 children and so on. Discussion of particular
 5 registrants' circumstances led to the preliminary
 6 conclusions that the guidelines should be annual
 7 income of
 8 "-- £18,000 for a single person ...
 9 "-- £30,000 for somebody living with
 10 a partner."
 11 Then if we look down the page there to 5072, we
 12 can see what the Board appeared to be doing here is
 13 looking at income and benchmark level but at 5072 they
 14 say:
 15 "Although household income was above the
 16 benchmark level", and so on.
 17 It looks there that it was household income
 18 that was being considered. Do you think that's right?
 19 **A.** I think that probably is right, yes. But with all
 20 these cases --
 21 **SIR BRIAN LANGSTAFF:** Sorry, 5089 says the couple's
 22 income, so that looks like the same approach.
 23 **A.** Yes.
 24 **MS SCOTT:** Can I ask you just one more point on the reg
 25 pay.

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1 because we made these judgments looking at the figures
 2 that Susan Daniels put together for us from her
 3 contacts with the registrants and it would say on
 4 those figures, which I think are somewhere in another
 5 document, what was included in the income. So it
 6 would be clear there.

7 **MS SCOTT:** It might help if we look at this document
 8 EILN0000012_018. This is a minute of a board meeting
 9 on 24 February 2010 and we can see that you are
 10 attending, as is Ms Daniels. If we turn over to the
 11 second page of that minute, and we see the first full
 12 paragraph:

13 "Mr Spellman observed that the post-Archer
 14 settlement had provided an opportunity to identify
 15 registrants' needs with greater precision."

16 Then:

17 "Mr Mishcon added that these needs could be of
 18 a capital nature -- for example -- relating to housing
 19 improvements -- as well as those covered by income; it
 20 was agreed that the Trust should develop some minimum
 21 standards in key areas such as housing, transport,
 22 financial security, and holidays and respite
 23 ('standard items') which it would be reasonable to try
 24 to provide for all registrants.

25 "Mr Spellman further proposed that the Trust

30

1 Can we go to document AHOH0000017. This is
 2 a minute of a meeting from 17 February '94. And if we
 3 go over to page 4 of that minute, and it's under (c)
 4 "Payments to dependants":

5 "Subject of regular payments to dependants of
 6 deceased persons was discussed, and the historic
 7 causes and effects of such payments being made by the
 8 Macfarlane Trust were reviewed. It was agreed that
 9 the Macfarlane Trust system might be different if
 10 restarted at present from first principles, and it was
 11 not necessarily a good pattern to follow, at least
 12 until the Eileen Trust developed further experience on
 13 its own. It was, however, unanimously agreed that the
 14 Trust should help through the period of bereavement
 15 and readjustment. On this basis, it was determined
 16 that on the death of ..."

17 I'm sorry, this is the wrong reference for the
 18 question I was going to ask you, although I do want to
 19 take you to this reference later. So I'll see if
 20 I can find it in this document, and if not, I will
 21 just go on to the next question. I can't find it in
 22 this document, so let me ask you this question then.
 23 So:

24 "On this basis, it was determined that on the
 25 death of any person registered with the Trust or of an

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1 infected intimate, a payment of £1,000 would be
2 offered to the dependant or carer of the person
3 deceased. And in the case of dependants, any regular
4 payment made would be continued for six months at the
5 same rate. Any further support beyond this period
6 would be examined on a case by case basis."

7 So this is a question in relation to the
8 dependants, the non-infected community. We've seen
9 already from the 1995 annual report that many of them,
10 or some of them, were receiving regular payments.
11 This in the early days appears to be, was it, the
12 policy that on the death of the infected person,
13 payments would continue at the same level for six
14 months, and there would be a lump sum of £1,000, and
15 then it would be on a case by case basis as to whether
16 or not regular payment would continue. Is that how
17 you recall the early policy?

- 18 **A.** Yes. Yes, right at the beginning, but I think quite
19 soon, we started being more flexible, and we had
20 widows coming in and being paid, given reg pay for
21 such longer than six months. Not all of them, but on
22 a case by case basis.
23 **Q.** Isn't this policy suggesting that the payments that
24 the infected registrant received continued for six
25 months for everybody after their death, and then there

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1 and consistency, it was possible that these widowers
2 should also receive support."

3 Just pausing there. Is it your recollection
4 that the majority of widows and widowers with
5 dependant children were in receipt of reg pay
6 throughout the time of the Trust?

- 7 **A.** Yes, it is. Sorry, what's the date of this document?

8 **SIR BRIAN LANGSTAFF:** October 1998.

9 **MS SCOTT:** Yes. October 1998.

- 10 **A.** Yes, because in '96, we approved reg pays to seven
11 dependants, some of which were widows, and we approved
12 reg pay -- well, consideration of reg pay for three
13 widowers, so that is definitely my recollection.

- 14 **Q.** Then moving on down that paragraph:

15 "The Chairman said regular payments were being
16 considered as part of the Macfarlane Trust strategic
17 review. These payments were not given to jack up
18 a state system that was inadequate."

19 And then this:

20 "It was also suggested that there had been an
21 initial decision not to continue to support widowers
22 if they remarried. Staff were asked to look into the
23 marital status of the two widowers referred to."

24 Do you recall the initial decision being made
25 about the impact of remarriage on regular payments?

35

1 was --

- 2 **A.** Yes.

- 3 **Q.** -- then the Trust would consider on a case by case
4 basis whether ongoing regular payments should be made
5 to the dependants?

- 6 **A.** That's right.

- 7 **Q.** If I can just take you to another document then in
8 1998. EILN0000006_079. This is a Trust meeting
9 minute from 16 October 1998, and, again, we can see
10 you in attendance.

11 If we go over to page 4, please, of that
12 report, and it's "98.21b status report -- widows and
13 widowers":

14 A status report on all widows and widowers were
15 considered by trustees. The report indicated that all
16 widows with dependant children --"

- 17 **A.** Sorry, I missed all of that last bit you said.

- 18 **Q.** Sorry. So "Status report widows and widowers":

19 "The status report on all widows and widowers
20 was considered by trustees. The report indicated that
21 all widows with dependant children and four widowers
22 with dependant children were in receipt of regular
23 monthly payments from the Trust. However, two
24 widowers with dependant children were not currently
25 receiving regular payments. For the sake of fairness

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- 1 **A.** No, I don't, no. And it seems surprising.

- 2 **Q.** Do you recall whether, in fact, the Eileen Trust took
3 into account remarriage when deciding whether or not
4 to provide regular ongoing payments to widows or
5 widowers?

- 6 **A.** I don't recall.

- 7 **Q.** Can we now -- I'm now going to ask you some questions
8 about the position of children. EILN0000006_128. I'm
9 going to take you to two documents and then ask you
10 questions about the position for children.

11 So this is the first one. This is the minute
12 of the meeting on 30 January '98. We can see you in
13 attendance. And if we turn over to page 2 of that
14 document, at the top, "Dependant children and young
15 people":

16 "The secretary also reported concerns that
17 a growing number of dependant orphaned children and
18 young people, pointing out that due to adolescent
19 trauma some dependants were still in need of
20 assistance from the Trust when they were beyond what
21 might normally be regarded as the age of independence.
22 Following discussion, it was agreed that flexibility
23 should be applied when considering future support for
24 such youngsters. Social worker was asked to review
25 a number of cases, and if further support was

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1 required, convene a 'mini-alloc' similar to those used
2 in Macfarlane Trust."

3 Then can I also just turn up EILN0000016_056
4 which is the annual report from 1998; 31 March 1998.

5 Can we turn to page 3 of that report. It's about --
6 the paragraph below "sadly". "There are 13
7 children ..." Halfway down that page:

8 "There are 13 children dependent on the Trust
9 or Trust Registrants for financial assistance, a
10 number of whom have been badly traumatised by the
11 death of one or both parents from HIV-related illness.
12 Trustees have agreed that where children's education
13 has been interrupted by trauma, support from the Trust
14 may continue until completion of further education,
15 though this may be delayed beyond the normal expected
16 age of graduation."

17 So do we understand from these documents that
18 the Trust policy was for a child who had lost either
19 one or both of their parents, they could be provided
20 with support beyond the usual age of graduation, if
21 that was appropriate?

22 A. Yes, exactly.

23 Q. And did the Trust, in fact -- without mentioning any
24 names or any specific cases, can you recall whether
25 the Trust did, in fact, provide such ongoing support

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1 gave grants for what was initially called respite
2 breaks but became holiday breaks because we deemed
3 that as something that was very necessary. But, as
4 I say, it was always on a case by case basis.

5 Q. Do you recall whether applicants were required to fill
6 out sort of income and expenditure forms so that the
7 Trust could assess what the level of disposable income
8 was?

9 A. I don't know whether they were at the beginning.
10 I certainly don't remember us looking at them in the
11 early days. As time went on and when Susan Daniels
12 was on board -- and she would know all that kind of
13 information because she had found it out really in
14 order to be able to help sometimes get rid of debt or
15 manage their finances. So we did know it, but I don't
16 think it massively came into our decision-making
17 process because, by definition, they needed the money.
18 It was -- I suppose we spent more time thinking about
19 whether they needed whatever it was or whether it was
20 right for us to give whatever it was that they were
21 asking for.

22 Q. Rather than whether or not they could show
23 financial -- that they show financial need?

24 A. Yes. I mean, I think there were probably the odd
25 occasion where we'd say we'd pay a contribution

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1 for dependant -- for children?

2 A. Yes. I definitely can, and we definitely did.

3 Q. Do you recall whether the Trust, the Eileen Trust,
4 ever provided any loans to any of its registrants?

5 A. I don't remember it, but I think I've seen in some of
6 the minutes that there were one or two loans.

7 Q. And you don't have any recollection of the
8 circumstances in which those were made?

9 A. No, I don't.

10 Q. The Trust also, as well as providing regular payments,
11 also provided single -- provided payments on
12 application for single grants; is that right?

13 A. Yes.

14 Q. Can you recall how the Trust assessed those
15 applications?

16 A. Always and right from the beginning on a case by case
17 basis because that was how we felt it was the most
18 effective way to do it.

19 Q. And what was the criteria that the Trust applied in
20 assessing whether or not the grant should be made or
21 not?

22 A. Well, I suppose initially it was financial need, but
23 that was always the case. And then it was that it was
24 relevant to health, which could be interpreted,
25 obviously, in several ways. So we -- increasingly, we

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1 towards X.

2 MS SCOTT: Sir, I am going to come on to looking at the
3 application process itself, and I note the time.
4 I wonder if now is a good time for a break?

5 SIR BRIAN LANGSTAFF: Well, yes. We will take a break
6 now, if that would be all right, until 20 to 12.
7 We've already had one impromptu break, but that was
8 impromptu. This now can allow people at home or
9 yourself to have a bit of refreshment mid-morning and
10 be back at 20 to 12.

11 (11.19 am)

(A short break)

12 (11.39 am)

13 SIR BRIAN LANGSTAFF: Yes.

14 MS SCOTT: Your witness statement suggests that -- let me
15 ask it this way. Do you have any independent
16 recollection of the process of applications for single
17 grants or is your statement based on a consideration
18 of the documents?

19 A. I'm afraid it's based on a consideration of the
20 documents.

21 Q. Can we --

22 A. Although -- sorry, just I would say that what I do
23 remember, once Susan Daniels was the case worker, that
24 then the process was that she would be in very regular
25

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1 contact, she would know their needs and she would tell
 2 us and there would be discussion but, if there was any
 3 paperwork, I would imagine that she would help them
 4 and she would -- she controlled them, she ran that bit
 5 and we trusted and knew that she was running it very
 6 well. So at that stage I did know the process.

7 **Q.** So if I can ask you some questions then on anything
 8 that you can recall about the process prior to Susan
 9 Daniels. If we can turn up MACF0000176_002, which is
 10 the Eileen handbook from 1999.

11 **A.** Can I ask you something about the handbook?

12 **Q.** Here it is.

13 **A.** It's only that it's called the Eileen Trust handbook
 14 but I wonder if this is the latest -- the final
 15 version because -- and I only noticed this last night,
 16 I'm afraid. It's got quotes in it -- it says it's for
 17 people suffering from haemophilia, it talks about the
 18 Trust being there since 1990, and various other
 19 things. I don't know if that matters but I don't know
 20 whether everything in it is how we behaved in the
 21 Eileen Trust or whether it's clearly based on the
 22 Macfarlane Trust and whether it's not the final
 23 version. I don't know if that matters but that's just
 24 what worried me about it.

25 **Q.** That was the focus of some of my questions. Do you

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1 have a final version.

2 **Q.** This is the only version that the Inquiry has. Do you
 3 understand that a version of the Eileen handbook,
 4 whether it was this one or a final one, was provided
 5 to registrants and to dependants?

6 **A.** Yes, yes absolutely, and was sent out from 1999 with
 7 an accompanying letter from the secretary.

8 **Q.** If we look at the page 9 of the document we can see
 9 there "Types of Single Payment".

10 Do you recall this being a document that the
 11 trustees referred to when applications for grants for
 12 single payments came in?

13 **A.** No, but they are the subjects that we would have
 14 considered as being appropriate to give grants to --
 15 for.

16 **Q.** Do you have any recollection of using this handbook
 17 yourself as a reference point for whether the
 18 procedure had been done correctly for applications or
 19 applications came within guidelines, and so on?

20 **A.** No, I don't. It was all by discussion.

21 **Q.** So do you think that the trustees, in fact, didn't use
 22 this as a guide?

23 **SIR BRIAN LANGSTAFF:** Well, this they may not have done
 24 because it may not have been this edition. So we're
 25 rather handicapped by not having whatever it was that

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1 have any recollection of the circumstances in which
 2 this handbook was produced?

3 **A.** Well, I know we talked about -- a bit earlier, before,
 4 I think in 1996 we talked about a handbook and decided
 5 not to do it but to carry on doing it *ad hoc*.
 6 Unfortunately, the two meetings -- there was one
 7 meeting in June '99 where we're told -- the trustees
 8 are being told it's being done and then the next
 9 meeting we're told it's been done and both of those
 10 trustees' meetings I wasn't at. But I would be
 11 surprised that we wouldn't have been shown the final
 12 version and I can't believe that we would have
 13 accepted this as a final version, not least -- I mean,
 14 I wouldn't have because I'm not in it and the staff
 15 aren't filled in and we would have spotted the
 16 differences. So that's not very helpful.

17 **Q.** So when you say you're not in it, if we turn to --

18 **A.** It doesn't list the trustees, it just lists --

19 **Q.** If we turn to page 14, I think it's going to be.

20 **A.** The staff isn't full. It just has somebody's name,
 21 somebody's initial.

22 **Q.** So it's just listed three trustees there, you're not
 23 there and the staff aren't there?

24 **A.** The second one, "A is Finance Officer", surely that
 25 wouldn't have been in the final version but I don't

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1 was the eventual edition for the Eileen Trust.

2 **A.** These are the sorts of subjects that we would have
 3 considered. So we would have used -- without seeing
 4 it, we would have gone through this sort of question:
 5 do they fit into these kinds of criteria?

6 **Q.** Do you recall using a handbook of any kind when
 7 assessing applications?

8 **A.** No, I don't think we did. I think I recall not using
 9 one.

10 **Q.** So a handbook was sent out, whether it was in this
 11 form or slightly different, to registrants and
 12 dependants but you don't think the trustees actually
 13 used that themselves?

14 **A.** I don't think when we were sitting round the table we
 15 ever had a handbook that we said "Does this fit the
 16 criteria", because I think we all took it that we knew
 17 what the criteria were, which were the same as the
 18 ones in the handbook. So I don't think we were
 19 operating a different system to the one that we were
 20 talking to our registrants about.

21 **Q.** Do you recall whether or not there were any particular
 22 requirements for applications for single grants in
 23 terms of evidential matters, having to provide quotes,
 24 having to do the application in writing or on
 25 a particular form or anything of that nature?

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1 A. I don't think they had to be in writing, particularly
2 if it was for a small straightforward amount or
3 something that the office could do. I think if it was
4 anything significant then I think we did ask for
5 quotes. I don't exactly remember but I would have
6 thought we would probably have asked for a couple of
7 quotes if it was easy and not too difficult for the
8 registrants to do.

9 We didn't want to make it difficult for them to
10 apply for grants and, certainly in the early days, we
11 had to encourage people to feel that they could,
12 I think.

13 Q. Why was that?

14 A. I don't know. Whether it was because they didn't like
15 the feeling of having to ask or whether it was because
16 they were new to the Trust or maybe they didn't have
17 the relationship with the Trust -- I mean, I'm talking
18 about the first two or three years. But it's
19 noticeable, even though they would be rung up and
20 written to regularly and they would be asked if they
21 wanted visits and they would be contacted by the
22 staff, it wasn't until, really, Peter arrived in 2001
23 when we started being, I think, more proactive.

24 I think we were quite reactive. We said, you
25 know, ask if you want something but I think once -- as

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1 that the limit of her authority was about £250, so she
2 could approve things up to a value of about £250.
3 Does that sound right to you? Is that what you
4 recall?

5 A. Well, I think -- in the office, I think it may have
6 been higher than that. I think I've seen somewhere in
7 the papers something which said if there was two of
8 them it could go up to 1,000, but that may have been
9 later. I couldn't be certain about that.

10 Q. Was there a process by which the trustees monitored by
11 which the staff reported back to the trustees the
12 grants that they had allowed for monitoring purposes?

13 A. Yes. They were in the trustees' meeting when we went
14 through each case, it would be itemised there.

15 Q. You would be looking at grants that had been given by
16 staff in those --

17 A. I think so.

18 Q. -- meetings?

19 A. I think so. I couldn't be sure about that now that
20 you mention it but I think we were.

21 Q. So just returning then to the handbook, do you think
22 that there was only one version of the handbook sent
23 to registrants, only in 1999?

24 A. Yes. There's no record of one after that and
25 I think -- I think possibly because from 2001/2 we

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1 time went on, we started, sort of, pushing people
2 more. So if you look at the number of single grants
3 that we awarded, you know, in the 1900s -- or the
4 1990s they are below 30 and then from 2000 they go up
5 45, 41, and then from 2002, when we were really every
6 Trust meeting going through every registrant
7 situation, the grants go up -- the single grants go up
8 to 69, 69, 68.

9 So I think that suggests that that policy of
10 the Trust being more proactive and saying there must
11 be things you want, and sometimes we would make
12 suggestions or -- we wouldn't, the case worker would
13 make suggestions because she knew what they needed.

14 Sorry, it's a rather long-winded answer.

15 Q. Your statement suggests that 60 per cent of the
16 applications were dealt with by staff. Would that
17 have been the social workers and then latterly Susan
18 Daniels?

19 A. Yes. I think there were more than more -- yes,
20 I think there were more than one member of staff who
21 were able to do it. I think the benefits -- I think
22 the secretary certainly was and the benefits adviser,
23 I think, may have been also able and I think that
24 sometimes two people had to sign.

25 Q. Susan Daniels in her evidence to the Inquiry thought

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1 were getting reports of every registrant at every
2 meeting, I think perhaps we felt that was the best way
3 of getting -- you know, if people had a need they
4 didn't need to look at the handbook because they would
5 be talking to the case worker, and certainly once
6 Susan was on board that was absolutely the case.

7 Q. So your understanding is that from 2002 there was very
8 regular contact with all of the registrants?

9 A. I think there was regular contact always. I think it
10 became more proactive in 2001/2002 because the
11 trustees were looking at it at every trustees' meeting
12 and in a position sometimes to say "Well, this persons
13 looks as though there's a need for X, should we be
14 offering it to them or asking them if they concur with
15 that?"

16 Q. So it was the regular one-to-one contact, was it, that
17 allowed the registrants to understand what it was they
18 could apply for?

19 A. I would think that was the case. I don't think it was
20 always face-to-face but it was certainly the regular
21 contact.

22 Q. Were there any other guidelines or documents that
23 you're aware of that were provided to registrants to
24 set out what the Trust did in terms of what was
25 available to them in terms of grants, and so on?

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- 1 A. When they were -- when they first started being
2 registrants they were sent a letter which outlined,
3 broadly speaking, the principles of the Trust.
4 I think it said there were no guarantees of what it
5 was there for but, basically, we were there to give
6 financial help -- and other help, but financial help
7 to needs that they might have that were related to
8 extra costs they were incurring because of being
9 infected with HIV.
- 10 Q. So there was that initial letter, and then in 1999
11 a handbook of some sort. Was there anything else?
- 12 A. No, there was newsletters.
- 13 Q. Were you involved in the drafting of the newsletters?
- 14 A. I was involved in making them accessible. The early
15 ones -- well, certainly the first one that I saw was
16 quite dense. You know, people are ill, you don't want
17 to give them too much information, or if they are
18 stressed -- it wasn't very accessible.
- 19 Q. Information about what the Trust was there to do and
20 what people could apply for was contained within those
21 newsletters, was it?
- 22 A. I don't know the answer to that but I can't think what
23 else would have been there. It was -- a reduced
24 version of the annual report was sent out one year,
25 I think, but I can't remember what else was in them.

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- 1 assess them individually.
2 It wasn't necessarily the easiest way of doing
3 it because you are not always comparing like with like
4 but the answer is not to really compare. I don't ever
5 remember us saying "We can't give X a washing machine
6 because Y needs a respite break". We spent what we
7 had to that we were able to.
- 8 Q. Do you think one of the risks of that kind of
9 decision-making is that the very subjectivity creates
10 a risk of its own unfairness or inconsistency?
- 11 A. Yes, I do, and I think that's a very real risk.
12 I think also if you've got a Trust where you've got
13 one very strong personality, their views might come
14 through, but I think we were quite fortunate in (a)
15 that we were small, so there was proper exchange of
16 views. Nobody was -- I mean, a big Trust very often
17 you can sit on the sideline and think, "I'm going to
18 let that go." We were small, and we were equal in our
19 forcefulness.
- 20 Q. Is there anything else you can tell us about what the
21 Trust did to guard against that risk of unfairness and
22 inconsistency as a result of subjective
23 decision-making?
- 24 A. I think we were quite good at asking the questions,
25 even the kind of hard question about whether it was

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- 1 Q. Were you aware of any dissatisfaction from registrants
2 as to lack of information? Is that information that
3 ever came to the Board, people didn't know what to
4 apply for, they weren't applying for things because
5 they didn't know that it was available?
- 6 A. No, I think because there were so few of them then
7 that was less likely to be the case but, actually,
8 I think even if there had been more, I think, partly
9 because there was -- it was us and them being -- it
10 was quite a direct channel of communication so I think
11 perhaps they just did know more. I think maybe they
12 were more aware.
- 13 Q. What do you think the advantages were for the Trust in
14 assessing all applications on a case-by-case basis so
15 without reference to criteria or guidelines?
- 16 A. Because I think that if you do it the way that we did
17 it and you do that carefully and thoroughly, it's not
18 as tidy as having guidelines but I think it's much
19 fairer because, you know, guidelines tend to, in my
20 experience, very often, just sink to the, kind of,
21 lowest common denominator of acceptability and,
22 actually, what we did -- I mean, we had the guideline
23 of financial need, which was the one that we were
24 obliged to have being a charity, but in every other
25 respect I think it was more useful and more fair to

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- 1 right to do something, and I think we all did that at
2 different times.
- 3 Q. I'm going to ask you some questions about the funding
4 of the Trust.
- 5 Do you recall the Eileen Trust's attitude
6 towards trying to obtain further funding from the
7 Department of Health in the early years, so in the
8 years under the Reverend Tanner?
- 9 A. In the very early years, we were -- we had half
10 million pounds, and if we were concerned about
11 anything, it was more trying if possible to just spend
12 the interest because I think -- well, I know because
13 it says in the minutes that Reverend Tanner wasn't
14 sure that we would get any money after that. You
15 know, he thought the first half a million might be it.
16 But, actually, as time went on and obviously we did
17 spend the capital, we applied for and got another half
18 million.
- 19 So in those days, the process was quite --
20 well, it didn't have to happen very often. It changed
21 when we got into 2002 or 2003 and the Department
22 became -- their attitude was different, and they
23 started just giving us annual amounts of money which
24 were never completely guaranteed, although I think we
25 probably always thought they would happen.

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1 Q. Was there a reticence, do you recall, about asking the
2 Department of Health for a further top-up after the
3 initial half million? Was there a feeling that
4 actually the Trust should manage on that *ad infinitum*?
5 A. No, not at all because by several years before we
6 applied for the second half million, we knew that we
7 couldn't manage on it, and then the same thing
8 happened and the sum -- I mean, we applied for the
9 money after the second half million when we were only
10 one year in to spending the first bit of that money.
11 So I don't think there was a reticence, no.
12 Q. Can I ask you to look at a document, AHOH0000017,
13 which it a Trust board meeting from February '94.
14 I think we've already looked at it, in fact. Yes
15 17 February 1994.
16 Can we turn to page-page 3 of this document
17 under "Further trawl". I want to ask you about the
18 relationship -- the nature of the relationship between
19 Department of Health and the Eileen Trust. "Further
20 trawl". I think what is being discussed there is
21 trying to find further -- if there are further
22 potential beneficiaries for the Eileen Trust and
23 talking about searching for people who had not yet
24 made a claim or received a payment in the first
25 paragraph. And then the Trust approve a draft letter

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1 reported to you by trustees as to how the Department
2 of Health might react if they were antagonised or
3 embarrassed?
4 A. No, I don't remember anything. I would imagine it
5 would be that they might not give us more funding, but
6 this is very early days when actually we didn't think
7 we were going to have more funding, so I can't really
8 understand what we were worried about. Well, yes.
9 Q. Would you agree that having that kind of a concern --
10 if the Trust was concerned about embarrassing or was
11 concerned not to embarrass or antagonise the
12 Department of Health, that could impugn their
13 independence as a charity?
14 A. I think it absolutely could. What I think is lucky is
15 that this was a concern probably in the early days.
16 By the time we got to the stage when we were really
17 having to argue and push and fight for money,
18 Peter Stevens was in charge, and the concern was he
19 wouldn't have worried about antagonising the
20 Department of Health.
21 Q. We heard -- the Inquiry's heard evidence from
22 Ann Hithersay that when she arrived at the
23 Macfarlane Trust and the Eileen Trust, she got a sense
24 that the trustees were not keen on spending money on
25 disbursements, that they were more concerned to keep

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1 and leaflet for distribution via the Department of
2 Health, and there's a discussion about providing
3 information to HIV co-ordinators from the national
4 AIDS manual. I will come on and ask you some
5 questions about that in due course. But it's the last
6 paragraph there:

7 "It was agreed that no further major action be
8 taken until results, if any, of the proposed
9 circulation could be assessed. Beyond that, further
10 action would be considered, though it was agreed that
11 it would be necessary to avoid action which could
12 embarrass and thus antagonise the Department of
13 Health."

14 That perhaps suggests a concern or a reticence
15 about doing something that might embarrass or
16 antagonise the Department of Health.

17 Is that, do you recall -- was that, do you
18 recall, a feature of the relationship between the
19 Eileen Trust and the Department of Health in those
20 early years?

21 A. I think in the early years it probably was. It wasn't
22 as much as it could have been, but there's no other
23 way of interpreting that, other than us being wary of
24 upsetting them.

25 Q. Do you recall anything ever being said to you or

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1 it in the bank earning interest than disbursing it.
2 Is that an impression that you would share, or do you
3 have any comment to make upon that, vis-a-vis the
4 Eileen Trust?

5 A. Yes, I heard that evidence. I would absolutely say
6 that's not the case in the Eileen Trust.

7 I mean, apart from the fact that it's
8 interesting in the minutes the money comes before the
9 registrants in the early days but not later. It
10 was -- I don't ever remember anybody saying, "We can't
11 do that. We need to save the money." It was --
12 I think it absolutely was not the case.

13 Q. Moving on then to the Peter Stevens years, and your
14 statement tells us that a funding bid was made in 2005
15 asking for an increased allocation from the Department
16 of Health to allow the Eileen Trust to give -- to have
17 £250,000 per annum for disbursements. Did you have
18 any input into that funding bid?

19 A. Unlike what I say in my witness statement, I was at
20 the meeting with Caroline Flint. I thought I was only
21 at one DoH meeting, and because (*unclear*) of the
22 papers, I got referred to another one, I assumed
23 I must have been wrong that I thought I was at the
24 Caroline Flint meeting.

25 So I remember being there and talking, but

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1 I don't remember -- I don't think I was involved in
 2 putting the figures together, except that we would
 3 have discussed them -- you know, the trustees would
 4 have known what was going to be said in that pitch.
 5 **Q.** So you don't think that you had any input into the bid
 6 as it went in to the Department of Health, but you
 7 were there at the meeting when that bid was discussed
 8 with Caroline Flint in July 2006?
 9 **A.** Yes.
 10 **Q.** Shall we have a look at that meeting? It's
 11 DHSC0006259_046. And we can see there the attendees
 12 are Minister of State who is Caroline Flint, and then
 13 a number of civil servants, and Peter Stevens, and you
 14 representing the Eileen Trust.
 15 Then the minute sets out the background, and
 16 then the nub of the claim from the Trust is set out in
 17 a number of bullet points. And I won't go through
 18 them all, but:
 19 "The Government has a moral obligation to
 20 provide these special payments to their registrants
 21 ... it can't be right for funding to be subordinated
 22 to the requirements and problems associated with NHS
 23 budgets ... there have been promises on several
 24 occasions to review provision regularly. The basis of
 25 the original settlement was that registrants were not

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1 infection on their lives and the needs for adequate
 2 funding to maintain their dignity and independence."
 3 And then it says at the bottom Minister of
 4 State listened carefully and effectively said she'd
 5 write and let you know what the outcome of her
 6 decision was.
 7 First of all, do you -- is this, as far as
 8 you're aware, a Department of Health minute? Is this
 9 a minute you'd seen before?
 10 **A.** I don't remember whether I've seen it before. There's
 11 another account of the meeting which you sent me, so
 12 maybe this one is the Department of Health one and the
 13 other one is ours because the other one is slightly
 14 different.
 15 **Q.** What can you recall about that meeting?
 16 **A.** I think that it didn't seem very conclusive. This
 17 seems a pretty fair account of what happened, and then
 18 we went away to see what she would come back with.
 19 **Q.** We can see the response that you ultimately get. It's
 20 HSOC0005411. It's addressed to Mr Stevens,
 21 28 July 2006:
 22 "Dear Mr Stevens. I am grateful for your
 23 taking the time to meet me [et cetera, et cetera] ..."
 24 And then:
 25 "I've considered carefully all the points, and

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1 expected to live [but, in fact, because of modern
 2 treatments they have, and the unexpected longevity has
 3 changed the role of the Trust]."
 4 And then at the bottom, there's a specific
 5 reference to the Eileen Trust:
 6 "Many registrants fear exposure of their HIV
 7 status, and for some this is even as a barrier to
 8 claiming their benefits from other sources ..."
 9 Then a reference to:
 10 "The Eileen Trust has a very conscientious case
 11 worker who assists registrants in seeking all the
 12 available benefits and in other areas such as
 13 minimising debt."
 14 And that, you're referring to Susan Daniels,
 15 are you?
 16 **A.** Yes.
 17 **Q.** And then over the page:
 18 "The current claim is the first comprehensive
 19 review of what the Trust is doing ... and for the
 20 Eileen Trust although, there are presently very few
 21 registrants, there's significant potential for new
 22 registrants to be identified in the coming years."
 23 And then it's said:
 24 "The Trust's representatives presented an
 25 emotive case described in the impact of their

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1 I'm satisfied an increase of £400,000, approximately
 2 11 per cent, will maintain an appropriate level of
 3 support ..."
 4 And for the Eileen Trust, that means £177,000
 5 for the year, as against your £250,000 that you were
 6 asking for.
 7 Can you recall what the Eileen Trust response
 8 was to that?
 9 **A.** I think we were -- both Trusts were quite cross about
 10 the response, not least because she says she's giving
 11 us £400,000 across the two which she says is
 12 11 per cent, but then she says that we'll have to pay
 13 administration costs out of that. Whereas, hitherto,
 14 both the Trusts had been receiving a Section 64 grant
 15 which was across the board -- the two was the
 16 equivalent of 330,000. So, actually, she was only
 17 giving us 70,000 which, if you work that out, that's
 18 not 11 per cent increase; that's a 1.9 per cent
 19 increase.
 20 So I think what we were cross about was (a)
 21 that she wasn't giving us the money, but also that she
 22 was dressing it up and kidding probably nobody but
 23 herself that she was giving us 11 per cent. And that
 24 just seemed -- I mean, it was a lie, and she must have
 25 been aware that it wasn't a truthful representation of

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1 what she was doing. So I think both Trusts were quite
 2 frustrated.
 3 Q. You attended a meeting shortly after receipt of this
 4 letter at the Macfarlane Trust on 21 August 2006. Do
 5 you recall that meeting?
 6 A. Yes. I mean, I remember being there. I don't
 7 remember -- if I didn't have the report you sent me,
 8 I wouldn't remember what we'd said.
 9 Q. Shall we turn that up? It's MACF0000020_102. You can
 10 see there the minute. It's 21 August 2006:
 11 "By invitation: Ms Sue Phipps."
 12 And then if we go down the page to 233.06:
 13 "The Chairman welcomed Ms Sue Phipps, a trustee
 14 of the Eileen Trust, who was present for the item on
 15 the minister's response to the business case for
 16 increased funding."
 17 Then the trustees' determination to consider
 18 a response to the minister's letter that we just
 19 looked at, and that was considered first. The formal
 20 letter was tabled. The Chairman referred to a report
 21 on it. And if we go over the page, there followed
 22 a wide ranging debate:
 23 "There had been, as widely reported,
 24 unprecedented levels of cutback in available resources
 25 to the NHS. It would be relatively simple for the DoH

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1 develop the funding situation over a period ... that
 2 the Trustees had a clear duty and responsibility in
 3 their duty of care to the beneficiary community."
 4 Then I think if we go over the page -- sorry,
 5 this is the right page, yes, the beneficiary
 6 community. If we go down to (k) I think we understand
 7 where the reference to resignation comes from:
 8 "The Chairman reported on the comments that he
 9 had received from two registrants and advised the
 10 board their contents, specifically:
 11 "-- ... Chairman should write to all Members of
 12 Parliament
 13 "-- ... Chairman should make a public statement
 14 in respect of the letter from the minister
 15 "-- That the trustees should resign *en bloc*."
 16 Then the next paragraph starts:
 17 "that after debating the response to the
 18 minister's letter dated the 28 July [relating] to the
 19 business case for increased funding, the invitation to
 20 attend a further meeting with officials should be
 21 accepted to re-express the key points in the business
 22 case and how they affect the community of care; that
 23 the letter from the minister does not address the
 24 views of trustees and that they are minded to resign
 25 and that there is a will to discuss with officials

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1 to report that against this climate an increase has
 2 been made against all expectations. All negotiations
 3 with the DH were political in content, and the Trust
 4 had no political constituency to offer as a bargaining
 5 counter."
 6 Do you recall discussions of that nature that
 7 the Trusts felt they had no political constituency?
 8 A. No, I don't and, in hindsight, I'm not sure that
 9 that's right. I don't remember what we said at the
 10 time.
 11 Q. Then if we go down, there's a number of points made
 12 about future negotiations and, if we go down to (e):
 13 "... the letter clearly indicated an offer to
 14 talk further, the key was how this 'offer' should be
 15 addressed."
 16 At(g):
 17 "... the business case, a view shared by all,
 18 had not been addressed in any meaningful way and that
 19 any future meeting should be demanded with urgency as
 20 this was a matter that reflected the needs of the
 21 registrants now.
 22 "(h) In terms of the way forward, the matter of
 23 resignations should be reserved; there was a need to
 24 understand the political situation that now confronted
 25 the Trust; use the meeting with officials to seek to

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1 what sum of money there is that accords with the
 2 business case where that might be found and from
 3 where'.
 4 "An amendment was put seeking to strike out any
 5 reference to resignation at this stage and to only
 6 accept the invitation to attend a further meeting and
 7 seek at least a three year continuation of funding at
 8 the level finally agreed.
 9 "That amendment was accepted and carried."
 10 Then you withdraw from the Board meeting.
 11 Do you remember the discussion about resigning?
 12 A. I don't think I do.
 13 Q. Presumably, it was -- was it -- well, if you don't
 14 recall it I don't think I can ask you any questions
 15 about it.
 16 But do you recall discussions about the Trust
 17 feeling or a discussion about whether or not the Trust
 18 should make a big or the trustees should do something
 19 significant to mark their unhappiness about the
 20 funding decision?
 21 A. Yes, I remember that sort of conversation but I can't
 22 remember the detail of what was said.
 23 Q. Do you recall whether the Eileen Trust had any similar
 24 discussions about either resigning or making some sort
 25 of big gesture to the Department of Health as

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1 a marker?

2 A. I don't remember it and there's nothing in the minutes

3 that go on in our meetings at this time. But I'm sure

4 we would have had discussions. I just can't remember

5 what we would have said. I think it's unlikely that

6 we would have supported resignation but that's only me

7 now saying what I think we would have done.

8 Q. Why is that?

9 A. Well, because I think, you know, you throw your toys

10 out of the pram, you are still in the pram, you

11 haven't got any toys. I don't know that it would have

12 got somewhere. I think we should have done more with

13 this letter because we were holding a letter signed by

14 a Minister of State with some facts that were not

15 right and that surely could have been used.

16 Q. Can we then look at the letter that was put on the

17 website following that meeting. It's HSOC0005409.

18 That is an email sent from Martin Harvey. Is that

19 cc'd into you, do you think? I know you're not -- the

20 full email address, isn't there?

21 A. I think I've got a copy of it but only because you

22 sent it to me. Hang on, where would it be? Yes,

23 I must be the one at the end.

24 Q. It says:

25 "I attach a copy of a statement for the MFT

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1 Then at the bottom of that page, it says:

2 "It was agreed that the Chairman of the Trust

3 should accept that invitation [which is set out

4 earlier, of a further meeting] and that the Trust's

5 tactics should not be revealed (including the threat

6 of mass resignation) in that letter of acceptance."

7 Then right at the bottom of the page:

8 "The Trustees were equally aware that any

9 political leverage is not available and the main

10 weapon is the moral argument in that it was the NHS

11 that inflicted this tragedy on the registrant

12 community, their families and dependants and that it

13 was and [over the page] remains the Trust's ambition

14 to seek additional funding to try and alleviate the

15 hardship this catastrophe has caused and continues to

16 inflict in terms of damage and deprivation."

17 Do you recall any discussions at the Eileen

18 Trust about political leverage and perhaps lobbying

19 Government and ministers, and so on, for increased

20 funding?

21 A. No, I don't -- and I suppose that by quite -- well,

22 relatively soon after this, when the Archer Inquiry

23 was announced, I think that's where we focused our

24 attention and our efforts.

25 Q. Soumik, you can take that down. There are some

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1 website that was prepared by me yesterday. It has the

2 approval of the Chairman and will be e-mailed to the

3 Webmaster today.

4 "It is under my name ..."

5 Do we understand from that then that you

6 wouldn't have seen the text of that letter before it

7 was put on the Macfarlane Trust website?

8 A. I don't think so.

9 Q. Then, if we go over the page, we can see the letter

10 and it's headed:

11 "The response of the Macfarlane and Eileen

12 Trusts Boards of Trustees to the Minister's letter

13 dated the 28 July ..."

14 It talks about a meeting on 21 August by the

15 Boards of both trustees:

16 "After a considerable debate, it was resolved

17 that the response from the minister was unacceptable

18 in that it failed to address the business case in any

19 way ... and the ... increase of 11 per cent in overall

20 funding was disingenuous."

21 Then it goes on to set out the various

22 negotiating tactics considered and sets out the

23 comments from a number of registrants, which we've

24 already considered and looked at in the minutes of the

25 meeting.

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1 references in the Board Trust minutes about

2 discussions about strategy with the Department of

3 Health, which I can take you to if it would be

4 helpful. But it simply says that -- in the Board

5 minutes it says there were discussions about strategy

6 with the Department of Health but they were not

7 minuted. This is around August 2008.

8 Can you recall what the content of those

9 discussions about strategy with the Department of

10 Health was and what the Eileen Trust's strategy was

11 with the Department of Health?

12 A. I can't recall what it was and I wish I could

13 because -- I mean, I imagine if we're not minuting

14 it -- and I don't know why it wasn't minuted. I don't

15 think I've got anything that's terribly helpful to add

16 to that.

17 Q. You can't assist us as to why it wasn't minuted?

18 A. No.

19 Q. What would the Eileen Trust like to have done for the

20 community had it had more funds?

21 A. Make it so they didn't have to apply for single

22 grants -- have the single grants as a safety net in

23 extreme circumstances but make it so that they had

24 enough money to live decent lives, not just kind of

25 get by on a week-by-week basis.

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- 1 Q. Is it right that the annual weekends for the Eileen
2 Trust started in around 2006/2007?
- 3 A. I think 2007 was the first. It was discussed back,
4 very early on, in 1995 and '6. We had -- some of the
5 registrants wanted to meet and it was explored but it
6 came to nothing in the end, but I think it's a shame
7 that we didn't perhaps encourage it more at that stage
8 because if we had even -- we just had a meeting with
9 four or five people, you know, that would have -- one
10 could have built on that and, as it was, we didn't
11 have a meeting until 2007, and then most years after
12 that there were events and they were successful and
13 useful and of huge value to everybody.
- 14 Q. Prior to those weekends, what was the -- did you, as
15 a trustee, have any contact with the registrants?
- 16 A. Not *en masse*. There was one particular registrant
17 [redacted] who was very -- he would come up I remember
18 him being in the pub with the trustees having a drink
19 at some occasion or other, he was very articulate.
20 From my point of view he gave me history lessons of
21 the politics and the history of everything that had
22 gone on before but, apart from [redacted] I didn't
23 meet any of the other registrants until the first or
24 the second, you know, registrants' meeting.
- 25 Q. What benefit do you -- was there any benefit, do you

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- 1 I think we already knew quite a lot. I think we
2 already understood a lot.
- 3 Q. So in the early years before Susan, do you think it
4 would have been helpful if you had been meeting the
5 registrants; do you think that would have helped your
6 decision-making?
- 7 A. I think it would have been -- well, I just think it
8 would be good for the running of the Trust. I think,
9 whether it would have helped -- yes, is the answer.
- 10 Q. Did the Eileen Trust have any formal links with any
11 other charitable or campaigning organisations which
12 represented the non-bleeding disorder HIV-infected
13 community?
- 14 A. I don't think so.
- 15 Q. Was that's ever discussed, to your recollection?
- 16 A. Whether we should be --
- 17 Q. Yes. Whether you should have -- form such links with
18 such organisations?
- 19 A. I don't remember that ever being discussed.
- 20 Q. The last topic of questions I've got for you is on the
21 Eileen Trust's actions taken to identify new
22 registrants. Your statement makes it clear that it
23 was for the Department of Health to identify potential
24 registrants for the Eileen Trust; is that right?
- 25 A. Yes, and then it was for us to approach them and try

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- 1 think, from meeting registrants to you as trustee --
- 2 A. You've frozen.
- 3 Q. -- when you were discharging --
- 4 A. I missed what you were saying. I think you were
5 probably saying what benefits did I have as a trustee
6 from going to the meeting.
- 7 Q. Yes, in meeting the registrants?
- 8 A. Oh, I think it's huge. You know, even though we have
9 very, very good reports from Susan and from, in some
10 cases, her predecessors, I think, you know, meeting
11 the registrants, in both ways for them to meet you and
12 us to meet them, it's -- you know, we are all on the
13 same side. We are all in this together. I think it
14 just gets rid of barriers. I think it's a huge
15 benefit and, obviously, I think -- sorry -- for the
16 registrants it's probably even more benefit for them
17 to meet each other.
- 18 Q. Given that you were making decisions about
19 applications that they were making for things that
20 they were saying they needed, did it help you to have
21 a greater understanding of who they were and the
22 circumstances in which they were living?
- 23 A. I suppose it put, sort of, colour into it but I think
24 we were so well informed by Susan that I don't -- it
25 brings it to life more but I don't think it was --

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- 1 and get them to engage with us.
- 2 Q. We've seen from the annual reports we've just looked
3 at that the Eileen Trust were concerned about the low
4 numbers of registrants registered with the Eileen
5 Trust; is that right?
- 6 A. Yes. Sorry, people -- from the applicants?
- 7 Q. Yes. So the people that had capital payments from the
8 Department of Health, not all of them, as I read the
9 annual reports, had then come on and registered with
10 the Eileen Trust. Was that the position?
- 11 A. That was the position.
- 12 Q. Did you raise that concern with the Department of
13 Health, do you know?
- 14 A. No, because, at that stage, if they were -- if they
15 had had their applications to the Department of Health
16 accepted then we were writing to them. So it was more
17 whether we were approaching them in the right way, and
18 I think we wrote subsequent letters. The trouble was
19 until they had said we had their permission we had to
20 use the Department of Health to send the letters to
21 them, or send letters to them, and we felt that,
22 actually, it would be better if the letter could come
23 from us.
- 24 So at one stage, instead of saying -- instead
25 of having a letter from the Department of Health, we

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asked them if it could be an open letter that we had written because we thought that that might get a better response. But there came a time when, I think, we assumed that if people weren't choosing to register with us then that was their choice and we had to respect it. But, you know, who knew why they weren't? Maybe it was just too difficult. Maybe they were too ill. Maybe they were too frightened of the stigma. In those early years it was such a different world to how it was even ten years later.

Q. Did the Department of Health allow you to send that open letter?

A. Well, I think they did. There's a minute saying we sent it to them and then much later there's talk about the letter having gone out and I assume it's the same one.

Q. Was there a concern that the Eileen Trust had that, in fact, the Department of Health weren't identifying all the potential beneficiaries?

A. That's the million dollar question, isn't it?

Certainly, they did do things they did get in touch, in the early days, with solicitors and HIV co-ordinators but ...

(Screen frozen)

... years of campaigning with the social work

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because registrants went on trickling through.

So, you know, while on the one hand that suggests that maybe people did know about it, I don't think there was that much done in a seriously concerted way. It didn't look like something that somebody was trying massively hard to do.

Q. Just for those listening, I will just take you to the annual report which sets out the steps in certainly '94/'95 that the Eileen Trust took to try and identify beneficiaries. It's DHSC0002779_002. And this is the annual report from 31 March 1995.

If we turn to page 4 of that document, which is the trustees' report, and it says there:

"... 57 people had qualified for a settlement payment under the scheme, and of those, 24 had made contact with the Trust. Although not every settlement payment results in eligibility for help from the Eileen Trust, it was nonetheless felt by the trustees that this gap was too large and that there could be many people who were eligible and who might need but were unaware that help was available. It has, therefore, been one of the major concerns of the Trust to identify and enrol those who are eligible."

Then the next two paragraphs set out what the Trust's done:

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press and the medical press, so that it was absolutely front of mind as opposed to just putting it in the National AIDS Manual, which is fine but isn't --

Q. Ms Phipps, I think we lost you a bit there, I'm afraid.

SIR BRIAN LANGSTAFF: Would you like to repeat the question?

MS SCOTT: Yes, if I repeat the question. So I said was there a concern that the Eileen Trust -- did the Eileen Trust have a concern that, in fact, the Department of Health weren't identifying all the potential beneficiaries.

I will read out where we got to with your answer. You said:

"That's the million dollar question, isn't it?"

Certainly, they did do things and get in touch in the early days with solicitors and HIV co-ordinators ..."

Then we lost you.

A. Okay. They had, which we didn't have, the resources both in terms of skills and expertise, and presumably the cash, to do a much more concerted proactive communication campaign. They should have been in the social worker press, and the press, and the medical press, and the nursing press, certainly every two or three years, because we know that people were there

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"This action has rested mainly on two projects. First, it was arranged with the Department of Health that they would send out another circulation to potential beneficiaries who had not registered with the Trust with a further invitation to do so."

So that's trying to close the gap, is it, between the 57 people who had got this capital payment and the 24 people who had registered with the Trust?

A. Yes.

Q. And then:

"Secondly, the Trust wrote to medical and social work staff at hospitals and to contacts in voluntary organisations connected with HIV giving information about the Trust and inviting referrals."

That's going, is it, to the fact that actually people may not have even got as far as the DoH to get their capital payment?

A. Yes.

Q. And --

A. Sorry. I was just going to say because if they'd missed -- if they'd only become aware of their HIV status later on, they wouldn't have picked up any campaign that was going on at the beginning.

Q. It says:

"Both of these methods achieved some (but

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1 limited) success, and the Trust has also arranged to
2 appear in the directory of the national AIDS manual
3 and other publications of this type. Additionally,
4 the staff take all opportunity to follow up any leads,
5 however slight."

6 Can I just then ask you some questions about
7 that last sentence, the following up of any leads,
8 however slight.

9 You see an example of this at AHOH0000019. So
10 that's a minute of a board meeting 6 September 1994.
11 Again, we see you present. And if we go down to the
12 bottom of that first page, "Registration/statistics":

13 "The secretary reported that there had been no
14 new registrations, but following a press report of a
15 boy in the Newcastle area orphaned in circumstances
16 which indicated eligibility to register, the staff had
17 taken action via both the DoH and the Newcastle area
18 HIV co-ordinator to try to establish contact with the
19 boy's guardian."

20 Then if you go over the page:

21 "During discussion, it was noted that this was
22 a case where Department of Health contact had only
23 been made via solicitors, and it was questioned
24 whether in such circumstances the circulars inviting
25 registration with the Trust had been passed on. The

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1 to try and find registrants, new registrants, were
2 sufficient, or do you think they could have done more?

3 A. I don't think we had the resources to do a lot more.
4 (*unclear*) to have been a group of people that one
5 could easily identify and you knew where they were, it
6 would have been easier to get their attention, but
7 our -- potential registrants for the Eileen Trust
8 could have come from so many different circumstances
9 that I think it required skills that we didn't have.
10 Everybody thinks that PR is easy, and it's simply not
11 the case. Something like this would have been way
12 beyond our capabilities.

13 MS SCOTT: Sir, those are all the questions that I had.

14 I don't know whether it would be convenient to take
15 a lunch break now so that the Core Participants and
16 their recognised legal representatives can submit any
17 further questions that they would like me to ask
18 Ms Phipps.

19 SIR BRIAN LANGSTAFF: Yes. Well, that would be sensible.

20 Let me just explain to Mrs Phipps what happens. There
21 are, as I told you earlier, quite a number of people
22 beyond this room who are watching, many of whom have
23 legal representatives who are invited to put forward
24 questions which occur to them, listening to the
25 evidence or having read your statement, and, if so,

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1 secretary was asked to take up this point with the
2 Department of Health.

3 "It was noted that the recent distribution of
4 the annual report to an address list obtained from NAM
5 had not resulted in any response, and it was agreed
6 that there was little further scope for broad
7 advertising, and further registration would be more
8 likely to rest on follow up to any leads, as in the
9 present Newcastle case."

10 So is that the sort of action then that the
11 Trust were taking? Reading a report in a newspaper
12 which may suggest that somebody qualifies for
13 eligibility and then following it up?

14 A. I think so, yes.

15 Q. In your witness statement, you make reference to the
16 Liverpool incident. Can you recall what that was?

17 A. Yes. That was when there were I think five --
18 three -- some infected blood had been used long after
19 it shouldn't have been possible, and there was a case
20 of I think it was five people being infected with HIV.
21 And I don't know how -- I think it must have come
22 out -- actually, I don't know how we knew about it,
23 but as a result of that, we got -- I think we had two
24 new registrants from that.

25 Q. Do you think that the steps taken by the Eileen Trust

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1 counsel to the inquiry will consider whether to ask
2 you those questions in due course. Obviously, she has
3 to know what the questions are. That takes time and
4 so they will talk to her over lunch.

5 So we will ask you to come back at 20 to 2. It
6 is now 20 to 1. 20 to 2 and see what further
7 questions there may be. The likelihood is -- I can't
8 promise it as a certainty -- but the likelihood is
9 that you will finish your evidence shortly after that.

10 Now, I don't know if you heard last time we had
11 a break that what you must not do is discuss your
12 evidence with anyone during the break, whoever they
13 are. So if you have lunch with your husband you can't
14 talk about what you have been saying to us but you can
15 talk about anything else you like.

16 A. Thank you.

17 SIR BRIAN LANGSTAFF: I look forward to seeing you back at
18 20 to 2.

19 (12.40 pm)

(Luncheon Adjournment)

21 (1.40 pm)

22 SIR BRIAN LANGSTAFF: Yes, Ms Scott.

23 MS SCOTT: Before the lunch break, I was asking you some
24 questions about the meeting with the Minister,
25 Caroline Flint, on 12 July 2006 and you mentioned that

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1 you had been sent two different minutes from that
2 meeting. Just so there's no mystery about it, can we
3 have up GLEW0000357. So is this the second meeting
4 minute that you were referring to?

5 **SIR BRIAN LANGSTAFF:** I am not sure if she heard the
6 question.

7 **MS SCOTT:** Is this the --

8 **A.** Sorry, I've got that one.

9 **Q.** Yes. Is that the one you were referring to when you
10 said you had been sent two minutes of the meeting?

11 **A.** Yes, because the other one is the one that went on the
12 website.

13 **Q.** So if we look halfway down the page, we see "Summary
14 of the exchange":

15 "Peter Stevens giving a broad overview of the
16 business case for both trusts ...

17 "The verbal dissertation was designed to ensure
18 that any rebuttal by the department was made as
19 difficult as possible. The strategy was to deliver
20 a message that could not be easily challenged."

21 Then there's a section on the Eileen Trust,
22 "Main general issues covered":

23 "-- Work is a rare option ...

24 "-- Trust is not a substitute for the Welfare

25 State ...

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1 the management transparency of support given to the
2 community of care et cetera."

3 Then if we go over to the next page, under
4 "Conclusion", it says there:

5 "It was clear from the ministerial response
6 that ..."

7 I think a T is I missing there:

8 "... [the] following was the case:

9 "That she had been badly briefed and was not
10 prepared for the strategy deployed by the Trust."

11 Then it talks about the attempts to go "on
12 brief", and eventually the minister changing tack and
13 saying this is a "listening exercise", and so on.

14 Do you know who prepared this minute? Is it
15 your document?

16 **A.** No. You sent it to me.

17 **Q.** You don't think you've seen this before?

18 **A.** Yes, I have both of these.

19 **Q.** Sorry, but not before today. Before the Inquiry sent
20 them to you do you think you had seen this document?

21 **A.** I think I must have seen it because I would imagine it
22 would be circulated to all of these people but the
23 thing -- no. The number at the bottom is that
24 something to do with you? The answer is, no, I don't
25 remember having seen it before.

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1 "-- Family support is there but not always.

2 Community support is unavailable, stigma being the
3 main fear for the vast majority of the registrant
4 community. State benefits are insufficient ...

5 "-- Longer life means different needs. Health
6 degradation is still a reality.

7 "-- Trustees seek to empower registrants to
8 make decisions not impose restraints."

9 Over the page:

10 "Many widows [are] living in acute poverty --
11 no financial base, return to work often impossible.

12 "Business case spells out requirement and that
13 has been calculated at [£250,000] per annum [and]
14 should remain open-ended due to the increasing number
15 of registrants -- 38 per cent in the last 2.5 years.

16 "-- Longevity was identified ..." and so on.

17 Then a little bit further down:

18 "Any restriction of funding will inflict damage
19 in the registrant community -- poverty and stress are
20 killers in much the same way as is HIV. It cannot be
21 departmental or government policy to shorten lives
22 with third party policy error.

23 "Sue Phipps spoke eloquently about the specific
24 needs of Eileen Trust registrants from her perspective
25 as a trustee. The valuable role of the caseworker and

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1 **SIR BRIAN LANGSTAFF:** I doubt it was circulated to
2 everyone, given that it talks about the Minister
3 having prepared her brief badly.

4 **A.** Oh, I see.

5 **SIR BRIAN LANGSTAFF:** It suggests --

6 **A.** I meant of us, the Eileen -- yes, of course.

7 **MS SCOTT:** I was asking you some questions about what
8 happened after the Minister gave her decision about
9 the 11 per cent increase, and we went through some of
10 the actions that were taken. Do you think that the
11 Eileen Trust could or should have done more in
12 response to the Minister's decision?

13 **A.** I think now, and I can't pretend that I pushed for it
14 then, because I think there would be evidence but
15 I think now that this letter, you cannot argue with
16 it. Those figures are there, they tie up with figures
17 in the annual reports. You can't argue with the fact
18 that she pretended that 400,000 was an increase when
19 actually she was taking away 330,000. So it seems to
20 me, if you've got a Minister of State doing something
21 like this, you know, she may not like it if we made it
22 public but we're not there to make her like us --
23 I just feel it might have been added pressure at
24 a time when pressure was building up and we were --
25 you know, we didn't know it but we were six months

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1 away from the Archer Inquiry being announced. I think
 2 we could have done this. I don't see what we had to
 3 lose really apart from perhaps slightly irritating
 4 her -- probably doing that now.

5 **Q.** I'll just ask you a question now about the assessment
 6 process for single grants. I think this is a question
 7 that must refer to the process before Susan Daniels
 8 was involved. Do you recall whether, when somebody
 9 made an application for a single grant, they would be
 10 required to have or offered a face-to-face assessment,
 11 or whether those grants were assessed on the basis of
 12 what was written in the application?

13 **A.** I don't recall absolutely but I think probably the
 14 latter but, on the other hand, we were -- the staff
 15 were making home visits, so obviously if the two tied
 16 up -- if that's as a result of a visit, an application
 17 came in, presumably, that would be part of the
 18 assessment.

19 **Q.** So is it right to say this, that you don't recall
 20 there being a requirement or a process whereby
 21 an application came in for a single grant and that
 22 would trigger a home visit?

23 **A.** I don't recall that being what happened.

24 **Q.** I asked you some questions about the capital payments
 25 from the Department of Health and I just wanted to ask

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1 the 500. Because later, in something like 2007,
 2 perhaps not then but some other time, the Department
 3 tried to make us pay for two new people out of our
 4 allocation and we said no.

5 **Q.** Were the trustees aware that registrants were required
 6 to make an undertaking to the Department of Health in
 7 order to receive capital payments under the scheme?

8 **A.** Yes, we were.

9 **Q.** What kind of discussion -- or what was the view of the
 10 trustees about that?

11 **A.** Well, I don't think we had any control over it, so
 12 there wouldn't have been discussion, and I can't speak
 13 for my fellow trustees, but I think I thought that was
 14 not -- I mean, not a good thing. I mean it just
 15 suggests there was a concern about -- anyway, I think
 16 it was not a good thing.

17 **Q.** I'm going to ask you a question now about the staff
 18 costs. You set out very helpfully in your witness
 19 statement, which is WITN4682001 -- I'll get it up on
 20 the screen. Try 13, page 13, WITN4682001.

21 So you set out there the figures from the
 22 annual accounts of the administrative costs of the
 23 Eileen Trust, you started in 1995, 16,000; by 2001
 24 it's gone up to just over 25,500. If we go over the
 25 page, 2002, 28,000 and then it goes up and up until

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1 you whether or not you agree with what Peter Stevens
 2 told the Inquiry. He explained to the Inquiry that
 3 the capital payments made under the scheme, so not by
 4 the Eileen Trust but under the scheme run by the
 5 Department of Health for those who qualified for those
 6 payments were, in fact, certainly in the early years,
 7 channelled through the Eileen Trust; in other words,
 8 somebody who was registered with the Eileen Trust
 9 would receive their capital payment from the Eileen
 10 Trust. Is that your recollection?

11 **A.** No, I don't think that's the case and I think there
 12 would be evidence in the annual reports. Oh, actually
 13 no, that's not true. That's not true. Yes, for
 14 instance, in 2000 there was special payments for two
 15 new registrants which was £132,500, so that was a new
 16 registrant, so Peter was right, of course. 2003
 17 another one and 2005, the equivalent of two more.
 18 These figures are all in the annual accounts. So that
 19 makes five special payments coming through for
 20 registrants.

21 **Q.** Those payments were not made out of the Eileen Trust
 22 beneficiary disbursement pot, they were provided
 23 specifically by the Department of Health to pay out to
 24 new registrants; is that right?

25 **A.** They were. So we got 500, then we got the 132, then

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1 the peak at 2008 at just short of 41,500 and then it
 2 starts coming down, and you've identified at 2012
 3 Susan Daniels being responsible. Was that when she
 4 became the secretary?

5 **A.** Yes. What is not clear in the way it's set out in the
 6 annual accounts is whether everything -- whether it's
 7 like with like all the way through but, as far as
 8 I was able to get the figures to tie up, I think that
 9 is the case, you can compare like with like.

10 **Q.** Then it starts to reduce very substantially and in
 11 2015 we see that the costs are £4,500 and then the
 12 next year £5,500. How was the Trust able to run on
 13 such a small budget over the years?

14 **A.** I think -- I may not be right but I think that we paid
 15 for Susan's salary out of the Trust money -- the grant
 16 money. I think that's the case.

17 **Q.** So those figures --

18 **A.** That would be another 12,000.

19 **Q.** So those figures don't represent all of the costs of
 20 running the charity?

21 **A.** Not all of the costs, no.

22 **Q.** Those are all the questions, sir, that I have from
 23 Core Participants.

Questions by SIR BRIAN LANGSTAFF

SIR BRIAN LANGSTAFF: Just a few questions, if I may, can

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1 I just take you back to the issue of the Caroline
2 Flint meeting at the Department of Health and if we
3 can just have a look, please, at her letter, which is
4 HSOC5411 -- sorry, 0005411, my apologies, Soumik. I'm
5 sorry.

6 Can I just understand what's being said here.
7 This is the response which was so disappointing and
8 the paragraph which contains the meat of it is the
9 third, and it says that:

10 "... satisfied that an increase of £400,000,
11 approximately 11 per cent, to the Trusts' funding will
12 maintain an appropriate level or support to their
13 remaining registrants and is within the current level
14 of Government funding that is available."

15 It says what it will bring the funding to. If
16 it had stopped there and hadn't had the last sentence
17 that would have been 11 per cent.

18 A. Yes.

19 **SIR BRIAN LANGSTAFF:** But the figures, it is said, include
20 provision for administration costs.

21 A. Yes.

22 **SIR BRIAN LANGSTAFF:** Was that what you had understood to
23 be covered by the section 64 grant or not?

24 A. Yes, because we were told that our section 64 grant
25 would be ceasing.

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1 means the previous total must have been 3,531. She's
2 giving us 400. The Section 64 grant in 2006 for
3 Macfarlane I discovered yesterday was 294. I know
4 ours was 336, so that's 330. So she's giving us 400.
5 She's taking away 330. That leaves 70,000 which, as
6 a percentage of 3,531, is 1.9.

7 **SIR BRIAN LANGSTAFF:** Can we just have a look at how this
8 was put by Martin Harvey at HSOC0005409. The second
9 page, please. Thank you.

10 You are something of an expert in
11 communication, given your work in publications and,
12 indeed, in communication I think from your previous
13 experience. I take it you agree with that?

14 A. Yes.

15 **SIR BRIAN LANGSTAFF:** Can you help me with the second
16 paragraph? My reason for asking is this, that when
17 Peter Stevens gave evidence, he talked about
18 11 per cent funding, but it was really 1.9 per cent or
19 something of that order, and I have to say I couldn't
20 quite understand where those figures came from. You
21 have made it very clear, and it is very clear, that it
22 is the difference between the 400 and the £330,000,
23 which is stark.

24 A. Yes.

25 **SIR BRIAN LANGSTAFF:** If he had expressed it in that way

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1 **SIR BRIAN LANGSTAFF:** In your witness statement, the part
2 which you have just recently been referred to, if you
3 can go back to it, 4682, page 13, I notice that in
4 paragraph 48 you recorded that the Department of
5 Health stopped paying the section 64 grant in the year
6 ending 31 March 2008.

7 A. Well, I think that's the case because I think she's
8 talking here about -- this is in July 2006. I think
9 she's talking about the money for following year.

10 **SIR BRIAN LANGSTAFF:** Which would be 2007 to 2008,
11 wouldn't it?

12 A. Yes, but, in fact, they kept paying it for one more
13 year but they still didn't give us any more than 177,
14 or I think it might have been 178,000 the following
15 year. But either way, they took away -- I don't know
16 when they took it away from the Macfarlane Trust but
17 this took away the section 64 grants which were over,
18 well, 330,000.

19 **SIR BRIAN LANGSTAFF:** Now, the difference between 440,000 ,
20 which is about 11 per cent, and 330,000 -- sorry,
21 400,000 and 330,000 -- 70,000, is highly significant.

22 A. Yes. I mean, I tried very hard to make sure these
23 figures were right. So she's proposing her two
24 figures added together, 3,744 and 177 -- she proposing
25 3,931 which she says is a 400,000 increase, so that

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1 to me, I would have understood. I waited to hear and
2 look at the documents, and you have explained it. But
3 the point is this: is it really getting the message
4 across to anyone who is reading the website to
5 describe the increase as disingenuous without saying
6 why it's disingenuous?

7 A. I don't think it is, and that, to be honest, is what
8 worried me before I started going down this track.
9 And I think there are slight complications in that
10 although she's said she was cancelling the Section 64,
11 I do think actually the Eileen Trust might have got it
12 for one more year. But, overall, given that this is
13 looking forward, it was certainly taken away.

14 The point is the letter -- whatever actually
15 may or may not have happened, the letter is saying
16 it's been taken away, and there is no doubt that the
17 administration costs did account for 330, and she's
18 taking them away. There's no doubt about that. So
19 I agree. I think this could have -- this could --
20 should probably -- I mean, "disingenuous" is a bit
21 kind of vague isn't it?

22 **SIR BRIAN LANGSTAFF:** Well, it's a word you read every
23 day -- almost every day in the press about what some
24 minister has said about something, and most people,
25 I suspect, would take no particular notice of it

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1 because it's just a word.
 2 But with the figures -- well, she says that
 3 400,000 is needed, and she gives very good reasons why
 4 it's needed in her letter, but actually it's not
 5 a grant of -- not a raise of 11 per cent which is what
 6 this seems to be saying. It is actually only 70,000
 7 for all these needs which she's recognising because
 8 she hasn't taken into account the size of the
 9 administrative costs. If she were to do that,
 10 plainly, she'd give much more --
 11 **A.** That's --
 12 **SIR BRIAN LANGSTAFF:** That would have been perhaps a basis
 13 on approaching the DHSS to say, "Have you really got
 14 this right? You are meaning to give us 400,000, but
 15 you are taking away more than three-quarters of it
 16 with the other hand."
 17 **A.** I mean, I agree with you. I just -- I can't think of
 18 any other explanation. That's not to say that there
 19 isn't one, but it seems terribly clear to me.
 20 **SIR BRIAN LANGSTAFF:** Because the one point which is not
 21 made in the response here, or for that matter it would
 22 appear reflected by any discussion at the board, is
 23 why the figures weren't being used to embarrass the
 24 Government and to obtain more money by that route?
 25 **A.** No, and I can't -- I mean, I'm sure I would have seen

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1 probably did a bit. And we were -- and I was -- they
 2 were much, much more expert in this whole world. And
 3 I think from my point of view, it probably took me
 4 a couple of years to really feel I had more to offer
 5 than perhaps I -- I had something to offer. And
 6 I think that's true always in a board. It takes time
 7 for everybody to bed down and work together.
 8 And by the time -- you know, it's not as though
 9 we were then fixed forever. People came and went, but
 10 as time went on, there was always a core -- we were on
 11 the same wavelength. We were on the same -- we were
 12 trying to do the same thing. It helped immeasurably
 13 that we felt we were on the same side, as I said
 14 before, of other beneficiaries. So we were -- you
 15 know, we couldn't always do what we wanted or what
 16 they wanted, but there was none of that tension that
 17 I've heard about in the last couple of weeks. It made
 18 it much easier for the Board to be good and to do what
 19 it was there to do. I think we cared. I think we
 20 really cared. It.
 21 **SIR BRIAN LANGSTAFF:** Can you help with this: it really
 22 goes back to your background which brought you on to
 23 the Board in the first place. You had done some work
 24 on stigma, I think, and in particular in relation to
 25 HIV.

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1 this letter, and there's no record of any of us, me
 2 included, saying we should do this at the time.
 3 I think we probably felt that the route down
 4 which we were going, more pressure through the
 5 conventional routes, was the appropriate way forward.
 6 **SIR BRIAN LANGSTAFF:** I see. Well, the next couple of
 7 questions are really quite general. You have said
 8 that one of the advantages perhaps of having a Board
 9 of Trustees which didn't change very much in the years
 10 that you were there was that you got better at it, as
 11 a board, you thought.
 12 **A.** Yes.
 13 **SIR BRIAN LANGSTAFF:** So can you just give me a sense of
 14 how the Eileen Trust changed and how, for that matter,
 15 it improved from 1993 when you began, right through to
 16 March 2017 when you finished?
 17 **A.** I think some of it was nothing to do with us. Some of
 18 it was the climate change, the way boards and trusts
 19 and businesses and people interacted with each other
 20 became much more transparent and much more accepting
 21 of alternative ideas, alternative view points. So
 22 I think the climate was in our favour. But I think we
 23 grew to trust each other more certainly as a -- when
 24 I started, I was much younger than any of the others,
 25 which shouldn't really matter but sort of did,

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1 **A.** Yes.
 2 **Q.** Do you have any thoughtful ideas about how best stigma
 3 of that sort of nature is avoided in the first place
 4 and, if it exists, is reduced or combated in the
 5 second?
 6 **A.** I've lost you.
 7 **SIR BRIAN LANGSTAFF:** Can you hear me?
 8 **A.** I got as far as -- I can hear you. I got as far as
 9 how it can be avoided.
 10 **SIR BRIAN LANGSTAFF:** That's the first part of it. The
 11 second part was how it could be reduced if it exists.
 12 **A.** I think it's the same with stigma or any kind of
 13 prejudice of any kind, that the more you know about
 14 the things that you're frightened of, because it's
 15 always about fear, the better.
 16 When I lived in London, I was surrounded by and
 17 worked with in the local school all sorts of people
 18 from all different worlds, and everybody could ask
 19 questions of anybody without any fear of anybody
 20 getting offended. And now I live in the country, and
 21 it's sort of different because we're all too similar.
 22 So I think just making people communicate with
 23 people who are maybe slightly outside their comfort
 24 zone. Then you discover actually they're not outside
 25 their comfort zone. We're all in the same comfort

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1 zone.

2 **SIR BRIAN LANGSTAFF:** How do you make them communicate?

3 **A.** Find a safe environment. Find something they've got

4 in common. Get them to perhaps do stuff while they're

5 talking. You know, if you're cooking with somebody,

6 you chat. If you are sitting looking at them, it's

7 awkward. You just have to engage people in something

8 really trivial at the same time as asking them about

9 the meaning of life.

10 **SIR BRIAN LANGSTAFF:** So it's a mixture of providing

11 accurate information and enough of it to overcome the

12 fear. It's a question of rubbing shoulders in some

13 way or another perhaps by doing something jointly with

14 people who do not necessarily share your immediate

15 background but may be different and have different

16 things to offer. Those are the two things you've

17 identified. Have I got that right?

18 **A.** Yes, but I think now it's much harder. I mean, we all

19 saw last year the endless completely false stories

20 going out about coronavirus which were making people

21 very, very frightened and driving people apart.

22 I think with the way the media works now, it's even

23 harder than it ever was. On the other hand, that's

24 maybe an opportunity to bring people together.

25 **SIR BRIAN LANGSTAFF:** It all begins, does it, with

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1 **SIR BRIAN LANGSTAFF:** I think you were muted because --

2 well, I don't know why but we froze the transmission.

3 So can I just go back to the answer to the question.

4 You got the question, I think, and you launched into

5 an answer which I wanted to hear and I couldn't hear

6 any of it. So I'm sorry about that.

7 **A.** I think what I was saying was that the other trustees

8 had much more experience and personal experience of

9 HIV and the stigma and all of the issues around it.

10 So I think it was something that was very front of

11 mind in how we approached what we were doing. I think

12 we were always very aware of the need to be

13 sensitive -- *(witness connection frozen)*

14 *(Pause)*

15 **SIR BRIAN LANGSTAFF:** It looks as though we've lost again

16 I'm afraid. Are you back with us? We are having

17 a tough time. So perhaps I shall ask you simply to

18 note down your thoughts in writing and let us have

19 them later because otherwise we will never finish.

20 I'm sorry about that, but that was the last question

21 I had to ask.

22 Ms Scott?

23 **MS SCOTT:** Ms Phipps, is there anything you would like to

24 add to your evidence?

25 **A.** I don't think so.

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1 accurate information being given without exaggeration

2 from the top?

3 **A.** Yes, but that's not as easy as you make it sound.

4 **SIR BRIAN LANGSTAFF:** It's easy to state. I quite agree.

5 Does the same apply to reducing and combating

6 stigma, if it exists, do you think?

7 **A.** Yes, I think so. I mean, you know, we go back to

8 Princess Diana shaking hands. Such a small thing to

9 have done and such a huge impact from, you know,

10 something -- some people have a gift for doing it, and

11 she was obviously one of them. I think it is possible

12 because stigma is not -- almost by definition is not

13 justified. Surely that's -- is that the meaning of

14 stigma? I think it is.

15 **SIR BRIAN LANGSTAFF:** Yes. How do you think those ideas

16 about reducing and avoiding stigma or combating it,

17 how do you think they were reflected in how the Eileen

18 Trust worked?

19 **A.** I think the intention -- *(connection frozen)*

20 **SIR BRIAN LANGSTAFF:** We've lost the transmission again,

21 I'm afraid.

22 **A.** -- of HIV --

23 **SIR BRIAN LANGSTAFF:** Sorry, we lost you for a moment.

24 *(Pause)*

25 **A.** Sorry, for some reason I was muted.

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1 **SIR BRIAN LANGSTAFF:** Well, thank you very much indeed.

2 You understand, having spent 24 years working with the

3 Eileen Trust, why you are so important to us because

4 you really span the whole period, pretty much, of the

5 Trust's existence and operation. You plainly have

6 an independent mind to look at and recall, albeit in

7 this forum with the assistance of the documents, and

8 thank you very much for the work you have done on

9 those, which has been illuminating in itself.

10 Can I just thank you for that and for the care

11 which you brought quite plainly to the work you did

12 for those who were registrants of the Eileen Trust.

13 So thank you very much indeed. I'm sorry that you

14 have been dogged with bad transmission. I think

15 you're the one who has come off worst but there has to

16 be someone who comes off worst in this, it looks as if

17 it may be you. I do apologise, I really do.

18 **A.** It's not a problem.

19 **SIR BRIAN LANGSTAFF:** Well, thank you.

20 **A.** Thank you, Sir Brian.

21 **SIR BRIAN LANGSTAFF:** Ms Scott, do we need a short break

22 before we start?

23 **MS SCOTT:** Yes, we will need a short break before we hear

24 from Mr Bateman.

25 **SIR BRIAN LANGSTAFF:** Yes. We will take -- how long do

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1 you think we need, ten minutes?
 2 **MS SCOTT:** Yes, I would have thought so.
 3 **SIR BRIAN LANGSTAFF:** So let's begin then at 25 past, just
 4 to make sure we have a proper connection.
 5 (2.13 pm)
 6 (A short break)
 7 (2.24 pm)
 8 **SIR BRIAN LANGSTAFF:** Good afternoon, Mr Bateman. I'm
 9 sorry you have been kept waiting. Can you hear me?
 10 **THE WITNESS:** Yes, I can, Sir Brian.
 11 **SIR BRIAN LANGSTAFF:** You can see me or at least most of
 12 me, given this?
 13 **THE WITNESS:** Yes.
 14 **SIR BRIAN LANGSTAFF:** You're talking to a room which has
 15 eight people in it, a very large room, we are all
 16 properly socially distanced, and all except Ms Scott,
 17 who will be asking you the questions, are wearing
 18 masks. For ease of hearing I may remove mine from
 19 time to time. You're talking really, though, not to
 20 us but to people who are elsewhere watching remotely,
 21 for obvious reasons. There are about 200 of them and
 22 they are waiting to hear what you have to say. I'm
 23 sorry, as I say, you have been kept waiting. Now, you
 24 are at home, are you?
 25 **THE WITNESS:** I am in my office which is in my home.

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1 those statements as I understand; is that right?
 2 **A.** Yes, if I may.
 3 **Q.** So in the first witness statement, and I'll just bring
 4 this one up, WITN3487001, and if you go to page 6 of
 5 that document, please, Soumik, you are talking there
 6 about experience of Government decision-making and you
 7 talk in paragraph 29 about the DWP carrying out
 8 a review of cases of people with haemophilia who were
 9 refused PIP, and I will ask you questions about that
 10 in due course. You say:
 11 "This demonstrated there were many poor quality
 12 assessments of the impact of haemophilia on people's
 13 functional ability."
 14 If we can go over the page, and you give
 15 reasons why that is, and I'll ask you to speak to that
 16 in due course:
 17 "... private assessment companies were required
 18 by the DWP ..."
 19 Then -- the DWP were required -- required the
 20 private assessment companies to provide new guidance
 21 to their staff.
 22 Paragraph 32, you talk about the impact on
 23 people with haemophilia and hepatitis C. Then it's at
 24 paragraph 33 that you want to make the amendment. You
 25 say:

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1 **SIR BRIAN LANGSTAFF:** Right. Is there anyone else around?
 2 **THE WITNESS:** My wife is in the main house not in the
 3 office. I'm on my own in this office.
 4 **SIR BRIAN LANGSTAFF:** Right. Well, Mary will now ask you
 5 to take the oath.
 6 **NEIL MARTIN BATEMAN, affirmed**
 7 **Questions by MS SCOTT**
 8 **MS SCOTT:** Mr Bateman, you were an independent benefits
 9 adviser to the Macfarlane Trust and its registrants
 10 between 2008 and its closure; is that right?
 11 **A.** Yes. I have actually checked my records and the first
 12 case did actually come in in 2007.
 13 **Q.** Sorry. You also provided independent benefits advice
 14 to Caxton Foundation registrants between December 2011
 15 and its closure; is that also correct?
 16 **A.** That is correct.
 17 **Q.** You are currently providing independent benefits
 18 advice to some registrants of the English Infected
 19 Blood Support Scheme; is that right?
 20 **A.** That is correct. I also provided welfare rights help
 21 and advice to three people registered with the
 22 Scottish Infected Blood Support Scheme. That's quite
 23 recent.
 24 **Q.** Now, you have provided two witness statements for the
 25 Inquiry and you wanted to make some amendments to

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1 "The comparatively rare nature of the
 2 conditions which infected blood victims have, made it
 3 harder for staff working on assessments, who are
 4 overwhelmingly not doctors. This was revealed to the
 5 House of Commons Work and Pensions Committee, by
 6 senior staff in the assessment companies, who carry
 7 out ..."
 8 You have written the words "accurate
 9 assessments of the functional ability"; do you want to
 10 change that?
 11 **A.** Yes, please. It's really probably a typing error. It
 12 just makes it clearer if we remove the word
 13 "accurate". I don't think it -- as I say, I think
 14 it's a typing error.
 15 **Q.** Then in your second statement, I won't take this up,
 16 you are giving evidence in paragraph 22 of that about
 17 a recollection you have of Martin Harvey asking you to
 18 submit monthly case reports, and you give the date
 19 there as October 2011. I believe you want to change
 20 that, do you?
 21 **A.** Yes, the reports actually started in November 2011.
 22 I think he must have asked me in October.
 23 **Q.** Thank you. Before I ask you questions about the
 24 advice that you've given, and so on, to registrants,
 25 I'm just going to run through with you your background

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1 and qualifications. So is it right that you're
 2 a qualified social worker --
 3 A. I am.
 4 Q. -- and that you have a law degree and hold two post
 5 graduate diplomas in social policy and social work --
 6 A. Yes, that's right.
 7 Q. -- and that between 1982 and 2003 you worked as
 8 a social worker and in welfare rights for a range of
 9 local authorities, health authorities and for the DWP
 10 Department of Work and Pensions?
 11 A. I was seconded in 2000 for six months to the
 12 Department for Work and Pensions to provide policy
 13 advice on pension poverty but your summary is
 14 otherwise correct, yes.
 15 Q. In 2003 you became a freelance welfare rights adviser.
 16 A. Yes.
 17 Q. Your work in that role includes advising on welfare
 18 rights, representing claimants at all levels of Social
 19 Security appellate systems, including the First Tier
 20 Tribunal and Upper Tribunal hearings?
 21 A. Yes.
 22 Q. You deliver training in welfare rights --
 23 A. Yes.
 24 Q. -- and you advise on policy and write on the subject,
 25 including having authored or contributed to 16 books?

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1 years, and then there was a further problem that
 2 sprung out of that, which was a problem with his
 3 Council Tax benefit and it did take some
 4 correspondence and also a formal complaint to the DWP
 5 to get them to resolve it and also reinstate his
 6 benefits at the correct rate.
 7 That was the first case. I'm not entirely sure
 8 how he heard of me. I think it may have been he found
 9 me on -- found my website. I'm not sure.
 10 Q. So do you understand that the benefit support that was
 11 available at that stage to beneficiaries of the
 12 Macfarlane Trust was the through the Terrence Higgins
 13 Trust?
 14 A. That's what I was told by Martin Harvey but I do not
 15 know the detail of it.
 16 Q. I think you suggested in your witness statements that
 17 it was a light touch benefit support that they were
 18 being offered; is that right?
 19 A. Well, again, that's what I was told.
 20 Q. After that case, you began to work more frequently,
 21 did you, for registrants at the Macfarlane Trust?
 22 A. Yes. Word got out and people started seeking my help
 23 with various benefit problems and, of course, this was
 24 before the impact of the changes to benefits for
 25 people with long-term conditions that was brought

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1 A. That is correct, yes.
 2 Q. In addition to that, you are a member of the Expert
 3 Witness Institute and have undertaken work as
 4 an expert witness in both civil and criminal matters?
 5 A. That is correct.
 6 Q. Can you tell us how you first came across the
 7 Macfarlane Trust.
 8 A. I had a phone call one day, and I have now pinpointed
 9 it as 2007, from a man who -- he phoned me up and he
 10 said he was in difficulty with his benefits. He said
 11 that he was registered with the Macfarlane Trust and
 12 that he had spoken to Martin Harvey, the chief
 13 executive, and they were willing to pay me to sort out
 14 his benefit problem that he had. He said he'd had
 15 some input by the Terrence Higgins Trust and he
 16 actually, also -- I remember he said he had been to
 17 a firm of solicitors to try to get the problem solved.
 18 Basically, he had moved house and, unfortunately at
 19 the same time, had found himself in hospital and all
 20 his benefits had stopped.
 21 So I did contact Martin Harvey just to confirm
 22 the arrangements and then I took on the case,
 23 effectively. It wasn't straightforward. There was
 24 a whole series of administrative failures by the DWP,
 25 one of which, if I remember correctly, went back some

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1 about by Employment and Support Allowance. It wasn't
 2 a huge amount of work but there were -- you know, it
 3 was a -- regular requests coming in for me to sort out
 4 people's various benefit problems.
 5 I remember there was a very tricky overpayment
 6 case which someone had got themselves into difficulty
 7 with. There were various issues to do with undeclared
 8 capital. I remember, actually also, there was a very,
 9 very sad situation, which I did manage to resolve, of
 10 a man who was a registrant with severe haemophilia and
 11 HIV who used to enjoy a game of golf with his father
 12 once or twice a week, and the Department for Work and
 13 Pensions put him under surveillance and stopped his
 14 benefits and mounted a prosecution, and I successfully
 15 challenged the stoppage of his benefits, albeit
 16 I didn't quite get it back at the rate being paid
 17 before. But obviously the prosecution didn't proceed.
 18 That took quite a lot of time and effort. It was
 19 quite a harrowing case actually. I dealt with him
 20 subsequently on various issues that he had.
 21 Q. I'll certainly come on to ask you some questions about
 22 the issue of undeclared payments from the Macfarlane
 23 Trust and other trusts and schemes.
 24 A. Sorry, can I just clarify that that particular case
 25 wasn't alleged undeclared capital or income from the

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1 Trust, it was -- he was alleged to have not reported
 2 an improvement in his condition for Disability Living
 3 Allowance purposes and, given that these are
 4 deteriorating conditions, you can see straight away
 5 there's a problem.

6 **Q.** Yes. What did you know in 2007/2008 about people with
 7 haemophilia being infected with HIV through their
 8 treatment?

9 **A.** Well, obviously, I was aware from media coverage, you
 10 know, the terrible tragedy. When I spoke to Martin
 11 Harvey, I can remember him telling me what the
 12 Macfarlane Trust did and I can remember him giving me
 13 the awful figure. I remember that the guy I spoke to,
 14 who first instructed, if you like, first instructed
 15 me, he was telling me about the numbers involved and
 16 the background, he told me about the settlement that
 17 people in Ireland had. I remember being really,
 18 really shocked, particularly by the circumstances of
 19 the first man, because he not only had HIV, but he had
 20 hepatitis C and he was also on the new variant
 21 Creutzfeld-Jakob disease list, as having contracted
 22 that, and that was on top of having severe haemophilia
 23 with really, you know, very badly damaged
 24 haemarthropathy, an aggressive osteoarthritis that
 25 people with haemophilia get in their joints.

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1 Caxton Foundation -- that there were two routes for
 2 registrants to get help from you. The first was
 3 a referral by the Macfarlane Trust or by the Caxton
 4 Foundation to you, and the second was a request for
 5 the beneficiary themselves to work with you, that they
 6 would make to the Macfarlane Trust or the Caxton
 7 Foundation. Is that right?

8 **A.** Well, it was a bit of a mixture. The people quite
 9 often came to me direct and said, "Oh, I've got this
 10 problem, you know, with my benefits. Please can you
 11 help me?" Or -- and I would always say -- because
 12 obviously Macfarlane were funding the work -- I say
 13 Macfarlane; Macfarlane and Caxton were funding the
 14 work -- and also because I thought it really important
 15 that they were aware of people's needs and the kind of
 16 benefit problems and challenges that folk were facing.
 17 I'd always ask them just to contact the trusts, the
 18 charities, and to get a referral to me. And that way,
 19 it was all kind of sort of, if you like, sort of set
 20 up properly.

21 But, I -- you know, over the years, I've
 22 received, you know, very, very many requests for help
 23 from people to sort out the sort of problems they had
 24 with their benefits.

25 **Q.** So when the charities were referring people to you, do

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1 I had done some work with people with
 2 haemophilia when I had been a social worker, albeit
 3 not very much. I was also aware -- well, more than
 4 aware, actually -- quite familiar with the benefit
 5 rules as they applied to people with HIV and how the
 6 benefit entitlements had, sort of, gradually over time
 7 changed as treatments had improved.

8 **Q.** We can see in some of the documents that you have
 9 written, and we'll come to some of those in due
 10 course, that you now know quite a lot about how
 11 haemophilia impacts on people, and HIV, and so on.
 12 How did you go about educating yourself about the
 13 issues faced by the Macfarlane Trust registrants?

14 **A.** Well, I spoke to Martin Harvey on more than one
 15 occasion, actually, to get background. I looked at
 16 their website. I did actually read up about HIV,
 17 haemophilia and haemarthropathy. I had a look on the
 18 web and I perhaps had a basic medical textbook, which
 19 I often used just to check things. I wasn't really
 20 very aware of how the payment system worked at all.

21 **Q.** Do you refer in there to the Macfarlane Trust payment
 22 system?

23 **A.** Yes. Sorry, yes.

24 **Q.** Is this right, that when you were working for the
 25 Macfarlane Trust -- and this may also apply to the

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1 you know how -- what criteria they applied in making
 2 that decision for referral?

3 **A.** As far as I'm aware, it was just if someone asked.
 4 I'm not aware there was any filtering out.

5 **Q.** So, as far as you were aware, if someone asked that
 6 they could be referred to you, there was -- you were
 7 not aware of circumstances where people asked to be
 8 referred to you and that was refused?

9 **A.** I would be really actually shocked if that was the
 10 case. I'm completely unaware that people were told
 11 "No, we don't think you need Neil Bateman's help."

12 **Q.** Were you aware that some people were required to meet
 13 with you and get advice from you and, indeed, follow
 14 your advice?

15 **A.** Well, as I said in my witness statement, it's very
 16 common practice amongst grant-making charities for
 17 them to require people to maximise their benefits and,
 18 you know, there are good reasons for that because,
 19 obviously, it provides potentially more sustainable
 20 income and also gives them a right of appeal to an
 21 independent tribunal if they're unhappy.

22 So I have looked back over my records. It's
 23 taken me a very, very long time since I read my
 24 witness statement. And I think that about between 5
 25 and 10 per cent of the people that I dealt with were,

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1 if you like, required to have a referral to me. It
 2 was said that, "Please can you get Neil to check your
 3 benefits?"
 4 You know, I'm not really aware of the
 5 objections that folk made other than, you know, one or
 6 two occasions.
 7 Q. So, in the main, if the referral came in that way,
 8 it's your experience, is it, that it didn't make very
 9 much difference --
 10 A. You mean if people were asked to have a referral to
 11 me?
 12 Q. Yes. It didn't make much difference, in terms of how
 13 receptive they were to working with you?
 14 A. No. Most people were very happy because very often
 15 I would pick up some things; some under-claiming.
 16 Also, you know, quite often there would be quite
 17 complex benefit problems with people's benefits having
 18 been stopped or, you know, all sorts of things. And
 19 also quite a lot of people, as I recall, whose
 20 circumstances had changed. You know, they'd maybe had
 21 hepatitis C for some time, but the symptoms from the
 22 liver disease were such that they could, you know,
 23 carry on their lives -- they were continuing working,
 24 for example -- and then things had got to the stage
 25 where they needed either to have treatment, or the

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1 I know that was done verbally on recommendation, as
 2 well as being on The Haemophilia Society website and
 3 in a leaflet that they had published.
 4 Q. So for -- when a registrant either came to you through
 5 referral from the Macfarlane or came to you directly
 6 and then you routed them back to the Macfarlane Trust
 7 or the Caxton Foundation, is this right, that you
 8 would be provided with details of that registrant by
 9 the relevant charity and outline of the problem that
 10 they were having and details so that you could contact
 11 them directly in order to progress the --
 12 A. I'm really not a believer in bureaucracy, having spent
 13 most of my career challenging bureaucracy. And
 14 I wanted to have -- you know, I said to them, "We
 15 really need to have as simple a system as possible."
 16 And so when they would send me a referral by email, it
 17 was really just a sentence or two, plus name, address,
 18 phone numbers. And, you know, it would say this
 19 person's a primary beneficiary and that their
 20 employment and support allowance has been stopped, for
 21 example. You know, it was really that simple.
 22 I wouldn't really be wanting to have -- I mean,
 23 the other problem is if you get lots of information --
 24 I've been here before with other organisations. If
 25 you get lots of information, you know, only a little

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1 symptoms were coming worse. At which point, you know,
 2 they would need some advice about their benefit
 3 entitlement because, obviously, their other income had
 4 stopped.
 5 Q. Do you know anything about what registrants -- what or
 6 how registrants were told about your service? Do you
 7 know how -- did you know how it was publicised to
 8 registrants?
 9 A. Sorry, could you just repeat the question?
 10 Q. Do you know how it was publicised to registrants by
 11 the trusts -- by the Macfarlane Trust, by the Caxton
 12 Foundation?
 13 A. My services?
 14 Q. Yes.
 15 A. Oh, right. There was information on their website;
 16 quite good information. There was certainly a very
 17 active grapevine because I used to get a lot of
 18 people -- still do even now -- who say, "Oh, I've
 19 heard you are really good at sorting out benefit
 20 problems, and I've got this problem."
 21 Also, at some point -- sorry I don't know
 22 when -- The Haemophilia Society started telling people
 23 that if they had infected blood -- if they'd had
 24 infected blood and they had haemophilia that they
 25 should come to me to sort out their benefit problems.

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1 bit of it is actually really relevant to what you need
 2 to do. So it's all a bit of a waste of everyone's
 3 time, as well as obviously potentially, you know, just
 4 being --
 5 Q. Then with Macfarlane Trust, you were a contractor, and
 6 you would carry out the work, submit a bill, and then
 7 they would pay it. Is that how it worked with
 8 Macfarlane Trust?
 9 A. Well, my company was a contractor.
 10 Q. Was that -- sorry.
 11 A. Yes. I mean, I would -- every month -- well,
 12 initially because the cases were sort of somewhat *ad*
 13 *hoc*, I would invoice them once I'd finished work on
 14 the cases. I can't remember at what point
 15 I started -- it was when the work started really to
 16 build up that I started invoicing them monthly. So
 17 there would be an invoice showing the total time and
 18 together with the break down of the time spent on each
 19 case.
 20 Q. I'll just look at a break down in a moment, but was
 21 that broadly the arrangements for the Caxton
 22 Foundation as well?
 23 A. Yes, it was.
 24 Q. So if we look then at one of your reports back of work
 25 done. Can we have, please Soumik, WITN3487007. So

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1 this in your witness statement you say is a feedback
2 from a month that you chose randomly; is that right?

3 A. That's right. I just (*unclear*) out of the file. And
4 you can see the invoice and time-sheet was emailed I
5 kind of think separately.

6 Q. What this looks like, is this right, where the black
7 marks would be different registrants' names, and then
8 a sentence or two on what work you've carried out?

9 A. Yes. Originally, I'd use the, as they called it, the
10 registrant number, but then that was getting a bit
11 confusing after a while, particularly if I look back,
12 I could -- you know, I just couldn't work out who it
13 was. So I started using names. So, yes, the names
14 were there.

15 Q. Was the -- was it a similar arrangement for the Caxton
16 Foundation?

17 A. Yes, it was the same. As you can see, it's really,
18 you know, thumbnail, very, very, very brief. These
19 are really what I would call activity reports rather
20 than outcome reports. Of course, people were telling
21 me -- you know, people have told me a lot, a lot of
22 stuff about their lives, but I didn't put those in the
23 reports. I wouldn't. Very, very personal stuff they
24 were telling me.

25 Q. Then moving on to your work with Caxton Foundation

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1 A. Yes. I mean, it's -- I'd like to -- well, I can
2 confidently say, actually, I provide a 360 degree
3 service. You know, it really isn't just a question of
4 checking their benefits and telling them what they
5 could claim. I mean, I will help them through the
6 claims process, particularly for employment and
7 support allowance and personal independence payment
8 where there are quite lengthy self-assessment forms to
9 complete.

10 I will also deal with problems arising out of
11 that. That can range from delays through to gathering
12 further medical evidence, or maybe even evidence from
13 carers sometimes, filtering out evidence that they may
14 have put together that actually is not really very
15 relevant or not very helpful in some way. You know,
16 sometimes people put in lots of evidence like copies
17 of appointment letters which don't really help anyone.

18 If they then have to undergo an assessment,
19 they would contact me, and I would then brief them on
20 what to expect and, you know, how to, you know, get
21 that across, pointing out, to be honest, some of the
22 trick questions that are asked during some of these
23 assessments. Then they would let me know what the
24 result was when they got the decision through. If it
25 was a good decision, then obviously that's the end of

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1 which started in December 2011. Again, how did that
2 come about?

3 A. I can't remember whether it was either a phone call or
4 because I happened to be at the offices for some
5 reason. I mean, I didn't go to the offices very often
6 at all. Martin Harvey said that there had been the
7 Archer Inquiry and that, as a result of that, the
8 Caxton Foundation was being set up to help people
9 who'd had contaminated blood that had resulted in them
10 having in hepatitis C.

11 And then I remember a sort of briefing, if you
12 like, from Ross Riley who told me about their early
13 experiences in understanding of registrants' needs.
14 I didn't really know what hepatitis C was, so I did
15 a bit of research. I looked on The Hepatitis C Trust
16 website. I actually also asked a doctor friend of
17 mine to explain it. I sort of tried to get up to
18 speed with it.

19 From what I could gather, the Caxton Foundation
20 was a sort of mirror image of Macfarlane Trust, in the
21 terms that it would make payments to people.

22 Q. Have you been able to provide a full range of work for
23 registrants for the Macfarlane Trust and the Caxton
24 Foundation, including advocacy and representation at
25 tribunal hearings?

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1 the case, unless there's any passported benefits that
2 then need sorting out as a result of that. Because
3 sometimes when people are awarded a benefit such as
4 personal independence payment, they may become
5 entitled to higher rates of means-tested benefits, or
6 a carer may qualify for carer's allowance.

7 If they are turned down then, obviously, you
8 know, a lot of work then has to be done -- awful lot
9 of work. You have to get hold of the assessment
10 report, ask the client to go through it, identify
11 obvious errors, factual errors, things they didn't say
12 or that are clearly wrong, send the report to me.
13 I go through it, identify inconsistencies, check the
14 registration of the health professional, put together
15 a challenge to that.

16 Since 2013, we've got a two-stage appeals
17 process which the Government introduced. So you draft
18 up a mandatory reconsideration which is the first
19 stage. It may also involve getting some medical
20 evidence from their professionals or other sources,
21 then submitting the mandatory reconsideration,
22 possibly chasing it up.

23 I'm sorry, I'm going on, but I'm trying to give
24 you a picture of just how complex this work is.

25 And if that is successful, then all well and

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1 good. If it's not, then the next stage starts which
2 is to draft up a notice of appeal to the first tier
3 tribunal. Then you wait. You might have to chase.
4 The DWP might have to apply to the judge for
5 directions to get the DWP to adduce their submission.
6 Their submission comes back, usually around
7 about 100 pages typically. Go through that making
8 notes. Put together my own written submission in
9 response to that. Maybe some further medical evidence
10 again. Send that off to the tribunal, to the
11 tribunal's office, and then wait for a hearing date.
12 Hopefully, on the back of all of that, the DWP would
13 have revised their decision favourably. Sometimes
14 they did; sometimes they didn't. Actually,
15 increasingly they do. If you then, you know, have
16 a -- it has to go to a hearing before the first tier
17 tribunal then, obviously they are going to need
18 representing. Most of the time, they are going to
19 need representing. And on it goes.

20 You know, I have had cases which -- you know,
21 where the first tier tribunal refused -- you know, the
22 appeal was dismissed, and so I've had to appeal --
23 submit an appeal to the -- sorry I'll start again.

24 They had to make an application for leave to
25 appeal to the Upper Tribunal and some cases, indeed,

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1 paragraph 19:

2 "I was given complete freedom to represent
3 clients and to be a vigorous advocate against the DWP
4 and local authorities. Many charities, especially
5 those with links to government, get anxious about 'not
6 upsetting' government departments, but it is a tribute
7 to those charities that they always fully supported
8 eye work on behalf of beneficiaries."

9 You can take that down now, Soumik.

10 So that was your experience, was it, of both
11 the Macfarlane Trust and the Caxton Foundation?

- 12 A. Yes, absolutely. It's one of the reasons I continue
13 to work for them. I mean, I have worked for -- you
14 know, done work for various charities, and so on.
15 Sometimes people get very sort of nervous about
16 someone being a vigorous advocate. I was surprised
17 because, you know, I was aware that they were funded
18 by the Department of Health and, you know, I am aware
19 sometimes that senior officials from one department,
20 you know, might go and have a quiet word with one in
21 another department saying "Can you get this guy to
22 tone down what he's doing", and I'm aware that that's
23 happened to advice workers and, you know, it's -- they
24 have been told -- they've have their wings clipped by
25 the organisation they work for and, you know,

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1 have thence gone to the Tribunal, and then sometimes
2 actually remitted back to the First Tier Tribunal.

3 Sorry, that's very long answer but I just
4 think, you know, it would be helpful to know and --
5 obviously unless you are familiar with this area of
6 practice.

- 7 Q. So, presumably, if you are not available to assist
8 a registrant to go through all of those steps that's
9 something they'd have to do on their own?

- 10 A. Sadly, yes. Increasingly so, because there has been
11 massive retrenchment in the funding for the advice
12 sector since 2010. One of the areas of work I've done
13 over the years is to do reviews of the advice services
14 and audits of advice provision, and I'll never forget
15 a Citizen's Advice Bureau in North London, where
16 queues start forming at 6.30 in the morning and they
17 open the doors at 9.00, they let in 20 people, and
18 then they close the doors and they deal with those 20.
19 That's all they can deal with. That's actually -- and
20 that situation, actually, if anything, it's got worse
21 since then.

- 22 Q. Soumik, could we have up WITN3487001. I just want to
23 take you to a paragraph in your first witness
24 statement. You say this about the Macfarlane Trust
25 and the Caxton Foundation on page 4, please,

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1 particularly actually local authorities sort of
2 getting upset at the vigour of certain welfare rights
3 advisers who challenge their decisions.

4 So I always found them very supportive and they
5 were well aware of what I was doing. My monthly
6 reports are saying "We submitted a second complaint",
7 and, you know, "It will probably take three months,
8 here we go again", I'll put in another complaint
9 because they haven't done it properly, I am going to
10 refer it to the person's Member of Parliament to get
11 them to sort it out.

12 I can remember you know going through
13 a terrible stage from 2012 to about 2014/15, where
14 you'd win a case on employment support allowance
15 particularly and you'd win this at Tribunal maybe, or
16 get the DWP to revise the decision after you've
17 applied for a reconsideration, and then you'd find six
18 months later they're forcing the person to undergo yet
19 another assessment. So, of course, you know, I mean
20 I'd get on to it straight away and, you know, it
21 smacks of disability discrimination, actually, that
22 kind of behaviour, and I've made very, very strong
23 representations.

24 The charities knew I was doing that and they
25 supported me in it. The meetings we had with the DWP,

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1 you know, they heard some of the strong words I had to
2 say about the DWP's decision-making on benefit
3 entitlement and on dealing with the people who had not
4 declared their charity monies. I call it charity
5 monies just collectively.

6 Q. We'll certainly come and look at some of the detail of
7 both of those issues, continual assessments and
8 declaration of charity monies, a little bit later on.

9 You also tell us that you provided *pro bono*
10 advice to two registrants of the Skipton Fund but
11 there was no opportunity for you to take that any
12 further, is that right, because there was no mechanism
13 by which the Skipton Fund could pay for your services?

14 A. No, that's where not quite right. There were two
15 cases. I'm trying to think -- I think it was
16 Nick Fish phoned and said that -- this was before
17 Caxton was set up, that there were people who had some
18 benefit issues and he said there was nothing to -- you
19 know, there was no funds. I said "Don't worry, I'll
20 do it *pro bono*", and so I phoned them. I remember one
21 of them, I had several conversations to point them in
22 the right direction but, actually, they were both
23 cases where it wasn't necessary to do any ongoing
24 casework anyway.

25 If there was, I don't know how I may have done

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1 process so that I would send the invoice for my work
2 each month to the individual clients and those people
3 would then forward the invoice to EIBSS, but it just
4 fell apart as soon as it happened because some people
5 say they never received my invoices, some people sent
6 the invoices to EIBSS using a free post address that
7 they provided and it was never received and, in fact,
8 a few months later got returned to them, and some
9 people paid me direct and then sent the invoice onto
10 EIBSS. I mean, it was just a mess.

11 So I rang Chris Tempest and said "Look, this is
12 just not going to work", and so he said "Let me go and
13 have a word with my colleagues in contracting and
14 procurement", and it was then agreed that what I would
15 do would be I would send the invoice direct to EIBSS,
16 it would be an invoice on behalf of the people that
17 I'd helped, and that's worked pretty well. They pay
18 very quickly. It's a straightforward process now.

19 Q. Again, is there any limit on the assistance you can
20 provide to registrants of EIBSS, EIBSS registrants?

21 A. What do you mean "limit"?

22 Q. Will they pay for certain kinds of casework but not,
23 for example, advocacy at tribunals or the like?

24 A. No, no, they pay for advocacy at tribunals as well.

25 Q. You described that the transfer to EIBSS not being

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1 it.

2 Q. Then turning then to ask you some questions about the
3 arrangements with the English Infected Blood Support
4 Scheme and, indeed, the Scottish Infected Blood
5 Support Scheme, can you explain the arrangements that
6 you have with the English Infected Blood Support
7 Scheme? I understand you are not a contractor with
8 them. You contract directly with the registrant; is
9 that right?

10 A. Yes, sorry. Can I refer to them as "EIBSS" because
11 everyone does. Yes, it was a very difficult period in
12 this sort of transition from the charities to EIBSS,
13 and I was carrying out, if I remember correctly,
14 I think it was about 15 cases that were, you know,
15 they were, sort of, casework cases involving tribunals
16 and/or managing reconsiderations. A week before,
17 I had a call from a very helpful man called Mr Chris
18 Tempest in EIBSS and talked through what could happen.
19 He said that they didn't want to undertake a direct
20 contract with me and, in fact, I wouldn't want
21 a direct contract with them because my concern would
22 be it might affect my independence as an advocate
23 against the DWP.

24 So he said that I needed to have a contract
25 with people. They originally asked me to set up this

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1 straightforward, I think you say in your witness
2 statement there were teething problems. Did those
3 problems adversely affect any of the cases in your
4 case load?

5 A. No. I mean, I just carried on working on them because
6 that was the right thing to do but I did actually have
7 to say to them "Look, I can't carry on working on all
8 these cases, you know, without being paid". If it had
9 been one or two it probably wouldn't have been
10 a problem but, you know, it was a lot. Also, people
11 generally, beneficiaries, the community, needed to
12 know that I was still available. You know, I was
13 picking up feedback, people still wanted to be able to
14 use me.

15 So it didn't actually affect, if you like, the
16 operation of the work. It certainly, I know for some
17 people, it caused some anxiety because they didn't
18 know whether I was going to be able to continue on
19 their case. I suppose it's inevitable, really, when
20 you get -- set up a new organisation so it's never
21 going to be entirely smooth.

22 Q. As far as you are aware, again, did EIBSS -- if
23 somebody wants to use your services, there's
24 a registrant at EIBSS and they can and there's no cap
25 on how many people you can help or the kinds of people

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1 you can help?

2 A. No, if they are registered with EIBSS, that's it. The

3 only cap, to be honest, is my workload but I've not

4 yet had to say no.

5 Q. The Inquiry --

6 A. Sorry, just to say, I mean, I've had a couple of

7 people -- and it is literally two, maybe two or three,

8 or one or two -- really, really small numbers, where

9 people have asked me "Can you help me sort out

10 appealing against a decision by EIBSS that I don't

11 qualify for a payment", and, you know, it's not really

12 what I do, it's not my area of expertise so I have to

13 say "I'm very sorry, I don't", but, you know, I've

14 said to them, you know, do use the appeals procedure.

15 I had one gentleman who was struggling with

16 a stage 2 payment application because he had mental

17 health issues and his first language wasn't English,

18 and he had no-one else to help him complete the

19 paperwork, actually. He was on his own and very

20 isolated where he lived, so I -- he got quite a lot of

21 community hostility, so I completed that paperwork for

22 him and liaised with his haemophilia nurse.

23 Q. The Inquiry's received evidence to suggest that at

24 least one EIBSS registrant has asked EIBSS to pay your

25 bills that she's incurred, instructing you to help

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1 EIBSS also do say to people quite often --

2 I understand anyway that people will contact EIBSS and

3 say "Oh, I've got this problem with my benefits", and

4 I've certainly had cases where EIBSS have recommended

5 people contact me for help. I did have one person who

6 said the Inquiry had recommended me. I don't know if

7 that's true.

8 Q. Do you know what the criteria EIBSS use for advising

9 people to contact you?

10 A. To the best of my knowledge, it's simply that someone

11 needs benefits advice, welfare rights advice.

12 Q. And do you know what information EIBSS registrants are

13 given about your services; how they would know that

14 you exist and could help them?

15 A. I have asked them to put some information on their

16 website because it has that kind of sort of generic

17 comment that people go to Citizens' Advice Bureau and,

18 as I explained, that's not really very practical all

19 the time.

20 I think there's some information's gone out.

21 I've had contact with the Tainted Blood campaign, who

22 I get on well with, and I picked up very early on that

23 some people thought that I was no longer providing

24 service. And I'd have people contact me, and they

25 said, "Oh, I didn't know that we could still get your

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1 with benefits issues, and EIBSS have refused to pay

2 the bill. Do you know how that could have arisen?

3 A. I don't really know the criteria, other than -- am

4 I right in thinking that there's a gap in the

5 provision for -- I was going to say children, they are

6 not children they are adults now, but offspring of

7 people who were infected? I mean, I don't know the

8 rules and the criteria that they operate.

9 I am aware of that situation. It did happen in

10 another case. Circumstances were different, actually,

11 and I thought this is just so unjust to do this to

12 people. So I stuck my neck out and made very strong

13 representations to EIBSS, they really were quite

14 strong, and they did actually then agree to pay in

15 that case as a one-off.

16 I mean, I don't want to be critical of them

17 but, you know, I do think that's a deficiency, it's

18 a gap.

19 There's not that many people who would be

20 affected actually.

21 Q. But as far as you are aware, if somebody is

22 a registrant of EIBSS and you are able to take on

23 their case, EIBSS will pay for you to assist them with

24 benefits work?

25 A. Yes, that's my understanding, yes. Can I just say

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1 help." So I actually -- through Tainted Blood, I sent

2 out a message saying, "Look, I still exist, and I'm

3 able to help." And there's been a couple of occasions

4 I've put out similar messages. I don't know the

5 detail of what they do. They also -- I think

6 I noticed they mentioned it in their annual report.

7 Q. We looked at the feedback form that you give -- you

8 gave to the Caxton and Macfarlane Trust. What sort of

9 feedback do you give to EIBSS?

10 A. That's the same sort of stuff.

11 Q. Is it right -- I think it is right from what you said

12 that you don't at the moment provide any advice to any

13 registrants of either the Welsh Infected Blood Support

14 Scheme or the registrants of the Infected Blood

15 Payment Scheme for Northern Ireland?

16 A. No. I understand that in Wales, there is some

17 arrangement with some advice workers employed by the

18 Velindre NHS Trust. And Northern Ireland, I don't

19 know what happens. Northern Ireland, some of the

20 benefit rules are slightly different as well.

21 Scotland, they've just -- I was told -- I had a call

22 in August from an official there who said that they've

23 done a survey, and people had said they need access to

24 benefits advice and specifically mentioned me. So

25 they asked me to -- would I be willing to take

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1 referrals, so I said yes. As I say, it's quite
 2 recent. I've only had three from them.
 3 **Q.** And the arrangements there -- what are the
 4 arrangements there? Do you contract with individual
 5 registrants, or are you --
 6 **A.** It's slightly different. They ask me to -- I mean,
 7 they sent me a referral with some basic details --
 8 again, very, very basic details -- and then they said,
 9 "Just send us the invoice when you finish the work."
 10 **Q.** You mentioned --
 11 **A.** The cases I've had have not been very time-consuming
 12 so far actually.
 13 **Q.** You mentioned The Haemophilia Society had started
 14 recommending you to their members for benefits work.
 15 Do you have any kind of arrangement with them, that
 16 The Haemophilia Society will pay fees if you undertake
 17 work for their members?
 18 **A.** No. No. Well, there was one case. It was a very
 19 unusual case. It was not an infected blood case. It
 20 was not someone who had been infected. It was
 21 extremely complex, probably the most complex case
 22 I have ever, ever dealt with involving -- I don't want
 23 to say too much about it, really. But the DWP's
 24 tribunal submission was nearly a foot high, and they
 25 did contribute towards paying for that. In fact,

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1 So is this form something you would have
 2 received in respect of every client that you helped at
 3 the Caxton Foundation?
 4 **A.** The vast majority. I mean, I'm trying to think when
 5 this came in. Maybe it was 2012/2013. I mean, I had
 6 always understood that people had given verbal consent
 7 to -- you know, for me to communicate with the
 8 charity.
 9 I think it's also inherent in the fact that
 10 you've got people who were engaged with the charity on
 11 a long-term basis, on an ongoing basis, that
 12 information flows back and forth. And then,
 13 obviously, as a professional who's sort of working
 14 with the organisation, albeit I'm independent, it's
 15 sort of inherent that there will have to be that sort
 16 of exchange of information.
 17 That final paragraph, I really can't remember
 18 anyone coming to me who didn't give their consent.
 19 I wouldn't have done -- you know, I just wouldn't have
 20 done the work on the case. Maybe there was one or
 21 something, in which case I didn't do a report. But
 22 I remember when that was drafted sort of feeling a bit
 23 uncomfortable about that paragraph. But having said
 24 that, you know, I know that grant-making charities
 25 have those kind of restrictions and conditions, and

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1 actually, I've done a load of *pro bono* case work on
 2 that case as well. It's ongoing.
 3 **Q.** Soumik, can you turn up WITN3487006. I am going to
 4 ask you some questions about the consent process that
 5 you go through with your clients on sharing personal
 6 data.

7 So this is a form that you've provided to the
 8 Inquiry with your witness statement. This is the
 9 consent form, is it, from the Caxton Foundation which
 10 requires registrants to consent to two things at the
 11 bottom half of that page:

12 "I hereby confirm that I would like a referral
 13 to the benefits adviser. I consent to details about
 14 me and any family member being passed to the adviser
 15 by the Caxton Foundation and the Skipton Fund
 16 if applicable and necessary. And I consent to the
 17 adviser providing a report to the Caxton Foundation
 18 regarding the advice given to me and recommendations
 19 made."

20 Then it says:

21 "Please note, we will refer you to the benefits
 22 adviser without you giving us consent to receive
 23 a report and recommendations from them. However,
 24 without this information, it may be more difficult for
 25 us to assess the best way we can help you."

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1 a lot of them require people to maximise their
 2 benefits before they will give a grant. Or a lot of
 3 them, especially the smaller ones, require people to
 4 apply through a third party professional, be it a GP,
 5 social worker or whoever.
 6 **Q.** You said -- you just said that you felt uncomfortable
 7 about a paragraph. Was that the paragraph in brackets
 8 you felt uncomfortable about?
 9 **A.** Yes. If I remember correctly, and I may be wrong,
 10 I think I asked them to take it out or something. But
 11 then I could also see their point of view that, you
 12 know, knowing that someone's benefits had been
 13 maximised was useful information for them because it
 14 revealed people's poverty.

15 And the other thing is, there were people
 16 contacting both charities -- well, actually,
 17 particularly Caxton -- who said, "I've got no money to
 18 live on. Can you help me out?" You know, that type
 19 of request. And, quite rightly, they were referring
 20 people to me, you know, because a lot of the time,
 21 most of the time, I was able to sort out some benefits
 22 for them. And, I mean, they are still not going to be
 23 well off, but, you know, it keeps the wolf from the
 24 door a bit.

25 **SIR BRIAN LANGSTAFF:** This isn't really a question about

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you and your services but more about the way in which the Caxton Foundation was referring people or communicating with its own registrants.

The objection that I can see to the first paragraph and the piece in brackets is that it seems pretty pointless to say to someone, "Can you please consent. But, by the way, it doesn't matter if you do or not; we're going to do it."

The second observation, and by all means make a comment, is that it refers to somebody consenting details about me -- well, that's fine -- and any family members who one might have thought had the right to consent themselves to their information being passed on.

But these are not matters really for you to comment on unless you want to do so. It's more a matter of the relationship between the Caxton Foundation in this respect and the individual.

- A. Yes. I think the issue with family members is so odd because particularly so many people are having to claim means-tested benefits, people's partners and dependant children are aggregated into the benefit assessment, so you end up having to ask about partners' earnings. And sadly, actually, even you have to sometimes even ask, you know, if the

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Do I understand from your previous answer that in cases where there wasn't one of these forms, either because it was a client that you had before this form was generated or for some other reason, you didn't seek explicit consent to provide information to Caxton following the conclusion of your work?

- A. Well, no. As I say, my understanding was that verbal consent had been given for me to do that.

Q. Been given to you or to Caxton?

- A. Sorry, to -- the client had given verbal consent to Caxton for me to communicate with them about that.

Q. And did the Macfarlane Trust have a similar form to this, do you recall?

- A. It was -- as I recall, it was the same.

Q. And do you recall whether it came in at the same time?

- A. I think so, yes.

Q. And so, presumably, your answer about the assuming that there had been verbal consent between the benefit -- the registrant and Caxton Fund also applies equally to Macfarlane?

- A. Yes. Yes. I'm using it sort of interchangeably really, I think.

Q. Then just dealing with the position with EIBSS, can we have, please, Soumik, NBAT0000016. Again, this is a document that you have provided to the Inquiry. Is

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youngster's got capital in their own right, and occasionally it crops up; not with this group, though. But that's the benefit system. That's not me being intrusive.

SIR BRIAN LANGSTAFF: I don't suggest it is you at all.

A. Sorry?

SIR BRIAN LANGSTAFF: I don't suggest it is down to you at all. This is really more of an observation on the content of the form.

- A. No, I think it's a reasonable observation, Sir Brian.

I mean, one thing I would say: I think given much greater public awareness of privacy and data protection issues which has developed over the years, you know, it's easy to look back at arrangements that happened even maybe 10, 15 years ago and say, "Oh, that's not very good." Whereas now, you know, if you look at a website you have to agree to, you know, have cookies or whatever it is on your computer. And, you know, the whole thing of privacy and consent is much, much tighter these days than it was back in the day.

MS SCOTT: So if you have a client that had filled out one of these forms, for example, the second tick box, "I consent to the adviser providing a report to Caxton" clearly gives you explicit consent to share information with Caxton Foundation.

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this your form that you've generated for your clients?

- A. Yes. This is the current iteration of a consent form. It's much more specific, I accept. In the light of experience, and also following the GDPR, general data protection regulation, which was, what, I think three or four years ago I think it came into force -- I may be wrong on the date -- I think all organisations have reviewed their data protection and privacy arrangements.

The other thing that made me change this form and so on, the final -- where are we? The final sentence:

"Information will only be disclosed without my consent when it involves a risk to myself or the health and safety of a third party."

I think that's always been sort of implicit in what we do. I mean, for example, as I understand it, the professional conduct rules for solicitors state that, you know, if a client reveals information that places a third party at risk, then the normal confidentiality rules don't apply, and the solicitor can pass that information on.

I had one case in particular, it was child protection issues that arose, where the client disclosed to me that he had -- he had administered an

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illegal substance to his children in order to "calm them down". As an ex-social worker myself, and having done child protection work in the past, that obviously rang fairly major alarm bells, and I did speak to the social worker who -- there was already child protection involvement. The children were subsequently removed from the family and placed elsewhere.

Q. So this form:

"I give consent for Neil Bateman and Neil Bateman and Company to disclose any personal data about me to the NHSBSA ... they hold on me or about me [and equally the other way: they can disclose data to you]."

Would you -- for the three clients you have that are registrants of SIBSS, would you have had a similar form?

A. I've asked them to pull one together. They have operated on the basis of verbal consent, but I have actually asked, and they said they are going to.

Q. Soumik, you can take that down, thank you.

What proportion of your work is concerned with those infected and affected by contaminated blood?

A. Well, at the moment it's strange times, isn't it? So I wouldn't want to draw any conclusions from what

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of, general conversations. Occasionally, actually I'd get a call from Ros Riley who would say "Neil, this doesn't sound right that someone has had X, Y and Z happen to them", so you would have a conversation, explain it and obviously that's a learning exercise for that person, for Ros.

I wouldn't expect them necessarily to give benefits advice. I have to say that the benefits system has become increasingly dysfunctional and increasingly complex. When I started doing this work back as a law student in the 1970s, the handbooks I had were two little handbooks that were about that thick (*indicated*). Now, the books I have to use take up nearly 2-foot shelf space.

Q. Is this right, that you were not involved, in the main, in formulating policies for either Macfarlane Trust or the Caxton Foundation? I think there's one instance where you are asked to advise on a policy and I'll come back to that in due course but, in the main, you weren't -- well, you weren't involved in formulating policies although you might have been asked to give some advice in respect of policies; is that right?

A. Yes, that's basically it, as I've set out in my witness statement.

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happens at the moment. I did measure it back in 2017 and the work's just built up and built up because of welfare reform and very bad benefit decisions, and so it was about two-thirds then.

Q. Do you know whether Macfarlane Trust and Caxton Foundation employees, when those charities were operating, and EIBSS staff now are expected to provide some advice on benefits to their registrants?

A. I'm not aware. You'll have to ask them. I know that they do -- hang on, I know that they do give general advice that's reflected in the document, for example, it's on the EIBSS website about the way that payments from EIBSS are treated for social security purposes.

I don't know. You would have to ask other people.

Q. You haven't been asked to provide any training to staff in order to allow them to deliver advice on benefits from any of those organisations?

A. Not at EIBSS, no. I was asked to do some training for Caxton and Macfarlane staff by Martin Harvey, and then Martin was off sick and left and it never happened.

What I would say, though, is that, you know, obviously I've written quite a lot of information that's gone out to beneficiaries, in one form or another, and has been on their websites, and so on, and I've had, sort

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Q. Is that the same for EIBSS and SIBSS?

A. I had no involvement whatsoever in SIBSS. I don't even know how they -- what their policies are. EIBSS, I noticed on their website there was a form for applying for discretionary payment, and it had such horrendous mistakes on it. I mean, it was asking for details of benefits that don't even exist, I remember. So I did -- what did I do? I think I rang Chris Tempest and said, "Look, you really need to amend this", and I emailed -- if I remember correctly, I emailed him with suggested changes and then they did correct that. But I've had no involvement policy-wise.

I've had discussions with a couple of managers there about what can we do about this vexatious issue of people being asked to attend compliance interviews or interviews under caution about undeclared benefits. I think we've got some improvements done, in the sense they will turn out a standard letter to help people. But, other than that, I don't think that I recall any policy discussions.

Q. I am going to come on and ask you about that issue. Is it also right that you were not involved in making decisions about the support that could or should be given by those organisations, by the Macfarlane Trust,

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1 by the Caxton Foundation and now by EIBSS, and SIBSS
2 to their registrants?

3 A. No, I'm just, sort of, not interested at all and
4 wouldn't want to do it. As I've said in my witness
5 statement, the charities have their place and they
6 perform a valuable function in terms of filling gaps
7 in State provision, but having sat on various
8 committees in a previous life dealing with
9 applications for discretionary help, I feel very, very
10 uncomfortable -- I don't enjoy it at all. It's not
11 really what I want to do. I'd much rather be fighting
12 for people's rights.

13 Q. Is this also right, that the only circumstances in
14 which you have ever made a recommendation that support
15 should be provided to a client from one of those
16 organisations is when their benefits have been stopped
17 and you have been working to reinstate those benefits,
18 so you've made a recommendation to the relevant
19 charitable body, Macfarlane Trust, Caxton, that they
20 should have effectively plug the gap, make the
21 payments while that challenge is ongoing?

22 A. As I recall, they were all Caxton cases and,
23 obviously, one of the things you ask people when their
24 benefits are stopped is "Are you going to manage
25 okay?" and if they say no, then I'll say "Well, I'll

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1 relationship in order to help my clients.

2 Q. So then, having established the things you don't do,
3 if we can run down the things that you do -- the
4 services you do provide. Is this right: you have
5 provided advice on benefits and changes to the benefit
6 systems to the organisations as a whole, to
7 Macfarlane Trust and Caxton Foundation?

8 A. Yes. I attended some meetings. I would also,
9 actually -- I can remember phoning Jan Barlow and
10 Martin saying "Look, I'm really concerned what's
11 happening with this trend of cases, it's indicative of
12 a deeper problem", particularly with Jan, I remember
13 saying "Look, we're getting all these ridiculous
14 decisions refusing people Employment Support
15 Allowance, you know, we need to approach the DWP to
16 try to change that". I would write little, sort of,
17 newsletters and stuff which went out to people.

18 I remember going to a meeting of registrants in
19 Reading, in a hotel, a chain hotel, and spending
20 I don't know, two hours or whatever briefing them,
21 almost doing a mini-training session on the benefit
22 changes and answering their, sort of, questions and
23 having discussions with them.

24 Q. Do you recall attending any similar meetings for the
25 Caxton Foundation or for any of the other

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1 contact Caxton", and Caxton actually were very good at
2 that. They would get a decision turned around pretty
3 much immediately and also paying it out to people, if
4 they needed it.

5 The -- there were a couple of cases where
6 people were in real difficulty. I mean, there was one
7 that I'll never forget, this woman -- I think she was
8 a widow -- who was just drowning in debt and couldn't
9 afford the rent and had all sorts of difficulty with
10 her children and stuff, and I did, you know -- they
11 asked me to do a, sort of, more extensive report,
12 which was about a page setting that out. But I mean
13 I studiously -- I'll rephrase that.

14 I studiously kept clear of getting involved in
15 the sort of decision-making on discretionary payments.

16 Q. So you haven't ever assisted a client in challenging
17 a decision made by the Macfarlane Trust, the Caxton
18 Foundation or now EIBSS?

19 A. No, because, as I said earlier, it's not really my
20 area of expertise. I think the other thing is, it's
21 not so much with EIBSS because I am more distant from
22 them, but with Caxton and Macfarlane, I think
23 potentially, it could have created problems in the
24 working relationship and, you know, it's really
25 important to try to maintain a good working

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1 Alliance House organisations?

2 A. I've never had any involvement with the Eileen Trust.
3 I didn't really know very much about them, other than
4 Martin Harvey told me the group they supported and
5 that they were very small. I don't recall going to
6 any meetings with them. I used to send out
7 occasionally, from time to time, bits of information
8 particularly through Tainted Blood. I knew that could
9 get to people.

10 Q. Has the Macfarlane Trust or any other of the Alliance
11 House organisations ever asked you to provide a note
12 setting out the statutory framework for the benefits
13 disregard?

14 A. I certainly would have mentioned it to them and it
15 certainly came up at meetings with the DWP and,
16 I mean, it's just taken as read that the payments are
17 disregarded, so you don't -- a conversation with the
18 Macfarlane Trust -- I have a feeling I did draft
19 something. I remember, actually, one case where DWP
20 fraud investigators had obviously picked up that
21 someone was getting payments from Caxton or Macfarlane
22 or MFET, and written -- actually, no, two cases,
23 that's right, and they had written quite sort of
24 assertive letters to the charities demanding details
25 of the payments. One was a local authority fraud

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investigator, the other was DWP. So I can remember drafting a fairly strong but polite response for them to send, saying "We're not going to tell you because we don't have to tell you and, anyway, they are fully disregarded under this regulation, particular regulation", and that was the end of those two cases.

Q. Then you have mentioned that, is it right, to sort of rather crudely divide the sorts of work you do into two different cohorts, one is benefits check, which is effectively checking that the registrant is getting all the benefits that they should be getting, and the second is all the other work, dealing with any particular problem that the registrant has with their benefits in whatever -- the many different guises that those problems can arise?

A. Yes. So it could be -- yes, that's broadly so. I mean, you do a benefits check, which is a sort of assessment of their benefit entitlement, anything that they are perhaps not claiming. That may or may not reveal areas which need further work. In addition, like, for example, the consent form you put up from the registrant, you know, that's very clear that's casework from the off, his ESA had been stopped.

Q. Lastly, on sort of general points, is this right that the way that you work with people is through phone and

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4 o'clock.
Now, you are giving evidence. You must not talk to anyone about the evidence you have given or anything that you think you might yet be asked to explore in evidence. 4 o'clock.

(3.47 pm)

(A short break)

(4.00 pm)

SIR BRIAN LANGSTAFF: Yes, Ms Scott.

MS SCOTT: Before the break, I said I was going to ask you about the example of when you were asked to advise the Macfarlane Trust on welfare policy, and the time has arrived when I'm going to do that.

I'm going to do it, or start off by doing it without reference to the document that shows the actual policy itself, partly because the document's not terribly clear in working out what the policy is. But if you do need to see the document, then do let me know.

In December 2008, you wrote a letter to Martin Harvey at the Macfarlane Trust because he had asked you to advise on a proposed welfare policy, and that letter is at WITN3487008. Do you recall this?

A. Yes, I remember writing it.

Q. And so what seems to have happened is that a proposed

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presumably email contact, rather than face-to-face?

A. Yes. Having managed advice services, having carried out lots of reviews and audits of advice work, including work done by solicitors firms, home visits are very nice but they are immensely time-consuming, particularly bearing in mind that people are sort of scattered to the four corners of the United Kingdom. You know, it can take you all day or two days to do maybe one visit. So I work by telephone. Because of the pandemic, we'll be doing stuff like this on Zoom.

It's worked very effectively and I know lots of specialist level advisers who do work like that. I'm not unusual in any way. Obviously, if I do a Tribunal I would meet the client, I'd meet with them before the hearing as well.

MS SCOTT: Sir, I note the time. We've been going for about an hour and 20 minutes? I don't know if now is an appropriate time for a break.

SIR BRIAN LANGSTAFF: Yes, how much longer do you think you are going to be.

MS SCOTT: I think I am probably -- I have probably more than an hour of questions left, I would say.

SIR BRIAN LANGSTAFF: Right. Well, let's take a break now until 4 o'clock and allow people to have an afternoon cup of tea, if that's what they would like to do. So

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welfare policy seems to have been sent to you, and you have been asked to provide your comments on it; is that right?

A. Yes.

Q. And you set out your thoughts. You say:

"I think the proposed policy is very complicated ... is inevitable when one drafts a means test on to another means test, which is effectively what's happening here."

Were you there referring to the means test from the benefits system and then the Macfarlane Trust drafting their own means test on to the top of it?

A. I think this is revealing my problems typing. Drafts -- clearly, I think what I meant was "grafts" a means test on to another means test. And, yes, as a general principle, it's not a very good idea to have a separate means test for people who have already been means tested often to death by the DWP.

Q. So what the Macfarlane Trust seem to have been suggesting is that there should be a means-tested support for registrants. Is that how you recall the policy?

A. Yes. I mean, I've no longer got the policy, and I can't really remember -- I can't remember the detail of it, I'm sorry; it's a long time ago. But as you

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1 say, I also was concerned that they didn't seem to --
 2 it didn't take into account the costs of children and
 3 the costs of taking paid employment. And, you know,
 4 there's a substantial -- I mean, one of the things
 5 that should happen with any kind of means test,
 6 because it does inhibit people taking up paid work, is
 7 try to mitigate that as far as you can. And one way
 8 is sort of the costs of employment, travel, equipment,
 9 that kind of thing.

10 Q. You say there -- sorry. I interrupted you, sorry.

11 A. I was going to say, obviously, they were proposing
 12 sort of step payments, and the problem with step
 13 payments is that it creates a cliff edge effect for
 14 people. And we get this elsewhere -- we actually get
 15 this in places in the social security system, sort of
 16 a bit of all or nothing, and it creates terrible
 17 problems for folk.

18 And then I think if I remember correctly, I was
 19 proposing a sort of tapered process a bit similar to
 20 how you would have, say, in tax credits or housing
 21 benefit.

22 Q. Yes. If we go over the page, you suggest:

23 "An allowance would also be made to include
 24 rent, council tax, tax benefit not covered by housing
 25 and council tax benefit, and also mortgage interest

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1 A. No. No, because my focus on was people's social
 2 security benefit entitlement, not on the payments.
 3 I used to get -- you know, from time to time, I'd get
 4 grumbles from folk about Macfarlane payments, and, to
 5 be honest, I was never really able to distinguish
 6 whether they were referring to discretionary payment
 7 or one of the sort of regular payments that came in
 8 later.

9 Q. So your answer to my question was: no, you didn't see
 10 those things. But is the reason -- but the reason for
 11 that was: you simply weren't looking for that; that's
 12 not your concern; you were concerned with their
 13 benefits?

14 A. No, that's not true. You know, it's -- I have a lot
 15 of experience of negotiating with organisations, local
 16 authorities the DWP, and I've negotiated I think with
 17 four secretaries of state and probably about nine
 18 junior ministers over the years. And, you know, we
 19 make these points continually about the way things
 20 could be better, and you just accept that, "Oh, I've
 21 made the point. I've made the case. Win some, lose
 22 some." And, you know, I just accepted that, you know,
 23 my -- they didn't accept my view. That's their
 24 prerogative.

25 Q. I'm now going to ask you about the work you did with

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1 payments ... any remaining ('excess') income after the
 2 above deductions would then be multiplied by
 3 36 per cent and the sum deducted from the maximum
 4 payment. This is known as a tapering
 5 calculation ... mirrors that used for tax credits."

6 A. I'm just trying to think. I think the 36 per cent,
 7 there may have been some research evidence at the
 8 time -- when was this? 2008. Yes -- from the -- what
 9 was it -- the Centre for Social Justice who came up
 10 with the original proposal for Universal Credit,
 11 although it wasn't called that at the time, and
 12 I think that was the taper that they had worked out
 13 through research and number crunching to be the sort
 14 of optimum one for means testing -- means-tested
 15 benefit. I may be wrong on that. That's kind of what
 16 I can roughly recall.

17 Q. The Inquiry's aware because it has got the
 18 documentation and has heard evidence from witnesses
 19 over the last few weeks that the Macfarlane Trust did,
 20 in fact, put in a banded means test welfare policy.

21 Do you recall whether the concerns that you
 22 were expressing in this letter creates poverty traps
 23 and, as you say, a cliff edge? Did you see that the
 24 result -- did you see that with your clients as
 25 a result of that policy; can you recall?

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1 the Macfarlane Trust around the introduction of the
 2 ESA.

3 Can we have, please, Soumik, MACF0000090_006.
 4 So the events I'm talking about here took place in the
 5 summer of 2008, and I'm showing you here an email
 6 dated 7 August 2008 from you to Martin Harvey, and it
 7 says:

8 "Martin. A few thoughts: on a political level,
 9 I think it's very important for organisations to be
 10 lobbying now to point out the various shortcomings
 11 about ESA."

12 You say the department:

13 "DWP/Government is locked in a fixed view that
 14 loads of people on IB could work if only their
 15 over-sympathetic GPs would stop signing them off."

16 And then make some other comments about the
 17 labour market and so on.

18 Then skipping down to the -- missing out the
 19 next paragraph, down to:

20 "Many of us are also very concerned at the
 21 dreadful level of service already provided by the DWP
 22 to customers, and how their staff already often
 23 display a remarkable lack of understanding and even
 24 sympathy towards people with long-term health
 25 problems. I am not at all confident at DWP's ability

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1 to manage the new system in a realistic and empathetic
2 way."

3 And I'm going to come on to ask you some
4 further questions in relation to that.

5 And then:

6 "I think there's a historical political
7 dimension for Government -- the problems associated
8 with contaminated blood products resulted in
9 a commitment by successive governments to compensate
10 those affected by various means, including passporting
11 those with AIDS-related conditions through the current
12 IB assessment. This Government has broken that
13 consensus, and many people will view that as a breach
14 of trust.

15 "I don't think concurrent DWP ministers have
16 been adequately briefed about the history of the
17 Macfarlane Trust and the scale of the damage caused
18 ultimately by Government-funded use of contaminated
19 blood. The Government is very quick to respond when
20 it's perceived as being harsh on the poor and
21 vulnerable and may respond to some high-profile
22 lobbying and publicity on this."

23 So just pausing there. How would you form the
24 impression that current DWP ministers were not
25 adequately briefed about the Macfarlane Trust?

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1 organisation to work with and to lobby. Very
2 difficult. They are very introspective and arrogant
3 sometimes. I mean, there are some very fine civil
4 servants working for them, very nice people, but it's
5 very difficult to influence them, and it's very
6 difficult to get at the minister. You know, there are
7 layers and layers of civil servants to have to work
8 your way through. The communication civil servants
9 will always -- you know, their office is right next --
10 I know this because I worked within the DWP in quite a
11 senior position on secondment. The communications
12 officials had their office right next to the
13 minister's. Would be advising, "No, we don't think
14 you should meet with this group because they might be
15 critical of the department or of your policy," and so
16 on. Or, "Yes, you should meet with these people.
17 They could be helpful."

18 So it's very, very -- it's -- you know, I think
19 I'm kind of -- I think that email's probably a little
20 bit of a -- kind of a bit of a sort of -- what's the
21 word -- stream of consciousness, attempting to try to
22 get something done.

23 As I recall, the outcome of it was that we
24 actually had a meeting with the then Chief Medical
25 Officer at the DWP who was responsible for ESA policy,

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1 A. Well -- sorry, what is the date? 2008. I mean, at
2 the time, I was involved -- I was a member of the
3 DWP's policy and strategy forum. That's
4 a consultative body that they used to have with the
5 advice sector, and I was there as a representative of
6 the National Association of Welfare Rights Advisers.
7 And we had, you know, I say "consultation"; it usually
8 consisted of them telling us stuff that they were
9 going to do.

10 We had presentations repeatedly from DWP
11 officials basically saying, "This is how it's going to
12 be. This is what's going to happen." I had no
13 indication that there was any understanding within
14 the -- amongst DWP ministers that they were aware of
15 the impact on the community. I can remember raising
16 it at these consultative meetings because, obviously,
17 the minutes of the meeting actually do get passed up
18 to ministers; I know that.

19 It was a very, very difficult time because the
20 then Labour Government was pushing through ESA which
21 would have quite clearly had and did have a very
22 detrimental effect on the infected blood community.
23 And we were trying to work out ways to get DWP to
24 mitigate that in some way.

25 I have to say that DWP are a very difficult

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1 or for the medical side of it, together with a deputy,
2 Dr James Bolton, who I maintained contact with over
3 the years. I'm sorry, it's a very long-winded answer,
4 that. I'm sorry about that.

5 Q. When you suggested high-profile lobbying, I mean,
6 you've said that it's difficult to lobby the DWP, but
7 what did you have in mind?

8 A. I didn't have anything specific in mind.

9 I mean, the other thing I would say is that all
10 governments can become highly defensive about
11 criticism. I'll never forget in 1998, the DWP
12 implemented something called BIP, the Benefit
13 Integrity Programme, which was a programme of spot
14 checks on people getting Disability Living Allowance.
15 And it was having catastrophic consequences for
16 people; their benefits were being suspended and all
17 sorts of things. And some disability activists went
18 and held a protest outside the gates to 10 Downing
19 Street and scattered red paint all over the ground and
20 over themselves, and they were obviously arrested and
21 so on. But I know that as a result of that, because
22 I was told when I was at DWP -- and I'm not breaking
23 any rules because I never signed the Official Secrets
24 Act. I was told that the Secretary of State had given
25 instructions that because of that, there were to be no

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meetings with the disability lobby, as they called it, and that -- well, no ministerial meetings -- and that officials needed to be ultra careful.

I can think of several instances like that when I was there. It was a real insight into how they operate of, you know, not wanting to have lobby groups given an opportunity. I mean -- sorry, I'll give you another example.

There was a leaflet which I was largely responsible for writing when I was at DWP which was for pensioners and was about entitlement to the income support that they could then get and the higher rates they could get, and it was to encourage take-up of the benefit by older people, poorer older people. There was to be a launch of it, and I wrote this memo suggesting it would be good to have some advice agencies there.

Anyway, this memo found its way up to the Secretary of State. I'll never forget the communications officials emailed the Secretary of State and said, "We don't think this is a good idea because they might use it as an opportunity to criticise the Department." And this was actually particular Age Concern they were referring to, and which was actually very unfair on its own terms. So

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because it's the right thing to do, and the press has run a story, it's been picked up by, you know, other media and, you know, Government has quietly backed down.

But I have to say, it's always been on the fringes, on the margins, you know. You know, you had a Government that was pressing ahead with implementing ESA. They wanted to reduce the numbers by 30 per cent, I have an email from the DWP's former chief economist stating that, and I challenged him about it at a meeting and he emailed me afterwards explaining the rationale, and there was enormous pressure on Government.

I'm just looking at it objectively. There was enormous pressure on Government from, particularly, the sort of tabloid press who kept going on about, you know, these people were swinging the lead, all these people on incapacity benefit, you know, they could get jobs and, you know, then they'd highlight some fraud case of someone who had been and -- you know, working while they were claiming, "That proves it", you know, "You need to crack down on these people". There was all that kind of noise going on and, indeed, it continued for quite a few years afterwards under the Coalition Government.

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the launch went ahead with no advisers, no advice agencies there.

So that's what you are dealing with. It's very, very difficult, and I wasn't really clear how we could do it, but what we ended up doing -- I mean, I had several conversations with Martin over the phone about what we were going to do because, clearly, ESA was going to have a really, really bad effect on people, and sadly I've been proved right.

Q. What you are suggesting here is that, in fact, the Government is quick to respond when it's perceived to be harsh on the poor and the vulnerable and that there is a role for Macfarlane Trust to lobby and make the case to the DWP who seem, at that stage, to be unaware of the impact that their policies are going to have.

So at least to that extent, whether one calls that high-profile lobbying or providing information, you clearly thought that there was a role for the Macfarlane Trust; is that correct?

A. Yes, but it would have to be something like going to the press with a real, you know, shock story and, you know, in my time, I have done that on several occasions where, you know, I've discovered things that the DWP was proposing and I've taken it to the press, you know, and really stuck my neck out for people

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Q. Moving down the email, sorry, Soumik, can we have that back up MACF0000090_006 the next paragraph you say:

"I also think that registrants would welcome lobbying by MFT on this -- the ones I have dealt with have all [had] bad experiences with DWP and I think it is important for MFT to be seen to be protecting their interests."

Did that comment -- was that a general comment made or did that come because you sensed that, actually, the registrants were unhappy or there was some disquiet about the way that Macfarlane Trust were fighting their corner with Government?

A. It's just about, you know, we've got to challenge this it's in the interests of our community, of our registrants. I know that they would welcome us doing something or Macfarlane doing something, and I thought it would demonstrate to registrants that they were not alone, that Macfarlane was, you know, standing up for their rights and trying to protect their interests in the face of, you know, a tsunami of benefit change.

Q. Then in the next paragraph, you say:

"So in a nutshell, I don't think there will be any change from lobbying for social treatment for registrants within the policy terms of ESA and the statistically biased view that work is the best cure

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for illness. But one might be able to embarrass the government into some minor changes. It will also improve the MFT's good standing with registrants."

Now, we'll come on to look at the meeting that arose after this email but are you aware of any actions taken by the Macfarlane Trust that would amount to embarrassing the Government, trying to put some political pressure on them to get the Government to back down because they would be seen as harsh on the poor and the vulnerable?

- A. I am aware that they certainly raised it with Department of Health officials. Obviously, there would be a read across from quite senior level within the Department of Health as well as to the DWP. I know from past experience, not dealing with this community, that that can be effective in -- around the margins, and Government tends to make its decisions in very silo-approached -- silo-based approach decision-making and policy making. So you can -- you know, if you can get someone to cut across that, it can sometimes be effective. But usually it's on the same minor changes.

I have some vague recollection of it being raised politically but I can't be specific, and I know Jan Barlow also did raise it with the Department of

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So one of the issues that you identified in that previous email that the DWP is under-briefed on the Macfarlane Trust, this meeting was there to address that, in part, was it?

- A. Yes. I mean, bearing in mind you are talking to very senior civil servants, both of those two, and it was -- it wasn't a tense meeting, you know, unlike many I've been at with the DWP, and it was a very good opportunity to try to get the case across. I thought actually Martin did make the case really, really well. The minutes don't actually reflect -- I have a strong recollection of him really laying down, you know, what the circumstances were and, you know, I remember him, you know, talking about people who were co-infected and, you know, the terrible, horrible death rate from hepatitis C.

You know, I think we did make as good a case as we could.

Having said that, loads and loads of organisations in the disability world and the voluntary world, the Legal Action Group, the Law Centres Federation, as I recall the Child Poverty Action Group, Disability Alliance, as was, Citizens' Advice nationally, you know, all to a person, all to an organisation were making the case around "Look,

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Health. I spoke to her about that.

- Q. Some years later, would that have been?

A. Yes. It's just a horrible era of, you know, endless cases, it felt like, with people having their benefits stopped, being told they were fit for work, people being assessed for ESA, re-assessed for treatment, horrible, really awful actually, when I look back it makes me want to weep.

- Q. So then we come to the meeting in September 2008 that you have mentioned on a few occasions, it's MACF0000127_057.

This is a minute of a meeting between the MFT and the DWP. Is this the meeting that you're referring to, 11 September --

- A. Yes, this is with Moira Henderson, yes.

- Q. The purpose of the meeting is set out there:

"... to discuss the soon to be implemented Employment and Support Allowance ... which will be replacing Incapacity Benefit and Income Support paid on incapacity grounds for new customers from 27 October 2008 and, more specifically, how it will affect [Macfarlane's] beneficiaries in the future. It was also intended to raise awareness of this cohort amongst DWP staff so that they are recognised when being reviewed for ESA."

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you've got to be more sensitive to the needs of our group of people", you know, be it people with schizophrenia or people with this disease or that disease, or that condition, you know, and we were sort of *(unclear: audio distortion)* in the draft guidance that we saw, and everybody -- we were all doing -- lots of us were doing it and we were making very little progress. They just weren't listening. It was ploughing ahead with the introduction of ESA.

As I say, it was a very -- you know, looking back, a pretty depressing period.

- Q. Then we can see the next paragraph down Martin Harvey making the case for Macfarlane Trust and then the paragraph after that Martin Harvey offering further information from Dr Mark Winter to make presentation to those responsible for assessing ESA claims, so that they could show the special difficulties that the Macfarlane Trust beneficiaries face. That invitation was declined on the basis that the purpose of ESA is to individually assess somebody's functionality and capability to work.

So there you have got the Department of Work and Pensions saying "No, thanks very much, we don't need your help".

Then over the page --

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1 A. I have to say that's right and, you know, tragically,
2 you know, if I had a pound for every time I've seen
3 that response, you know, it would be good.

4 Q. Then over the page we have, on the last paragraph
5 before the bullet points:
6 "Martin concluded by stating that although he
7 understood [Macfarlane] beneficiaries could not
8 receive a blanket exemption from assessment, as with
9 the DLA ..."

10 So that was something that had been flagged up
11 and had been rejected, was it?

12 A. Mmm.

13 Q. "... he hoped that their plight and unique combination
14 of medical conditions would be flagged up to medical
15 assessors and taken into account when they make their
16 assessment. Neil requested that something be put on
17 the DWP intranet about the history of the [Macfarlane
18 Trust] for staff reference purposes and Moira and
19 James agreed that it could."

20 Then you can see from the action points that
21 a history of the Macfarlane Trust was going to be
22 provided with a hyperlink to the benefits waiver
23 letter and that would be placed on the DWP intranet
24 where medical assessors would have access to it and
25 the Macfarlane Trust would be provided with a copy of

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1 So lots of Macfarlane registrants at the time,
2 and indeed Caxton ones who came on board later, would
3 have simply just been passported through the
4 assessment for Incapacity Benefit. But Government was
5 very, very clear. They thought that was being abused,
6 that sort of passporting process. They thought if
7 everybody was assessed using this new assessment that
8 was in some way work-focused it would help people move
9 into employment and it would, you know, enable the
10 numbers to be reduced by 30 per cent.

11 The reality, what happened very few of them
12 moved into work. Large numbers just had their
13 benefits stopped and, of course, it wasn't helped by
14 the fact that in 2008 you have the financial crisis
15 and the labour market became a far more insecure
16 place.

17 Q. So you have raised in various documents that you
18 provided to the Inquiry some of the problems with the
19 assessments, the poor quality of the assessments
20 carried out by the DWP and private companies that they
21 contract with for the registrants of the -- now the
22 new schemes.

23 Can you just outline to us some of the problems
24 that you have come across.

25 A. Where do you want to begin? The people with

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1 the ESA handbook, and you would provide information on
2 ESA to be put on the Macfarlane Trust website, and
3 then brief notes from Nick Fish.

4 So that was the end of that particular
5 interaction with the DWP at that stage, was it?

6 A. No, because it continued -- sorry, can I just clarify
7 the "blanket exemption from assessment as with DLA",
8 some people thought there was there; there actually
9 wasn't. There was some guidance which, to be honest,
10 I'm never seen but certainly, as a matter of law,
11 there was no passporting.

12 Can I just add at this point, one of the
13 reasons we're very concerned about Employment Support
14 Allowance was that, under the old system for
15 Incapacity Benefit or the assessment they did for
16 Income Support for people who didn't qualify for
17 Incapacity Benefit, there was a whole series of
18 passporting arrangements, fairly lengthy list,
19 actually, and it included people who had
20 an AIDS-related illness, it included people with
21 severe mental impairment, it included people with
22 severe mental illness, it included people with
23 poly-arthritis. There was a whole range of groups,
24 people on the highest rate DLA care component at the
25 time.

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1 haemophilia, particularly severe haemophilia and
2 haemarthropathy, you know, the aggressive and painful
3 form of osteoarthritis caused by bleeds into joints;
4 typically into ankles and/or knees, a fairly
5 consistent failure to it assess whether they can walk
6 50 metres without significant discomfort. That's one
7 of the criteria to get through the assessment.

8 As I said in my memo to the House of Commons
9 Select Committee drawing upon my experiences with the
10 community, failure to take account of the
11 psychological impact of infected blood and the stigma
12 attached to it. The fact that a lot of people have
13 repeatedly told me how, you know, they don't like
14 telling their friends. They -- just this week,
15 I dealt with someone who still hasn't told their
16 parents. Just endless cases of very bad
17 decision-making.

18 I mean, one chap I remember with very severe
19 and actually somewhat unstable HIV in the early days,
20 he was assessed -- he was found fit for work. Apart
21 from the fact his elbow actually didn't have much
22 flexion (*unclear: audio distortion*) because of the
23 haemarthropathy. One of the points that we made was
24 that in a workplace, he couldn't actually do his
25 Factor VIII injections because, as you know, it's

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quite an involved process involving in intravenous injection. The response from the DWP and from their medical assessor was, "Oh, well, if he has a bleed when he's at work, he can just go aside and quickly inject himself." You know, they thought -- it was almost as if they thought it was a sort of intra-dermal insulin injection.

What other ones? People being told to use wheelchairs because that's part of the criteria for assessing whether someone can walk 50 metres without severe discomfort. And we'd have to point out: no, they can't use a wheelchair because their elbows are damaged, or it will trigger a bleed into their elbows. Horrible cases. Sorry. It goes on and on. I can talk about this all day.

Q. What about -- have you had experience of assessments being carried out by people who don't even have basic understanding of haemophilia?

A. Oh, yes.

Q. And assessors who have little knowledge --

SIR BRIAN LANGSTAFF: I think that goes down as "definite yes" on the transcript.

A. Yes, definitely.

MS SCOTT: Experience of assessors with little knowledge of the impact of HIV, and in particular the impact of

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wouldn't even get past -- I've said in this tribunal submissions that, you know, it wouldn't even come up to scratch for GCSE psychology. It's based on simple observations of whether someone has good eye contact. Are they trembling? Well, you know, very few people do tremble unless they're highly anxious or they are on some sort of major anti-psychotic medication or they have got a neurological disorder, for example. You know, what's their eye contact like?

So we get these sort of, you know, really woefully inaccurate -- and groups like Mind, Sane and many others have repeatedly expressed concerns to the DWP in consultative groups, in meetings with ministers *ad nauseam* about the inadequacy of the mental health assessment.

There's apparently been some improvements after a while at Atos, the company that do the assessments who have the contract to do them. They introduced what they call mental health champions, but I have to say, from my experience, I couldn't see any evidence of that having an impact.

A large part of the problem is that the health professionals that they decided to use -- I think when I was at DWP I was told that was to save money, but I may be wrong, but the health professionals -- there

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having lived with HIV for many years before modern treatment.

A. Absolutely. I think the problem with HIV, from a benefits perspective, is because treatments have moved on so much that people who are not familiar with it can think, "Oh, it's easy. They're just on their medication. That will be fine."

Q. What about a knowledge and understanding of the experience of widows but other family members who have had -- who have cared for many years for partners seriously ill with HIV and then have to suffer bereavement. Has there been an understanding of their experience and the impact that has on their ability to work?

A. In my -- I am sure the DWP would dispute what I'm saying. You know, you would have to ask them. It is a fact that us advisers, we get a slightly skewed view because we see the problems, you know.

But as regards, you know, widows, former partners, survivors, often the impact is psychological, and often very, very significant psychological impact.

The assessments that are done of people's mental health difficulties for ESA, in my view, are facile, almost laughable. You know, I mean, they

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are very few doctors. The evidence given to the House of Commons Select Committee inquiry on ESA and PIP assessments, I think it revealed there were three doctors employed by each -- by the two assessment companies.

A lot of them are general nurses, and all due respect to general nurses, you know, they are not skilled at identifying mental health issues. Paramedics who are great at assessing crisis situations but may not have the knowledge to, you know, to do functional assessments.

I mean, I've just raised this, as I say, *ad nauseam* all the time in appeals. One of the things I do is I look up what the registration status is of the health professional, and, you know, it's often quite revealing.

Q. You have spoken in your --

A. Sorry. I'm giving very long answers, and I'm sorry about that, but, you know, it's a subject I feel passionately about and it's a real cause of injustice to this community who have already suffered enough.

Q. You have spoken in your evidence today and in your written evidence and the documents you have provided to the Inquiry about the real concern that you have about the repeated assessments that this community

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1 have been subjected to as a result of ESA and PIP.

2 Can you tell us what the impact is that you see
3 on this community of being subject to repeated
4 assessments by someone often who doesn't understand
5 the issues that they face and as a result of which
6 their benefits may be stopped.

7 A. Well, it's -- as I said in my witness statement,
8 I think I use the words, not necessarily in this
9 order, sort of disbelief, anger and anguish, not to
10 mention the financial -- I mean, just a few weeks ago,
11 I had a call from a chap. You know, unfortunately, he
12 had done his own PIP self-assessment form, and they
13 took away his enhanced rate mobility component, even
14 though he had had that for years. Somehow, he had
15 improved. He said to me, "The consequence of that,
16 you know, means that I cannot take my daughter to
17 school." And it was just terrible. Terrible.

18 And to be repeatedly assessed -- you know, what
19 I am seeing, and I have raised it within the DWP even
20 just actually this week yet again, is people who have
21 been awarded the enhanced rates of both components of
22 PIP -- as you probably know, PIP has two components
23 paid at one of two rates. You know, they're awarded
24 it, you know, two years, four years, five years, when
25 really what should happen is that they should be put

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1 of getting people off any further assessments. It was
2 announced by Damian Green when he was Secretary of
3 State for work and pensions at the Conservative Party
4 conference. And they introduced that, but the
5 criteria are really quite strict. I'm not sure how
6 thoroughly it's been implemented anyway. I did give
7 some figures of very, very low numbers.

8 I mean, often people don't know whether they
9 have been covered by that guidance. And, as I say,
10 it's not even an appealable decision, so you end up
11 having to make a complaint. The DWP say it's
12 not a service failure, so we're not going to deal with
13 your complaint. I escalate it to stage 2 or to the
14 independent case examiner, and, you know, they either
15 do or don't uphold that point. Rather perversely,
16 I found actually submitting a mandatory
17 reconsideration seems to get that changed. But, you
18 know, it's hard graft. Shouldn't be having to do this
19 to get people to avoid people being reassessed, but it
20 seems to be an ongoing problem.

21 As I say, the impact on people is pretty
22 massive, really massive. And at the end of the day,
23 it's a waste of the DWP's time, and it's a waste of
24 public money paying the assessors to reassess people.

25 Q. You have told us in your witness statement that you

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1 on -- awarded it on an ongoing basis where they then
2 have -- the DWP carries out what's known as
3 a light-touch review after ten years.

4 In the case of ESA, I had situations where
5 people were getting very short periods of assessment.
6 I challenged that. The problem with challenging the
7 period of assessment for ESA, it's not actually an
8 appealable decision. It doesn't actually form part of
9 the decision. It's an administrative decision as to
10 when somebody should be reassessed, based very often
11 on the recommendation of the contractor who's carried
12 out the assessment.

13 And I think it's still the case now -- I may be
14 wrong, so I would be happy to be corrected -- that the
15 DWP's computer was incapable of awarding ESA for more
16 than three years. So people would be awarded ESA,
17 even though their condition is not going to improve.
18 If anything, it's going to deteriorate. These are
19 long-term deteriorating conditions.

20 So -- and I mounted a couple of challenges to
21 that over the years; one case sort of threatening
22 judicial review. The situation slightly improved with
23 the -- sorry, I can't remember the date; it's in my
24 witness statement -- where they introduced this thing
25 called the Severe Conditions Guidance which was a way

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1 were instrumental in getting the DWP to carry out
2 a review of cases of people with haemophilia who were
3 refused --

4 A. Did I use the word "instrumental"?

5 Q. I think you did, yes.

6 A. Did I? I don't think so.

7 Q. I'll check that.

8 A. It was the word --

9 Q. But you were involved in -- can I put that I way,
10 then, while I just check that -- getting the DWP to
11 carry out a review of cases of people with haemophilia
12 who were refused PIP.

13 Is this right, that a systemic problem with how
14 the functional needs of people with haemophilia were
15 assessed by PIP was discovered, and they decided to
16 review 410 cases. And 62 per cent of those cases that
17 they reviewed were awarded PIP or a higher rate of
18 PIP, and so the average case received an average of
19 more than £5,000 of back payments. Is that what
20 happened as a result of that review?

21 A. Yes. A working party was set up with various campaign
22 groups, and I heard about it. I'm trying to think
23 who. It was someone in one of the campaign groups
24 told me. I said, "Could I join that, please?" And
25 I said, "Actually, you know I've got a lot of

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experience of this." But I was told there was some objections from one or two individuals who didn't see me as independent, which was unfortunate. But I did feed in to that review to my contacts. I also submitted some written questions at one point.

Q. I've just checked --

A. I also spoke to Dr Clare Leris at the DWP who is the sort of senior medical adviser on PIP, and I gave her lots of examples, and I sort of pointed to the appeal success rate I was having. And, of course, it does take a while for you to identify a pattern when a new benefit comes in.

Q. As a result of that review, is this correct, that new guidelines were provided to assessors?

A. Yes.

Q. -- carrying out these assessments? Have you noticed a difference? Have things been better since the new guidelines?

A. Yes. Things -- yes, to be fair, things are better, but, again, maybe it's my skewed view of customers.

You know, I'm still coming across cases where there are bad decisions made. And there was one I had to have a tribunal hearing about last year. It was clearly wrong. I sent it to the -- I used the disputes procedure and the appeals procedure and also

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Can I just tell you about this case in Scotland that's just occurred to me, you know, it was a man, one of the infected blood community, and the fragility of his haemophilia was such that he gave the example of standing on a dog biscuit at home and that triggered a bleed into his ankle, and from the waiting room to the Tribunal, which was about 15 yards, if that, he had to stop, I remember, because of the pain.

There's another case, again in Scotland, where the chap had gone to his assessment and he decided he would look smart, so he got in a suit and in the assessment report it said he was casually dressed. Okay, that may not be material but it's indicative of the poor quality.

Q. I'm going to ask you some questions now about, again something you mentioned several times in your evidence, the difficulty that many registrants face in terms of the cross-matching, data-matching exercises undertaken by the DWP for those on benefits as part of their fraud investigations, and the fact that, because payments from previously the Alliance House organisations and now the new schemes are disregarded for benefits but will show up when those data-matching exercises are undertaken, they are often or can often be interviewed under caution to it investigate whether

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raised it actually with Dr Leris, and she got someone to review it, and they came back and said they thought their assessment was correct.

What then happened at the tribunal -- it was a telephone hearing, as has been happening with the first tier tribunals since last March, I set the client up, briefed him on what to do, what to expect. I then was in my office here. I had a phone call from judge, the tribunal judge, who said, "Mr Bateman, I just want to tell you we've looked at the papers, and we've decided your client's entitled to the enhanced rate of both components. There's no need for us to have a hearing." You kind of wonder why they refused them in the first place.

Q. Are you able to assist at all with experiences of assessments in Wales, Scotland and Northern Ireland?

A. Just the same. I don't know about Northern Ireland because they -- PIP didn't come until quite later because there were all the political problems around the Northern Ireland assembly, and so they didn't really have a functioning Government, so the PIP came in much more recently. And the tribunal procedure, or the tribunal process in Northern Ireland, also seems to be slightly different. But, yes, it's the same pattern in Scotland and in Wales.

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or not they are fraudulently claiming benefits.

First of all, in your witness statement you indicate that, in discussion with Martin Harvey, he estimated that about 50 registrants that he knew of had been interviewed under caution. Are you able to give us any assistance as to how common this problem is in the registrant community?

A. It's -- well, since the pandemic, the DWP have had to redeploy staff to deal with the 3 million new Universal Credit claims that they have had. They have also had, I think, 10 per cent of their staff either sick or self-isolating, so they -- I wouldn't say they've stopped, probably not right for me to say, but they have really reined in on compliance and fraud investigation work, so I've not had very much. I think, actually, I've had two cases since last March.

Before then, it was -- and certainly I noticed when I started doing the work, it seemed to be a sort of fairly regular flow, trickle, not a flood, you know, a bit like a leaking roof and, you know, sometimes it was like one a month, two a month, then you would go a couple of months, several months without anything. So it's been quite an ongoing issue and it's -- I've described it as vexatious. I think

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the other thing about it, even though the numbers, as a proportion of the community may not be massive, it's the fear that that generates amongst people and the anxiety that at any time they could be interviewed under caution.

Most of the interviews, actually, are not fraud -- you know, not interviews under caution under the Police and Criminal Evidence Act, carried out by a fraud investigator. They are actually compliance interviews but compliance interviews can lead to a referral to the Fraud Investigation Service.

Q. Are you aware of anyone that's been prosecuted from the community in relation to this?

A. Not that I've dealt with. People whose benefits have been stopped and I got them started again pretty quickly, yes, I'd say their benefits had been suspended, but I'm not aware of anyone who has actually been prosecuted for benefit fraud in relation to non-declaration of Macfarlane or Caxton Fund monies. If there is anyone out there, you know, then you need to deal with it because that clearly would be a miscarriage of justice if they were convicted.

The benefit fraud prosecutions I have dealt with amongst this community, I think there's about three or four, have all been disability

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then have powers under the Social Security Administration Act 1992 to make the bank or building society produce details of the account where the money is in and copies of the bank statements. That's fairly routine stuff that they do.

In the past registrants were told there was an administrative easement that the DWP brought in well before I was ever involved -- it goes back in the sands of time -- they were told they didn't have to declare that money to the DWP. In the case of Housing Benefit and Council Tax Benefit it was actually written into the regulations. So people didn't, you know, tell, it was -- I think the reason being the fear of leaking out information about their HIV status.

So that means that people often kept their Skipton money or Macfarlane money or the initial payment, which I think they had, in a separate account, and so it gets picked up.

Unfortunately, some people have mixed up, quite understandably, it's quite a reasonable thing to do -- have combined their, say, charity money with other money that they have got and that can get picked up on a data match, and I certainly have dealt with a few cases, one in particular, a very harrowing case of

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benefit-related ones.

Q. Your advice to registrants, is this right, has been to declare to the DWP the payments that they receive from the schemes and to keep those payments separately in a separate account from the benefits that they receive, even though prior to November 2017 there was no obligation to disclose that information; is that correct?

A. I'm really sorry, do you mind if I give another long answer?

Q. No, it's your evidence.

A. But I hope it will help the Inquiry. Shall I just start by explaining how the data matching works? It's a major part of the DWP's anti-abuse, anti-fraud activity because you do get people who have under declared, and they've got capital for means-tested benefits and, you know, don't disclose that they have got a bank account with money in it, and there's a process of them carrying out a data match with Her Majesty's Revenue and Customs, who the banks and building societies report interest payments to for income tax purposes.

DWP then cross-match that information against the records of people receiving means-tested benefits. It then flags up possible undeclared capital and they

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a woman who was infected, where she had had some money -- I can't remember where from but it was a significant amount of money but not a huge amount -- and it had been aggregated with her Macfarlane, et cetera, money, and the DWP discovered this, suspended her benefit but neither I nor her could easily work out how much of it was money to be ignored and how much of it was capital that should be taken into account properly, and it took three months to unravel all of that and, actually, in a large part and consequence of that case, which was quite early on, I started to advise people, and Macfarlane and Caxton both repeated this advice in writing and verbally: keep your charity money separate so that if it does get identified by the DWP it's easy to sort out.

So that was my advice, and I then further developed that to say -- and, certainly, I did it on an individual basis but I also remember putting out some written advice around the community, that you do have the choice to tell DWP about your charity money, you don't have to tell them but it might just prevent you getting asked to attend at one of these interviews. I know some folk have done that. It's entirely voluntary and if people don't want to do it that's their choice and I wouldn't push them to do it.

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1 Does that answer the question? I hope it does.
 2 I mean, I can say a lot more about the history of
 3 trying to sort this whole problem out.
 4 **Q.** That was the position, was it not, before
 5 November 2017. Is the position different now, that
 6 DWP has amended its legislation and there's actually
 7 now a requirement to disclose or to declare to the DWP
 8 the payments from the new schemes?
 9 **A.** Frankly, it's a mess. The amendment came in, neither
 10 the charity -- because I remember ringing Jan Barlow
 11 and saying "Do you know this legislation's come in
 12 about having to declare the new scheme's money?" and
 13 she said "No", you know. I wasn't aware. I just
 14 found it a through my normal updating processes that
 15 I subscribe to. I was really quite taken aback.
 16 But it is a mess because people have to declare
 17 their new scheme monies but they still don't have to
 18 declare the old monies. It's a ridiculous thing
 19 actually. But even when they do declare it it's going
 20 to be disregarded anyway, and if they fail to
 21 disregard it -- if they fail to disclose it, as most
 22 of them actually have, because they don't know they
 23 have to -- if they fail to disclose it, there's no
 24 criminal offence of knowingly or dishonestly reporting
 25 a change of circumstances that affects your benefit

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1 I keep asking "What has happened to the
 2 leaflet?" I have been told various things: "Oh, it's
 3 with ministers", "Oh, it's with our Comms team", "Oh,
 4 it's Brexit and ministers won't make a decision on
 5 it".
 6 I'm sorry, I just don't know what's going on.
 7 I've tried and tried and tried and it's been done at
 8 a pretty senior level, yes.
 9 **Q.** Have you come across any clients who are deterred from
 10 claiming EIBSS payments because they don't want to
 11 disclose either their own HIV status or their
 12 connection to somebody that had HIV, and by disclosing
 13 the EIBSS payment that would lead to that
 14 disclosure -- you haven't?
 15 **A.** I haven't come across that.
 16 **Q.** Just lastly, on this point, are you able to -- is
 17 there anything that you can add or is there any
 18 difference to the evidence you have given about
 19 data-matching interviews under caution, and so on, do
 20 those -- does that evidence apply equally to the
 21 situation in Scotland and Wales and Northern Ireland?
 22 **A.** I don't know about what -- I don't think I've ever
 23 dealt with a case -- well, I know I haven't dealt with
 24 a case in Northern Ireland. I'm trying to -- oh, yes
 25 I have I've dealt with, I think, one case Scotland

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1 entitlement.
 2 **Q.** You have been working with or you have been pressing
 3 the DWP, is this right, to provide a letter or some
 4 kind of information from the DWP to explain to people
 5 what their obligations are in relation to disclosing
 6 payments from the new schemes?
 7 **A.** Yes, there was a last -- I think there's a draft of
 8 a leaflet with my tracked comments on it. I have not
 9 seen anything further from them, I think -- is that
 10 2019? I recall a phone call with the senior policy
 11 official in -- yes, it was May -- just before May Bank
 12 Holiday, because I was visiting my father, and had
 13 a long conversation with her about the way forward and
 14 I suggested maybe issuing the leaflet in batches, you
 15 know, doing work with the community to prepare them.
 16 Don't just sent this out.
 17 I've heard -- you know, I don't know what the
 18 current state of play is. I do have named contacts at
 19 the DWP to deal with these problems and, to be fair,
 20 they have all been really, really good and really
 21 responsive, and when I have phoned them about
 22 an individual case they have got it sorted almost
 23 always within the hour. The longest I have had to
 24 wait, I think, was quite recently, actually. I think
 25 I waited two days to get it sorted.

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1 where obviously -- you know, I'm just really not up to
 2 speed on even the outline of Scots law in this area.
 3 I suspect it's -- I mean, I know the data
 4 matching is a widespread issue. I mean, what's
 5 happened is I did get a named contact, John Armstrong
 6 and, more recently, Bobby Towers, they have both been
 7 absolutely fantastic. You know, that when somebody
 8 does get asked to attend a compliance or fraud
 9 interview, it's immediately stopped.
 10 Also, John did deal with a couple of cases
 11 where there was appalling conduct by DWP staff. There
 12 was one where the compliance officer said words to the
 13 effect "I don't know why you're claiming income
 14 support, you get all this money from the Macfarlane
 15 Trust", and, you know, I think I spoke to the
 16 compliance officer as well and told, you know,
 17 "Perhaps if you had AIDS, you might not take that
 18 view". I was really quite angry with it.
 19 Then there was this awful incident where the
 20 woman was asked to attend, it was a widow, she was
 21 asked to attend a compliance interview, housebound
 22 because of her disability, she has a carer provided
 23 through the local authority, very difficult for her to
 24 get out, takes a lot of planning, a lot of work, a lot
 25 of the effort, and she phoned the compliance officer

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1 because they always give the name and phone number on
2 the letters, and she left a message saying "It's
3 really difficult for me to get out, I have to get my
4 carer, I'm housebound, please could you do a home
5 visit?" Now, she is very slow to answer the phone
6 because of her mobility problems and the compliance
7 officer rang her back, I think a day or two later and
8 a message was left on her answering machine saying
9 "This is such and such from -- the compliance officer,
10 please could you phone me back?"

11 Unfortunately the compliance officer didn't put
12 the receiver on the cradle properly on the phone
13 properly, so it was left recording at which point the
14 compliance officer started making mocking noises,
15 similar to how Donald Trump did of a disabled
16 journalist, saying "Oh, I'm always out, I can't get to
17 the phone", something like that, and it was
18 disgustingly offensive, and then her colleague who was
19 with her started laughing about that, laughing at
20 that.

21 I think it's the most humiliating experience
22 a client of mine has ever had with the DWP. To be
23 fair, the vast majority of DWP staff are totally
24 decent people. I immediately reported it and,
25 actually, a manager went out to see her within,

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1 I think tackling the need for people to claim means
2 tested benefits is a priority but the solution,
3 actually, does not lie in just increasing -- call it
4 what you like -- support payments or compensation
5 payments, because if those are disregarded, ignored as
6 capital, land or income, for means-tested benefits
7 people are still caught in the means-tested benefit
8 trap. What means-tested benefits do is that they
9 inhibit people's ability to do things like just get
10 a job -- I mean, I dealt with a case three weeks ago
11 where a guy has -- sadly, his ordinary capital has
12 drifted just slightly above the £6,000 lower limit, he
13 has to tell the DWP. That will all be reassessed,
14 paperwork back and forth. It inhibits people getting
15 a relationship. There's lots of research evidence
16 that's done by groups like Child Poverty Action Group
17 about the way particularly women either get forced
18 into a premature relationship because of the
19 means-tested benefit rules or they don't develop the
20 relationship that, you know, in a way one would expect
21 it to develop, in the normal course of events.

22 So I think if we can get people off
23 means-tested benefits that is really the way forward.

24 So the solution I have suggested is to make the
25 support payments or compensation payments, call them

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1 I think, 24 hours, deeply apologetic very, very,
2 apologetic. I actually wanted the client to sue the
3 DWP for, you know, an act of disability
4 discrimination. She was up for doing that and I spoke
5 to a firm of solicitors who had a contract at the time
6 for that area of law, and I spoke to a barrister
7 I know who deals with it. Unfortunately, she backed
8 out of pursuing it.

9 So, you know, sorry, I can talk all day about
10 this stuff because, you know, it's terrible what folk
11 have gone through, really awful. That's probably the
12 worst example but it was so -- I can't describe what
13 it did to that woman, the humiliation of it.

14 Q. The last topic I want to ask you about is the
15 suggestions for the way forward. You set out in your
16 witness statement clearly the attempts you have made
17 to try and improve matters particularly in relation to
18 the risk of being interviewed under caution and the
19 repeated assessments, and so on, and you set out some
20 ideas that you have for how matters could be improved
21 for this community. Could you just explain to us
22 where you have arrived at as the best solution for the
23 future?

24 A. Yes. I'm really pleased, actually, the Inquiry asked
25 this question because no-one ever asked me before and

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1 what you like, analogous to an occupational pension.
2 If it could be administered by, perhaps, an NHS body
3 I realise the NHS Business Services Authority
4 administer the NHS Pension Scheme, and the corollary
5 would be that those payments then count as income
6 against means-tested benefit, but if you increase the
7 payments, then the cost of that can partly be
8 (unclear) by a transfer of the means-tested benefits
9 paid to people, you can then devise a system that
10 lists people above means-tested benefit level, so you
11 know they leave the means-tested nonsense and
12 intrusion behind.

13 It also means if it's through one of the NHS
14 pension schemes, for example -- if someone, as
15 happened again quite recently, someone wants to --
16 they need to rent a new property and they've got to
17 explain to the letting agent what's EIBSS, the
18 infected blood support scheme, you know. It's not
19 a conversation you want to have with your landlord or
20 a letting agent, or if they apply for credit or want
21 to get a mortgage or whatever it is.

22 So, you know, the proposal I put forward in my
23 witness statement -- I mean, I commend it to you -- it
24 needs further work, but there's a lot of expertise.

25 There are economists and many others within the DWP

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and the Department for Health and Social Care to try to devise a scheme that is non-means tested, that lifts people above means tested benefit level.

As regards repeated assessments for ESA and PIP, I don't think there's an easy answer, given the direction of Government policy and their firm stance on doing that and their distrust of benefit claimants and almost the hostile environment that's been created towards benefit claimants over the years.

But certainly more rigorous application of the ten-year rule for PIP and also the severe conditions guidance for ESA would be a tremendous assistance to this group and, indeed, actually for lots of other people.

MS RICHARDS: Sir, those --

A. Sorry, it's another long answer.

MS RICHARDS: Sir, those were the questions that I had for Mr Bateman. Core Participants and their recognised legal representatives may well have some more questions that they wish to put to him.

SIR BRIAN LANGSTAFF: Yes. We will take a break until not before 5.30. That quarter of an hour will give Ms Scott a chance to see what questions there are. There may be quite a number. There may be very few. I just can't tell you. But at not before 5.30 we will

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more acute for women with haemophilia because it's perhaps less well known that women suffer from haemophilia?

A. I've dealt with very few women with haemophilia in this community. I'm not aware that -- no, actually I don't think I've done any PIP or ESA assessments for women with haemophilia. I've done issues -- I can remember one person who had -- one woman who had very, very pronounced von Willebrand's disease, and damaged joints as a result of that, but her treatment -- treatment or mistreatment by the DWP was as good or as bad as anyone else.

Q. I don't know, Mr Bateman, whether you will be able to help with this question but are you aware of probate having been halted in any case due to the DWP carrying out an investigation into the bank account of a deceased relative who was in receipt of scheme funds, scheme payments? Is that something you have come across?

A. I'm aware, certainly, because I got an email from someone about it last night and I haven't, obviously, had a chance to look at that. I have dealt with a number of solicitors, a number of cases where the DWP have lodged a claim for alleged overpayment -- alleged recoverable overpayments of benefits from

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come back. It may be a little bit longer if there are more questions than I might anticipate. If you would be kind enough to give us your time beyond that, I should be very grateful.

A. Yes, thank you.

SIR BRIAN LANGSTAFF: 5.30.

(5.14 pm)

(A short break)

(5.40 pm)

SIR BRIAN LANGSTAFF: Yes.

MS SCOTT: Mr Bateman, I've got a number of questions from Core Participants to ask you. The first one is a point of clarification about the evidence that you gave in relation to the changes to the legislation made by Government in November 2017, and it's this: can you clarify whether it is the position that payments from the new schemes have to be declared to the DWP?

A. Yes, that's what the legislation says.

Q. So those payments should be disclosed?

A. Yes.

Q. Thank you. You were giving evidence about the poor quality of assessments and the fact that many assessors have little knowledge of haemophilia. Are you able to assist with whether or not that issue is

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estates of deceased people.

Q. I was asking you questions about the lack of knowledge and understanding of assessors for people with haemophilia and for people suffering from HIV. What I didn't ask you and what I should have asked you is whether there is that same lack of understanding and knowledge in respect of people suffering from hepatitis and, in particular, hepatitis C.

A. I think that's a much more complex issue. I'm no medical expert, of course, but, in my experience and reading the literature, the presentation of liver disease seems to be so very, very variable and it's obviously a much more insidious and complex -- it is an insidious and complex disease, from what I can see, and the problem with the assessments for both is that they are really very black and white, even though there's actually now substantial amount of case law to try to make it a more nuanced approach.

The sort of symptoms of hepatitis C are very difficult to fit into the boxes, if you like, that are used for the assessment. With haemophilia and haemarthropathy in particular, it's much more straightforward, it ticks a lot of the boxes a lot more easily. So yes, I think, you know, it's a much more difficult issue, and I've certainly seen, over

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1 the years, some really, really poor decisions on
 2 people with hepatitis C and failure really to take
 3 account of the symptoms like brain fog and joint aches
 4 and generally feeling nauseous, that kind of thing.
 5 **Q.** So is what you are describing really two problems?
 6 One is that there may well be -- it's certainly in
 7 some cases -- a lack of knowledge and understanding of
 8 hepatitis C; and, secondly, even if that isn't the
 9 case, the way that the assessment is structured and
 10 the way that the questions have to be answered aren't
 11 suited to capturing the impact of hepatitis C on
 12 applicants?
 13 **A.** Yes, that's very well put.
 14 **Q.** Can you assist with this: in your experience, do the
 15 registrants applying for PIP have problems in terms of
 16 delays and on appeal and so on above and beyond the
 17 problems experienced by other claimants for PIP not in
 18 the registrant community?
 19 **A.** No. The delays are the same; they're universal. And,
 20 obviously, at the moment things are rather very
 21 exceptional because of the pandemic, but there have
 22 been tremendous delays in getting -- there's no legal
 23 requirement, no statutory requirement or case law
 24 requirement on the DWP to make a decision on the
 25 mandatory reconsideration within a certain timescale.

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1 and lost in the realms of case law and equity, rather
 2 than anything nice and clear in the legislation.
 3 **Q.** You've spoken about the fact that there isn't any time
 4 limit on the mandatory reconsideration part of the
 5 appeal process.
 6 Is there any time limit on the second part of
 7 the appeal process?
 8 **A.** No. Well, except the -- hang on. The DWP are obliged
 9 under the appeals -- the tribunal procedure
 10 regulations, first tier tribunal, social entitlement
 11 chamber -- social -- sorry --
 12 **SIR BRIAN LANGSTAFF:** Social entitlement chamber rules.
 13 **A.** Yes, sorry. They are obliged to produce their reply,
 14 as it's known to the appeals -- in other words, their
 15 submission -- within one month. If they fail to do
 16 that, Her Majesty's Courts and Tribunals Service, the
 17 tribunals office, have a procedure for chasing that up
 18 and referring it either to a nominated case worker or
 19 a judge within HMCTS who can issue directions to them
 20 to compel them to do that.
 21 If they persist in their delay, one thing I do
 22 from time to time -- well, when it's needed,
 23 actually -- is I then apply on an interlocutory basis
 24 to the tribunal judge that the Secretary of State, the
 25 respondent, is barred from further participation in

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1 We tried and tried and tried in our lobbying
 2 activities, and we failed in fortunately. They
 3 wouldn't even have it as a sort of administrative
 4 measure that compelled staff to do it quickly.
 5 And then appeals, there's just enormous
 6 backlog. It's, you know, difficulty in recruiting and
 7 retaining judges and the medical professionals and
 8 other -- the wing members on the first tier tribunal,
 9 combined with the surge in appeals caused by DWP's
 10 assessment and reassessment activity. So I'm afraid
 11 everybody is a victim of this.
 12 **Q.** Is there an outer time limit on the amount of time the
 13 DWP can take to assess a PIP application?
 14 **A.** No. There is some old case law *ex parte* CPAG going
 15 back to the '80s which is of some assistance and some
 16 leverage. Child Poverty Action Group have some
 17 template letters before action and suchlike which can
 18 be used.
 19 If you've got an excessive delay -- and that's
 20 a question, I suppose, of fact and degree in each
 21 case. If you've got an excessive delay, then one
 22 tactic that welfare rights workers often use is to
 23 send one of the pre-action protocol letters to the
 24 DWP's solicitors for sort of general breach of their
 25 general duties. But it's all kind of woolly and vague

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1 the appeal. And when those direct -- when a direction
 2 to that effect is given to the DWP, it normally
 3 focuses their mind, and they come up with the
 4 submission.
 5 Then, unfortunately, you have a very lengthy
 6 delay once that's in. I'm supposed to do my response
 7 within a month, which I think I've always managed to
 8 do, and then it's just the queue for hearings. And,
 9 you know, it's got better recently. And,
 10 interestingly, the telephone based hearings -- I was
 11 reading a report just last week, actually, that the
 12 waiting times have reduced considerably. The
 13 throughput of appeals is much better, and the
 14 attendance actually has improved as well.
 15 **MS SCOTT:** When benefits are stopped, what hurdles have to
 16 be overcome in order to have them reinstated, and how
 17 quickly or slowly does that happen normally?
 18 **A.** A woolly question, to be honest. Depends what you
 19 mean by "stopped" and which benefits. You mean if
 20 someone was found fit for work, for example?
 21 **Q.** In the circumstances that we are speaking about here,
 22 so poor quality assessment, for example, yes.
 23 **A.** Okay. So how long does it take to reinstate them?
 24 **Q.** Yes. What are the hurdles, and what's the sort of
 25 average time range for that to be reinstated?

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1 A. Well, the first hurdle is to see the decision letter
2 and try to work out from that. Then to get hold of
3 the assessment report, which in the case of ESA is an
4 ESA 85, and also if the client doesn't have a copy of
5 the ESA 50 self-assessment form, and try to put
6 together some grounds. Take instructions from the
7 client in order to put together a case. Consider
8 whether there's medical evidence required or other
9 evidence where they may have some. Point out obvious
10 inconsistencies that you can see and errors.

11 It's not an easy process. I mean, folk do do
12 this themselves. Most appeals to the First Tier
13 Tribunal on benefit issues are people doing it on
14 their own. I think the level of representation has
15 fallen. If I remember correctly, I think it's about
16 10 per cent. It's very low. It's the minority of
17 cases.

18 So they have got to, you know, have the
19 wherewithal to do all of that and that's a big ask and
20 often people -- I've seen cases, you know, actually
21 amongst the community where people have, sort of, done
22 that themselves and, you know, often actually not done
23 it very well, sometimes made their case worse, and
24 then you've got -- you know, people get very
25 intimidated when they get the DWP's submission,

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1 ministers are highly sensitive about it. So was it
2 a coincidence that they introduced a two-tier process
3 that would have the effect of reducing the numbers of
4 appeals? You'll have to ask them.

5 Q. Are you able to give us an idea of the sort of time
6 range that those steps that you've outlined might
7 take?

8 A. Well, assuming the person contacts you fairly quickly
9 after they've had the negative decision, to turnaround
10 a mandatory reconsideration and get it off to the DWP
11 is round about two to three weeks, depending on the
12 case and what evidence is to hand and then, as I said
13 earlier, you know, how long's a piece of string?

14 Sometimes they turnaround mandatory
15 reconsiderations very quickly. Increasingly,
16 actually, to be fair to the DWP they have got a lot
17 better at revising. I mean, we went through a stage
18 when they first came in, they were only revising
19 about, I think, 10 per cent of mandatory
20 reconsiderations in the Appellant's favour, in the
21 Claimant's favour, and it's now up, I think, about
22 50 per cent for disability benefits.

23 It's -- you know, it can be a long wait. At
24 the moment it's a horribly long wait and they are
25 prioritising mandatory reconsiderations where someone

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1 100 papers arrive of their doormat and it's, you know,
2 it's quite common for -- well, it's not uncommon for
3 people to say "I can't proceed with this any more".

4 Another thing that's also happened, as a result
5 of the two tier appeal process that came in in
6 October 2013, is that the numbers of appeals to the
7 First Tier Tribunal dropped by about 40 per cent
8 almost overnight. The DWP said that they had to bring
9 in this process because people were producing evidence
10 at hearings and that could have been produced at
11 an earlier stage. I've always disputed that. I said
12 you could simply change the procedure to draw out that
13 evidence very early on in the appeals process and
14 revise accordingly, revise a decision accordingly.

15 So a lot of people get appeals fatigue. We
16 said that would happen. We told the DWP through the
17 various consultative bodies that we're involved in,
18 that I'm involved in, and it's come to pass that
19 that's the case.

20 I'm sorry, I'm a bit cynical about all this
21 because the DWP have been losing appeals left, right
22 and centre, hand over fist when it comes to benefits
23 like ESA and PIP, and I've given the success rate at
24 appeals. That gets picked up by the press and is used
25 to criticise the DWP's performance, and so I know

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1 has no money. So if it's a dispute about the rate of
2 PIP, for example, that you can just expect to wait for
3 a very long time and, indeed, I am on cases at the
4 moment.

5 Then appeals, you know, it can be 12 months,
6 six to nine months once you have submitted the notice
7 of appeal to HMCTS, is usually the sort of kind of
8 benchmark timescales I give folk.

9 Q. What are the trick questions asked by the DWP in
10 assessments with which registrants of the Macfarlane
11 or the Caxton Fund have had difficulty?

12 A. Okay. Well, it's not the DWP who ask those questions,
13 it's their private medical assessors, companies that
14 do it. But the most common one is "How long can you
15 walk for?" and people reply -- I mean, if I was to ask
16 you that, you know, you'd probably respond "Oh, yes,
17 I can" -- you know, typically people say "Oh, I could
18 do a couple of minutes and then I'd have to stop", and
19 it's a sort of rhetorical answer that folk give and
20 that gets taken very literally, and there's some
21 figure somewhere that the DWP have got, based on some
22 research by a Government road traffic research unit,
23 I think it was, some time ago, about how people walk
24 at four miles an hour and, therefore, if you say you
25 can do two minutes, then, you know, that's going to be

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more than 50 metres and you therefore can't get the enhanced rate mobility component, and you lose your Motability car. That's one of the trick questions.

The other is questions about walking a dog: "Do you have any pets?" "Yes, I have a dog", "Do you take the dog out for a walk?" "Yes, I do", which is then used to infer that someone has all sorts of walking and other abilities, such the ability to hold a dog that's pulling on a lead.

When you -- if you drill down and ask the question properly, as I have done and as I do, you find, for example, the dog walk consists, for example, of them opening the back door and letting the dog out to run round the garden.

What other ones are there that come up? Oh, yes, sitting and watching television, that happens in ESA: "Are there any TV programmes that you like?" "Oh, yes, I like watching the News or EastEnders or, whatever, Coronation Street", and okay, so the news is half-an-hour and that is used to infer some sort of ability because one of the activities they assess is your ability to sit and stand. It's sort of goes on like that, really.

Q. So that is used to assume that you can sit for 30 minutes without having to get up to relieve your

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A. Sorry, I'm not sure what that question means.

Q. Perhaps I will come back to that because I'm not entirely sure what it means either.

SIR BRIAN LANGSTAFF: I think -- can I put it this way: do you think it could be possible for you or, for that matter, for DWP -- I don't know who the question is aimed at -- to put down on a couple of sides of A4 what the policy of the DWP is and how to deal with it when they get in touch? Or is life more complicated than that?

A. I wish it was that simple.

SIR BRIAN LANGSTAFF: So the answer is: not very easy.

A. No. You can summarise benefit entitlement and what the eligibility criteria are with bullet points.

For example, the spinal injuries charity Aspire have a really good -- I think it's just two sides -- very nicely designed leaflet on their website explaining to people the basic principles of personal independence payment.

You can summarise very shortly, you know, very briefly, some tips for people on how to deal with the Department for Work and Pensions. I mean, that probably wouldn't be too difficult. I mean, just simple things like, you know, having your National Insurance number and which telephone numbers are

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back or whatever it is?

A. Yes, that's right. There's some rather unhelpful case law -- sorry, I've got a shadow on my screen, is it showing at your end. I just wonder if I need to adjust the angle --

MS SCOTT: It is, yes.

SIR BRIAN LANGSTAFF: It is, yes.

A. Can I just try -- is that better or --

SIR BRIAN LANGSTAFF: Probably not. I think we'll bear with it. You have had it since we came back on the break but we would need the technical guys to get in and do it. Let's just move on because I think it might be quicker.

A. I think it is because of fading light outside.

SIR BRIAN LANGSTAFF: I think that is almost certainly the case. If you have any other light you can put on inside, that might help.

A. Yes, I do, if I can try that.

SIR BRIAN LANGSTAFF: Try that. That, I think, is very much better.

A. Yes, it is, yes.

MS SCOTT: How useful would it be for there to be a definitive policy and information statement covering all aspects of the community's engagement with the DWP?

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which.

It's really unfortunate that the DWP have been very, very resistant historically to having electronic access, unlike just about every other Government department. And, you know, they raise all sorts of issues about security and such-like. If they could find a way around that, it would be very beneficial for people.

MS SCOTT: Is there a list of passported conditions or special conditions within the DWP?

A. Which benefits?

Q. I think in your witness statement you say -- I think you do talk about special conditions, don't you? I'm not sure. I've now forgotten which --

A. Special rules.

Q. Special rules. Thank you.

A. Yes.

Q. So is viral hepatitis, or indeed HIV, on the list of -- is that contained within the special rules?

A. Well, HIV used to be, and it was one of the reasons a lot of Macfarlane Trust registrants managed to get awards of the higher rates of Disability Living Allowance and Incapacity Benefit. It required certification by a medical practitioner that their life expectancy could reasonably be stated as being

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1 six months or less.

2 I don't think it's possible to do that in the
3 case of hepatitis C, unless obviously it's getting
4 towards more serious liver disease.

5 In the case of HIV alone, because the
6 treatments have moved on, we can't really argue that
7 the special rules apply. And, indeed, when people
8 have tried that, they get turned down.

9 Q. Are there -- sorry.

10 A. I mean, I did try in the early days of ESA -- there's
11 a provision in regulation 20 of the Employments and
12 Support Allowance Regulations 2008 -- it's known as
13 the *(unclear: audio distortion)* provision to try and
14 use that to passport people through the work
15 capability assessment for ESA. I have to say it
16 failed, sadly, but, you know, you try these things,
17 especially in the early days of a new benefit.
18 Sometimes it works; sometimes it doesn't.

19 Q. You have described a range of services that you
20 provide to EIBSS registrants. Are you able to provide
21 all of those services to the SIBSS registrants as
22 well?

23 A. Could do, but I was going to say something about my
24 future.

25 Q. Presumably you are going to say that -- you will come

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1 agreed that there could be some devolution of social
2 security matters to Scotland -- the Scottish
3 Government -- and they are pressing ahead with
4 a number of changes. So gradually over time, the
5 Scottish social security system will become different
6 to the English one, and particularly in relation to
7 benefits for long-term illness and disability. And
8 I'm not really going to be up to speed with those when
9 those changes come in.

10 Q. Would entitlement to receive certain benefits have
11 been an accurate way of establishing what
12 a registrant's level of need was or is without further
13 assessment of disability needing to be undertaken by
14 Macfarlane Trust or the Caxton Foundation or, indeed,
15 the new schemes? I think sometimes you see that
16 referred to in the documentation as using the
17 assessment undertaken by the benefits agencies as
18 a proxy for understanding the needs in the context of
19 the trusts and schemes?

20 A. Yes, sorry, just to be pedantic, the Benefits Agency
21 hasn't existed since 2000. You are using it
22 generically but it is important to be precise with
23 these things.

24 As an assessment of financial need, I would say
25 yes. You know, someone's receiving Income Support,

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1 to that at the end, will you?

2 A. Yes, I think so.

3 Q. Okay. Is it your understanding that before you
4 received the telephone call in August 2020 from SIBSS
5 that there was no benefit -- that the SIBSS
6 registrants were not receiving any benefits advice?

7 A. Yes, that's what I was told.

8 Can I just say, at the point of setting up the
9 new support schemes, I had I think three or four
10 Scottish cases, and SIBSS did agree to pay me to
11 finish those cases off. I mean, it was fairly much
12 the tail end of them. I remember asking, "Are you
13 going to make any arrangements?" Because in Scotland,
14 the supply of advice services is way better than in
15 England, and it goes back to the -- is it the 15th
16 century where the principle of Legal Aid I think was
17 held to be an important constitutional principle in
18 Scotland. And I mean, having written the Scottish
19 Government's standards for advice and also knowing
20 lots of advice workers in Scotland, you know, it's
21 just much, much healthier. The need may be greater,
22 but the supply and availability of advisers in
23 Scotland is much, much healthier.

24 One thing about Scotland is that following the
25 referendum on independence, the Cameron Government

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1 for example, or income-related Employment Support
2 Allowance, if they are also renting property and they
3 claim Housing Benefit, they don't have to be means
4 tested again for Housing Benefit. There's a -- it's
5 called a passport, actually -- system of passporting
6 people over onto the maximum entitlement to Housing
7 Benefit. It doesn't mean they get all their rent met
8 but it's the maximum entitlement to Housing Benefit,
9 which just cuts out a load of bureaucracy and double
10 means testing and it happens seamlessly -- or should
11 happen seamlessly -- behind the scenes, so the
12 customer's unaware of it.

13 Q. What about in relation to health needs?

14 A. I don't know. I don't know about that. Because the
15 criteria for assessing, if you take PIP, for example,
16 there are -- if I remember correctly, there are nine
17 daily living activities that they assess and two
18 mobility ones. But there's things that they don't
19 assess for PIP, such as your ability to lift yourself
20 out of a chair. They don't assess your ability to go
21 up and down stairs, which I've always *(unclear: audio distortion)*. The assessment of mobility is based,
22 according to the case law, on your ability to walk
23 over on ordinary outdoor paved surfaces, including
24 kerbs that's level, but not uphill, not on an incline.

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1 So I think it could be problematic, is what
 2 I would say.
 3 **Q.** What was the role of the DWP working group on
 4 haemophilia and contaminated blood and what, if any,
 5 improvement in the system of benefits for these
 6 communities has it been able to achieve?
 7 **A.** Well, I think that really the -- I think there were
 8 two achievements, one is that it was fed into
 9 ministers so the ministers were more aware of the
 10 needs of the community, and that's always a good
 11 thing, even if it doesn't produce a tangible outcome.
 12 The other was the fact that it was clearly
 13 instrumental in getting this review carried out of
 14 Personal Independence Payment for people with
 15 haemophilia, not -- you know, not just people with
 16 haemophilia who have got infected blood either, but
 17 just people with haemophilia who've claimed PIP. So
 18 that was very good outcome.
 19 The results of that have continued, albeit
 20 I continue to get cases that I dispute. But as I said
 21 in my evidence, you know, things are better than they
 22 were.
 23 **Q.** You asked whether you used the word "instrumental",
 24 which was the word I put to you when I asked
 25 a question about that and I have checked back to your

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1 **MS SCOTT:** Sir, those are all the questions I am going to
 2 ask from the Core Participants.
 3 **SIR BRIAN LANGSTAFF:** I have no further questions to ask.
 4 **MS SCOTT:** Mr Bateman, would you like to add anything to
 5 your evidence?
 6 **A.** I'd just like to make a couple of points. I'm sorry,
 7 I won't give long answers this time.
 8 First of all, I am immensely proud of what
 9 I have achieved for this community. I mean, I worked
 10 through my monthly reports and they are not outcome
 11 figures but, since 2011, there were 945 people I have
 12 advised or assisted in some form and total extra
 13 benefit gains -- I mean, these are rough figures
 14 because I never kept outcome figures -- but I have
 15 helped people claim £3 million worth of benefits in
 16 that time.
 17 It's been a privilege to work for them. People
 18 have opened up and told me about their lives. It's
 19 been very moving, very powerful. Preparing for this
 20 Inquiry has been very, very difficult for me,
 21 emotionally. It's brought back memories of people
 22 I had very good working relationships with, who are
 23 beneficiaries, who are no longer with us, people who
 24 were dying and suffered terribly and, you know, when
 25 you are acting as someone's advocate you put those

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1 witness statement, and it's not a word that you used.
 2 It was my word.
 3 **A.** Don't worry, that's not a problem.
 4 **Q.** Last question: would clear nationally circulated
 5 advice from the DWP have assisted in avoiding the
 6 issues registrants have experienced with benefits
 7 disregard?
 8 **A.** Well, there was some clear guidance and they are
 9 enclosed on -- one of the exhibits in my witness
 10 statement is the letter, it was known as -- people
 11 called it the "waiver letter" which is probably not
 12 really the right phrase but -- and there was guidance
 13 that was issued to staff, DWP staff. The problem is,
 14 as I said in my witness statement, there are --
 15 I mean, there are millions of people who have claimed
 16 means-tested benefits, so when you have got
 17 a community of 2,000 maybe who are claiming
 18 mean-tested benefits, who are people infected or
 19 affected, it's such a tiny proportion of that and, you
 20 know, the information just gets lost.
 21 I remember once talking today to a DWP
 22 official, very long standing, actually it was John
 23 Armstrong. He said, in his entire career -- he spent
 24 his entire career in the DWP -- he said he had dealt
 25 with one such case.

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1 feelings away in a box and push them out of the way
 2 because they won't help you help the client. I have
 3 found those feelings have really come to the fore.
 4 I am now 65. I'm not getting any younger.
 5 I've found generally the work emotionally,
 6 intellectually and physically demanding, so it is
 7 my intention actually to retire this year. I have
 8 informed the England Infected Blood Support Scheme and
 9 asked them to consider making some succession
 10 planning.
 11 The other point I would make is really about
 12 the impact of welfare reform that, you know, if one
 13 looks at the research on it, since 1978 the value of
 14 means-tested benefits has fallen as a proportion of
 15 average earnings from 38 per cent to 17 per cent. The
 16 Disability Benefits Consortium has estimated that
 17 since 2010 the average person with a disability has
 18 lost benefits to the value of £1,200 a year, and
 19 nearly -- the Office for Budget Responsibility
 20 identified that there was a cut of between 9 and
 21 17 per cent in spending on working-age social security
 22 claimants, with a 5 billion cut from disability
 23 benefits by 2018. That's had a huge impact on the
 24 community, an absolutely enormous impact, and it's why
 25 people have ended up having to engage in so much

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1 dispute about ESA and PIP in particular. I mean, I'd
2 really just like to end with that point.
3 Can I thank the Inquiry for giving me the
4 opportunity to get across this evidence.

5 **SIR BRIAN LANGSTAFF:** Well, I want to thank you in return.
6 And can I put it this way: I wouldn't worry at all
7 about the length of your answers because it seems to
8 me they simply demonstrate yet again what passion you
9 have for remedying what you see as injustice. You've
10 put that in context, the context that we are dealing
11 with, because it's probably where you spend the bulk
12 or have spent the bulk of your time recently. But
13 it's been fascinating to listen to, and revealing, as
14 you can tell by the number of questions at the end.

15 I won't take any more time because I don't want
16 to take you away any longer from your weekend. Thank
17 you for your patience, and thank you for your
18 evidence, and good night.

19 **A.** Thank you. Thank you, Sir Brian.

20 **SIR BRIAN LANGSTAFF:** Now, Ms Scott, we're not meeting
21 next week.

22 **MS SCOTT:** We're not meeting next week.

23 **SIR BRIAN LANGSTAFF:** The week after, we have a full week,
24 have we not?

25 **MS SCOTT:** We do. We meet next the week after, that's

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1 Monday 22 March, and we begin the week with
2 a presentation on Skipton, and then after the
3 presentation, we will hear evidence from Ann Lloyd.
4 **SIR BRIAN LANGSTAFF:** So Monday, 10.00. That is not the
5 coming Monday, but Monday 22 March. Thank you very
6 much.

7 (6.18 pm)

8 (Adjourned until Monday, 22 March at 10.00 am)

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