

Friday, 3 February 2023

(10.00 am)

SIR BRIAN LANGSTAFF: Mr Stein.

Closing Statement by MR STEIN KC

On behalf of 23 individual Core Participants

MR STEIN: Good morning, sir. A number of people have indicated that they are looking forward to these closing submissions. All I can say is I pray I don't let you down.

Let me make three basic opening points. Treatment without consent was never acceptable. Treatment without consent is no excuse for substandard care. Those who treat without consent and cause harm should be hauled up before the criminal courts.

Sir, as you are aware my name is Sam Stein KC and, with Ms Milligan, instructed by Milners Solicitors, I appear on behalf of 23 of my clients. All of them are either infected or affected and victims of this disaster.

We thank you, sir, and the Inquiry team for its care, the respect with which all parties have been dealt with, and the depth of this investigation. The hard work of the entire Inquiry team, its support services and structures have made this Inquiry as accessible as possible and as positive an experience as it could be in

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evidence. This may feel a little like bereavement but this community is used to that.

Next, for a moment I want to single out for praise the Inquiry legal team, led so ably by Ms Richards KC. We thank them for the four years of weeks away from home and the evenings and sometimes the nights worked through to get this right. We recognise that this has not been a marathon for the Inquiry legal team; instead, this has been a series of ultramarathons, run towards what must have seemed at first to be a very dim light at the end of a very long tunnel.

Now let me turn to my own small but mighty client group we have had the great pleasure of representing before this Inquiry. We, their legal team, have learnt everything from listening to you, learning about what was done to you and what you did as a result.

Our clients have been infected, affected and killed by the scandal. We remember in this regard the loss of Peter Mossman, aka Mossy, an infected haemophiliac and great campaigner who died after developing pneumonia and was buried a year ago today on February 3rd, 2022. His son Gareth has said to the press, "My father was consumed by his need to get justice and battle for this Inquiry for so long", and it makes me feel emotional to think that the Inquiry is coming to an end on the

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the circumstances.

Sir, we also thank you and the Inquiry for the clear thinking and organisational skills which meant that we heard from the victims of the scandal first and returned to victims periodically throughout.

The evidence from the infected and affected -- and please understand, I understand myself how clumsy and objectifying those words "infected" and "affected" are -- the evidence from those people have given this Inquiry the bedrock of evidence that it needed in order to understand what happened as against the evidence from the clinicians, the bureaucrats and politicians.

It should be noted, sir, that the Penrose Inquiry only heard from a limited number of those infected and affected.

After Penrose, the infected and affected community were left devastated by the Penrose Report. The community thought that Penrose was the last shot at truth and meaningful reparations, and I know that some people wanted to give up. Mark Stewart, whom I represent, thought about taking his own life.

The evidence and the submissions in this, the Infected Blood Inquiry, finishes today. It will, I am sure, take time for everyone to cope with the loss of the constant engagement and consideration of the

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anniversary of his funeral.

Gareth went on to say, "It is massively upsetting that he is not here to see it."

Our clients' lives have been devastated and derailed by their and their loved ones' exposure to infected blood products. They have truly lived through the worst of times: the stigma, the fear, the desperate day-to-day ill health, the pain, the bain frog -- the bain frog! -- the brain fog and continual sleep deprivation.

Those infected and their families have been told that they won't survive their infections many a time. Mark Ward told us doctors told him on a number of occasions that he is going to die, yet instead he survives and continues his astonishing campaign to spread the word about healthy blood products to the world.

Some of our clients are women who supported their partners through terminal illness, and of those, few gave any thought at any time -- and some were in turn infected themselves. One of our clients, the terrific Colette Wintle has had to achieve recognition of her very own identity as a female haemophiliac, ignored and assigned to a bin of heavy women's problems or dismissed as a carrier.

Some of our clients had been misdiagnosed as

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1 haemophiliacs and then mistreated as such, cruelly
2 infected through blood products which they never
3 required. It would be wrong of me not to record that
4 our misdiagnosed clients remain of the view that they
5 have at times felt ignored by this Inquiry as it has not
6 been about mistakes made in their treatment but of
7 course how that treatment came to bear on those who
8 received it.

9 Sir, we have -- you may remember at the very
10 beginning of the Inquiry my misdiagnosed clients wore
11 a T-shirt. I have one here. Sir, whilst the Inquiry
12 is, of course, welcome to have it, I note that it is
13 probably more me sized, an XXL, than anyone else.

14 And, of course, many of our clients are campaigners,
15 who have fought and fought and fought for justice and
16 truth. If ignored, they knocked on another door. Like
17 great fighters, if ever knocked down they got straight
18 back up. They never stopped. And without them -- and
19 this needs recognition -- this Inquiry would never have
20 happened, and the government line would have prevailed.

21 All of our clients are passionate, unrelenting and
22 angry, but this is a righteous anger, sir. This is the
23 righteous anger of the ignored, the sidelined and the
24 discriminated. We don't apologise for our clients'
25 visceral anger. We don't apologise for their desire for

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1 structure of what we have to say. First of all, I will
2 be dealing with the DHSC, Department of Health -- I will
3 probably refer to it as Department of Health -- though
4 that will be the first chapter; then I will move on to
5 consent; risk; other medical choices; experimentation
6 and, sir, at that juncture, with your permission, I will
7 break. After the break then returning with licensing;
8 what should have happened; campaigners, recommendations;
9 and the way forward.

10 I have to say, sir, I am slightly conscious that
11 I could have come up with some snappier chapter
12 headings. Let me deal, first of all, with the
13 Department of Health.

14 We, like others I am sure, awaited with interest the
15 oral submissions to be made on behalf of the Department
16 of Health by Ms Grey KC, to see after all of this time
17 and after hearing all of this evidence how their apology
18 would be shaped after their opening remarks on
19 28 September 2018.

20 When speaking on behalf of the Department of Health
21 and Social Care in England and its predecessor, Ms Grey
22 KC said things happened that should not have happened
23 and that things went wrong. Now, sir, as you will be
24 aware, in the Department of Health, the DHSC's written
25 submissions, paragraph 1.7, they refer to their

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1 truth and for proper compensation for the damage done to
2 them.

3 Instead, let me be pinpoint clear. They are right
4 to be angry and they are right to demand compensation,
5 right to demand change and right to demand restitution.

6 It has been a privilege to represent all of our
7 clients, work with them and for them, and it is
8 an honour to be trusted with the responsibility of --
9 although rather nervously -- with the responsibility of
10 standing up here on their behalf.

11 I apologise sincerely to them for sometimes not
12 always understanding at first or getting the point only
13 slowly at times. But I hope we got there in the end.

14 I would also, of course, like to thank my juniors,
15 Alan Barker from Nexus Chambers for his hard work in the
16 early part of this Inquiry, and then more recently the
17 great Scarlett Milligan of my own wonderful chambers,
18 39 Essex. Myself and my brilliant but long-suffering
19 solicitor. I emphasise suffering, from me that is.
20 Mr Harrison -- who sits on my right, from the great
21 Leeds firm, Milners Solicitors -- and I have had many
22 a lively discussion over these last four years. He has
23 my enduring thanks.

24 Ben, we made it.

25 In making these submissions, let me describe the

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1 unreserved apology saying, as they do there, nothing in
2 those written submissions should be seen as changing
3 this.

4 Unfortunately, what will we got from Ms Grey on
5 18 January was "It's uniquely your role to make those
6 findings", referring to you, sir. Ms Grey went on to
7 say this "and we might have remained silent and made no
8 submissions but instead we have gathered together the
9 perspectives of those involved at the time".

10 Really? Was it really a choice for the Department
11 of Health that they thought that they might have
12 remained silent and made no submissions? After hearing
13 the submissions from Ms Grey, I reached for the
14 dictionary to look up the word "candour", just wanting
15 to check my own often inadequate understanding of common
16 words and, sir, as you no doubt know, it means of
17 quality of being honest and straightforward in attitude
18 and speech.

19 May I compliment Ms Grey as an advocate for the high
20 standard of her delivery of her clients', the Department
21 of Health's, submissions but sadly deprecate her
22 clients' instructions to her.

23 Those instructions seem to be that it is the
24 Department of Health's view that it is somehow
25 acceptable that they can hide behind the curtain as they

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1 feel they cannot be compelled to state a case, let alone
2 provide a meaningful apology, which references the facts
3 established and now known to us in this Inquiry.

4 Well, sir, you put it to Ms Grey, what exactly can
5 you -- was it at that time -- referring to their opening
6 submissions -- "As a matter of history, as opposed to
7 now, what was it that the Department had in mind that
8 you are apologising for?" We suggest that the
9 Department of Health's responses have shown an absolute
10 lack of candour and a failure by those currently in the
11 Department of Health to realise that apologies must mean
12 something.

13 Restorative justice requires not just the form of
14 an apology but the sense to those who are being
15 apologised to that the apology giver accepts wrongdoing.
16 We have a proposal for the Department of Health which we
17 hope helps. The very long fight for truth and justice
18 was never about the credible evidence that already
19 existed, that the long-standing campaigners discovered
20 and discussed and preserved, but it was about the
21 supreme effort that went into the Government denials,
22 lies, blocking and cancelling out of campaigners and
23 infected and affected voices.

24 It was always about the refusal to look at and
25 address what was plain on the documents. So we make

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1 told that time has dimmed their recollections.

2 Our clients and this community has not forgotten
3 about what the doctors told them or didn't tell them.
4 They have not forgotten about the fact of their
5 infection, or the way they learnt of their infection or
6 multiple infections, or being told that they will not
7 survive, or the hammer blow of letters in relation to
8 vCJD, or the deaths.

9 We suggest that the community has not forgotten
10 those points to the Department of Health. Let me be
11 clear, this response from the Department of Health is
12 simply a demonstration of the latest Government line
13 used to fob off the survivors of this tragedy. But in
14 taking the latest version of the Government line, the
15 apology at the beginning of this Inquiry now appears
16 contrived and the lack of true acceptance of fault is
17 disrespectful to everyone and to Lord Morris's comment
18 about blood products, that this is the worst treatment
19 disaster in the 75-year history of the NHS.

20 If nothing else, this perpetuation of harm should be
21 considered an aggravating factor in the compensation
22 decisions and deliberation.

23 No doubt my PI lawyer friends will tell me after my
24 speech how far that is actually possible.

25 I turn now to consent. We have witnessed in this

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1 an offer to the Department of Health: if you the
2 Government, Department of Health, are struggling to work
3 out what you need to apologise for, then we have the
4 people, we have the community, we have the survivors, we
5 will be happy to meet with you any time, any place to
6 have that discussion.

7 But, in the light of the empty apology, we suggest
8 and agree with my learned friend, Mr Dawson KC's
9 submissions that any reading of the Department of
10 Health's closing written submissions shows this in fact
11 it leans towards an attempt to provide a defence for the
12 Department of Health. Let me look at a couple of
13 points.

14 Firstly, the Department of Health suggests that the
15 years have taken their toll on recollections,
16 suggesting, paragraph 1.16, Department of Health written
17 closing, that of the effect of time on memory that:

18 "Such limitations affect the memories of all those
19 heard in this Inquiry whether former ministers,
20 officials, doctors or patients. Secondly, that again
21 due to the passage of time the documentary record will
22 be incomplete."

23 You will find that, sir, at paragraph 1.17. Well,
24 sir, I doubt whether any single patient who suffered the
25 long consequences of their infections appreciates being

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1 Inquiry the evidence given by all of the haemophiliacs
2 and family members and all of the witnesses about their
3 treatment with infected blood products.

4 We hope and believe that the Inquiry is likely to
5 accept the overwhelming preponderance of evidence from
6 the patients and their families which shows that
7 haemophiliacs were not properly informed and were not
8 provided with sufficient information to make an informed
9 choice as to whether they -- and "they" is the important
10 word, isn't it -- as to whether they, the patient, was
11 prepared to take a risk.

12 Consent, sir, is about and always has been about the
13 ownership of risk. On 17 January this year, we heard
14 the careful submissions from Mr Bragg, an individual who
15 had been infected with hepatitis as a result of a blood
16 transfusion. Mr Bragg, because of his work, referred to
17 the employment of risk analysis within the regulatory
18 world and, in truth, that is what both regulation and
19 medical treatment is all about.

20 Risk is one of, if not the main issue, to be
21 considered, monitored and reconsidered with regularity
22 as part of a doctor's or indeed regulator's function.

23 The questions are always what is the risk, what is
24 the degree of risk, changes in risk and what could be
25 done to ameliorate risk or avoid it entirely?

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1 So how should risk analysis have been addressed for
2 haemophiliacs when considering the treatment using blood
3 concentrates? First of all, there needs to be
4 consideration of the severity of the condition of the
5 patient who will suffer the consequences and side
6 effects of any treatment, and for haemophiliacs we have
7 broad and rather crude labels for the severity of
8 haemophilia. Those are mild, moderate and severe.

9 Those labels are an attempt to describe the effect
10 on an individual of the condition, mild haemophilia 6 to
11 50 per cent factor level, may only have minor bleeding
12 problems. Moderate haemophilia 1 to 5 per cent factor
13 level, may bleed one time per month. Severe
14 haemophilia, less than 1 per cent factor level, may
15 bleed one or two times per week.

16 Now, myself and Ms Milligan and Mr Harrison have
17 learnt that using these labels to describe the
18 individuals' lived experience of haemophilia is
19 a mistake. Some haemophiliacs with so-called mild
20 haemophilia experience a much more severe response to
21 bleeds than might be expected from that label "mild
22 haemophilia". So it is always about the experience of
23 the individual, rather than any broad or brush stroke
24 attempt to provide a label.

25 So as ever with risk, the analysis should be based

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1 that the patients had discussions with their
2 haematologists about the use of blood products,
3 commercial products, blood pools and the growth of
4 medical understanding? We think back, very little if
5 any at all.

6 Now we listened on 19 January this year to
7 submissions from Mr Kennedy KC, on behalf of the UKHCDO
8 and he included the point that patients are much more
9 prepared to ask questions than they were in the '70s,
10 when there was a more paternalistic approach, and that
11 you can also take account sir, he said, and
12 I paraphrase, of the patient protections from
13 organisations such as NICE.

14 So we suggest that this is and remains a submission
15 that could only be made by a doctors group. Not all
16 patients are able to ask questions. Not all patients
17 are confident enough to ask questions and not all
18 patients know what questions should be asked. It also
19 misses the point. In this scandal, the patients, if
20 told anything, were not told the truth.

21 The British Medical Association publication
22 *Professional Standards*, a statement prepared by
23 a special panel appointed by the Board of Science and
24 Education of the British Medical Association -- sir,
25 I will give on occasions Relativity references, I don't

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1 upon risk of treatment through the use of blood
2 concentrates or indeed any blood product for any
3 recipient, and then analysed for that recipient.

4 In short, should this treatment be provided for this
5 patient? The decision about treatment should therefore
6 be: what treatments are available for this patient?
7 What are the benefits of each of the available
8 treatments for this patient? What are the harms which
9 may be the result of any specific treatment? Is there
10 a treatment which may be less effective but less risky?
11 Overall, do the benefits outweigh the harm? And, of
12 course, the big question, what is the decision of the
13 patient or the patient's guardian when properly informed
14 of these questions?

15 Now, the decision by doctors as to their view
16 regarding treatment and the decisions made by patients
17 may change over time; as knowledge changes and as
18 products change, options change or may become more
19 limited. Sometimes it is useful to think about not only
20 the evidence we have heard but the absence of evidence.

21 What evidence have we seen that reflects upon
22 discussions with patients about the relative severity of
23 their haemophilia and how that affects treatment options
24 or of medical advice?

25 What evidence have we seen or heard which shows us

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1 expect them to come up on screen, I have some points to
2 go on the screen, and Lawrence knows them, as we go
3 through -- the reference for that is BMAL0000082,
4 page 9.

5 So this document from the BMA, *Professional*
6 *Standards* document, in the early '70s, discussed the
7 need for patients:

8 "... to maintain good communication and exchanging
9 information to patients and, of course, maintaining
10 patient confidentiality."

11 So have we found within this evidence over these
12 years any real explanation of why obtaining consent for
13 treatment was ignored? There are, we suggest, some
14 pointers. WITN3437002, page 24, Dr Winter says this:

15 "Relevant to this is that the nature of haematology
16 training changed in the mid-'70s. Prior to this,
17 haematologists had been trained in laboratories. But
18 under the new system haematology training required
19 postgraduate experience of general medicine and the
20 passing of the Royal College of Physicians exam. When
21 viral contamination issues emerged [he went on to say],
22 some centres were managed by doctors with very limited
23 experience in breaking bad news."

24 In his evidence to the Archer Inquiry, Dr Winter
25 made a similar point at page 90 of the transcript. He

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1 said this:
2 "Haemophilia was really a branch of pathology prior
3 to that and the senior haemophilia doctors had worked in
4 laboratories. They were gifted academics, they were
5 scientists, they were not experienced in, for instance,
6 dealing with very sick people."

7 In her interview for the Royal College of Physicians
8 Oral History Project, Professor Lee said of
9 researchers -- she spoke in this way about researchers:

10 "You would be wasted on medicine", she said.

11 "Well, tell me more about that", she was asked.

12 "I think that people who did pure science and
13 particularly at that time biochemistry was pretty new
14 science, regarded medicine as rather a simpler option
15 really, a less scientific option."

16 Reference to that is MACK0002586.

17 So there may have been a tension in haematology
18 between those of a more scientific background and those
19 trained primarily as physicians. Part of this issue may
20 be that haematologists came from a pathology background,
21 meaning that they did not come from a patient treating
22 background.

23 Such attention could and might explain some of the
24 differences in treatments administered by
25 haematologists. Dr Dormandy at the Royal Free as an

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1 Now, I will refer a few times to Peter Jones. He is
2 a name that's familiar to all. Didn't give evidence.
3 There are reasons for that. But he was a significant
4 person and a significant doctor, a significant
5 individual within the UKHCDO:

6 "Dear Mr and Mrs Longstaff,

7 "I am sorry that you could not come to the last
8 clinic and I enclose another appointment. You will have
9 received a letter from Lord Mayor Treloar asking for
10 your permission for Peter to participate in the special
11 trial of regular factor VIII injections."

12 Referring to other individuals:

13 "... parents have also been asked for their
14 permission. I saw the [redacted] last week and
15 explained that I was in complete agreement with the
16 trial and that it could do nothing but good for the boys
17 and for other patients."

18 Then the sales job:

19 "It has been most carefully worked out, was
20 discussed at the last meeting of the Haemophilia
21 Directors in Oxford, and has the support of the Medical
22 Research Council of the United Kingdom. I will of
23 course be extremely happy to discuss any points that
24 concern you about the trial when I see you, but wonder
25 if you would feel able to sign the acceptance form for

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1 example. Or the fact that some physicians -- Dr Winter
2 is an example of this -- made early switches to
3 heat-treated products based on their assessment of the
4 evidence at the time, whereas others, I'm being
5 generous, perhaps more rooted in scientific backgrounds,
6 were slower to move away from what were the obvious and
7 better treatment options.

8 It is possible differences in haematologists may
9 have arisen because those trained as physicians were
10 more focused on the condition of their patients, whereas
11 those whose training was rooted in pure science might
12 have been more inclined to wait until facts had been
13 established to a scientific standard of proof.

14 Let's have a look at 1973. Bearing all those points
15 in mind, let's have a look at 1973.

16 Lawrence, this is the first of the documents,
17 please, on the screen, WITN1055172.

18 Sir, this is a letter from Dr Jones at the Newcastle
19 Haemophilia Centre to Mr and Mrs Longstaff, the parents
20 of Peter Longstaff, who grew up and married Carol
21 Grayson.

22 A small point, but a point I will refer to later on
23 in these submissions, top right-hand corner, obviously
24 the heading, "Newcastle Haemophilia Centre", "Attic
25 Laboratory". 12 April 1973 is the date.

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1 Lord Mayor Treloar at this stage. I saw the doctors
2 concerned in London yesterday and they are trying to get
3 things organised for next term."

4 "Nothing but good". 1973. That's what's being
5 explained.

6 I turn now to my chapter heading which is "Risk".
7 Sir, a risk is a risk is a risk. You have been
8 addressed in differing ways trying to discuss with you,
9 sir, how to address the question of risk. Most if not
10 all treatments carry a risk of harm. Any "only
11 over-the-counter" medication will also carry a long
12 explanation in the tiniest of writing detailing the
13 known possible common and less common side effects.
14 Those are risks.

15 With blood products there is no need for debate; it
16 was always known that blood products bring with them the
17 risk of hepatitis. I repeat, a risk is a risk is
18 a risk. The words "possible risk" or its cousin
19 "potential risk" add nothing to the debate.

20 Clinicians knew of the risk from blood products.
21 Professor Tuddenham explained, WITN3435002, page 14:

22 "When I first began to treat people with haemophilia
23 at Liverpool Royal Infirmary in 1969, my senior
24 registrar told me the tragic story of a patient with
25 severe haemophilia A who had resisted being treated with

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1 cryoprecipitate because of fear of hepatitis. He had
2 come in with severe bleeding and my colleague convinced
3 him to have cryoprecipitate infusions. They controlled
4 the bleeding, but the patient developed hepatitis and
5 dies. From that time, I was well aware of the
6 potentially fatal consequences of treating haemophilia
7 with blood products and that the risk increased with
8 donor exposure."

9 Those risks could not have been more clearly
10 expressed than by Richard Titmuss in his book *The Gift*
11 *Relationship* in 1970. Chapter 8, page 142:

12 "To the recipient the use of human blood for medical
13 purposes could be more lethal than many drugs. The ...
14 use of ... certain blood products carries with it the
15 risk of transmitting disease, particularly serum
16 hepatitis ..."

17 He goes on to then refer to malaria, syphilis and
18 brucellosis. He then says this:

19 "in the United States, Britain and other modern
20 societies the most dangerous of these hazards is serum
21 hepatitis. It is becoming a major public health problem
22 throughout the world. No scientific means have yet been
23 found to detect in the laboratory the causes agents ...
24 in the blood before it is used for a transfusion or for
25 conversion into ... blood products. The quantity of

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1 '68, Professor Zuckerman's letter to the BMJ
2 entitled the *Price of blood*, warning of the dangers of
3 using paid donors and the greatly increased hepatitis
4 risk. Reference LDOW0000210, page 2.

5 Mr Aldworth KC submitted in the morning of
6 27 January of this year that paternalistic attitudes may
7 have been at least a partial basis in the clinicians
8 believing that they should spare the patients the worry
9 about the consequences of hepatitis.

10 And he argued -- I put it in my terms -- that it was
11 only after the studies in the later '70s, which he
12 suggests revealed the longer term effects of hepatitis,
13 that doctors became generally more aware of the risks.

14 Now, there have been some other submissions made
15 from this lecturn saying that it was only in the later
16 '70s that there was this increased awareness of the risk
17 within the profession.

18 Now, why is that submission being made?

19 Well, presumably, the point of making a submission
20 which is that the awareness of risk grew in the later
21 '70s, is that the blame and culpability should be
22 considered as having a late starting point after the
23 studies which related to biopsies concerned with liver
24 damage, Preston and the like.

25 It seems that from those submissions, that, sir, the

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1 infected blood that can transmit hepatitis may be as
2 little as one-millionth of a millilitre."

3 The risk from contaminated blood and blood products
4 leading to hepatitis were well known for years within
5 the medical profession.

6 Another example, in '43 it is referred to, in fact,
7 FACT000005 in 1943:

8 "Medical officers of the Ministry of Health
9 published a memorandum on homologous serum jaundice, in
10 which they stated: any doubt as to the reality of the
11 association is removed by the frequency with which
12 hepatitis has followed the injection of human blood
13 products."

14 The danger was recognised to be particularly acute
15 in pooled plasma products in journals in 1946,
16 RLIT0000052, where it was recommended that "pooled
17 plasma should not be used prophylactically" and "only
18 small pools should be used for transfusion purposes".

19 The further article in 1947, RLIT0000054, physicians
20 are advised that transfusion therapies should only be
21 administered when the clinical indications are absolute.

22 In 1966, RLIT0001219, the British Medical Journal,
23 BMJ, reported a high incidence of hepatitis transmitted
24 to patients who had been given whole blood or blood
25 products.

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1 Inquiry is being pointed in the direction of a finding
2 that with a growth of knowledge, or we presume at least
3 the availability of knowledge of these facts, that it is
4 from that stage the failings, which had been wrapped up
5 in the warm comfort blanket of the paternalistic
6 attitude designed to protect patients from the truth,
7 really started to hit patients.

8 We reject those arguments. They fall away against
9 the strong body of evidence that there was a general
10 knowledge, set out in detail within the Inquiry
11 presentations, within the material that has been long
12 sought through the diligent work of campaigners and
13 preserved, which demonstrates that blood and blood
14 products were well known to be dangerous well before
15 licensing and the common use of blood concentrates.

16 Clinicians did know that the risk from use of blood
17 and blood products was real. They always knew that.
18 They did know that the risk was serious. They did know
19 that, from the get-go, that infection with hepatitis
20 might mean death or serious illness. Blood and blood
21 products have long been known to pose a risk of death:
22 a killing risk.

23 We ask instead that the Inquiry, that you, sir, find
24 that in those early days the medical risks to patients
25 were known. Of course, there was a manifestation and

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1 the use of the moniker "non-A, non-B" and later turning
2 to hep C -- interestingly though Dr Wallace in Edinburgh
3 in his book about blood transfusion was already
4 referring to it as hepatitis C in, I think, 1975/76.

5 Now, what was going on, we suggest, was always
6 an enormous experiment in treatment on haemophiliacs.
7 Now, that doesn't absolve the doctors and clinicians
8 from responsibility but instead emphasises the
9 responsibility to inform the patient. In other words,
10 the responsible treating physician at the time should
11 have said -- if they believed that blood concentrates
12 was the right treatment, they should have said "We think
13 that these products will treat your haemophilia but
14 there are very real risks of infection with hepatitis
15 which can sometimes be serious and which might kill you
16 faster than non-treatment or treatment with other
17 options".

18 The point has been raised in the Department of
19 Health's submissions, and indeed by Mr Cory-Wright KC on
20 behalf of the Blood Transfusion Service, that access to
21 materials, research materials and the like, was more
22 limited in the past.

23 Okay, now there is a limited point to be made here.
24 It is right that perhaps obscure journals from remote
25 parts of the world might not have been as accessible as

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1 contributing to the pool, were discussed in the past,
2 leading up to the '70s. The leading haemophilia doctors
3 were aware of this and discussed it amongst themselves.

4 I turn to my next document to go on the screen,
5 which, Lawrence, fingers crossed, should be NHBT0000055.
6 As we see, this is a discussion about "Management of the
7 Haemophiliacs, Second and Third Meetings of European
8 Home Therapy Group Held in Newcastle upon Tyne (1976)
9 and Madrid (1978), Edited by P Jones and
10 J Martin-Villar", reference also to the *Scandinavian
11 Journal of Haematology*, supplement numbering something.

12 Can I then please go -- I think you have the right
13 page -- 62, on the screen. It is the bottom two
14 paragraphs, if you can highlight those. The first
15 paragraph helps us and this tells us what should have
16 been discussed with patients, the whys and wherefores,
17 what is useful to know.

18 Set out here is reference to -- I'm going to say his
19 name very wrong, I'm sure -- Dr Panicucci:

20 "The widespread use of plasma fractions in the home
21 and hospital treatment of haemophiliacs has brought not
22 only advantages, but also a significant disadvantage.
23 Factor VIII or IX activity is much greater in
24 freeze-dried concentrate than in cryoprecipitate or
25 plasma. They are also more stable and have a much more

27

1 they are now, using the power of the internet and the
2 advent of digital libraries. But most of the literature
3 that we have considered and has been considered by this
4 Inquiry has been mainstream, and we are talking about
5 specialists in the field, haematologists.

6 Three examples of the many well-known publications
7 are hard to miss sources of information: prince, AM and
8 others in 1974, his article *Long incubation,
9 post-transfusion hepatitis without serological evidence
10 of exposure to hepatitis A virus* in *The Lancet*; Craske,
11 1975, reporting a rise from 3 to 50 per cent of his
12 patients among his group of patients with haemophilia,
13 with 58 being infected and two deaths; an outbreak of
14 hepatitis associated with intravenous injection of
15 Factor VIII concentrate, reported clearly in *The Lancet*.

16 Wider information available to all. In 1975, the
17 World in Action documentary travelled with hepatitis
18 expert Arie Zuckerman to the US to look at the types of
19 donors who were being used in what was described as
20 "Skid Row", plasma donation clinics. Zuckerman noted
21 that these were donors that the UK would have rejected
22 straightaway due to safety issues, describing them as
23 affront to human dignity.

24 Issues, such as the greater incidence of infection
25 from the use of pool blood or the increase in numbers

26

1 predictable action. Concentrates do not produce the
2 allergic reactions which sometimes occur with cryo
3 or plasma. They have made home treatment practicable and
4 major operations on haemophiliac much easier. These
5 concentrates, however, which are prepared from pools of
6 more than 1,000 units, may expose the patients to a high
7 risk of contracting transfusion hepatitis. Random
8 observations during routine examinations revealed a high
9 incidence of elevated liver enzymes in patients with
10 haemophilia.

11 "112 of our patients with severe haemophilia A or B
12 and 24 with mild to moderate forms, were studied to
13 determine the incidence of liver damage which may have
14 resulted from blood product therapy. Physical and
15 biochemical examinations were performed on all the
16 patients at 3 and 6 month intervals. Most of them had
17 been heavily exposed to commercial concentrates. Only 4
18 patients had never received concentrates, whereas 23 had
19 received concentrate on more than 100 occasions. Acute
20 hepatitis with jaundice was found in 23 patients: 12
21 children ..."

22 In a nutshell, this discussion embodies either the
23 reason why blood concentrates should not have been used
24 or what should have been explained to patients so that
25 they can make their choice.

28

1 Now, I have considered with you, sir, the evidence
2 of knowledge of risk and the dangers of infection with
3 hepatitis but how well was the risk of hepatitis from
4 blood products known more generally within the medical
5 profession? In other words, is there a possibility that
6 it could have been missed by some doctors, even though
7 this was their special area of work?

8 Now, this is why we have had these submissions about
9 the lack of internet access, limited availability of
10 communications and the slowness of snail mail but they
11 want a finding, sir, from the Inquiry that doctors had
12 a limited knowledge of this matter. But the evidence
13 tells us that the dangers of hepatitis being transmitted
14 through blood or blood products was absolutely the stuff
15 of common medical knowledge.

16 The notes of the meeting of the Hepatitis Advisory
17 Group refer to their discussions on the 11 January 1971
18 at Alexander Fleming House, reference DHSC0000114.
19 I quote:

20 "Professor Dogood observed that the hepatitis hazard
21 was not only an anxiety for renal units, it was a matter
22 for the whole hospital and others to concern themselves
23 with. Communication was vital and material to be
24 communicated. It therefore followed that records of
25 tests and incidents should be kept assiduously. He

29

1 to his own transcript of that at PRSE0006080:

2 "I recall that routinely laboratory products and
3 request forms from patients who had received blood
4 products had yellow dangerous specimen labels applied."

5 Paragraph 27 of his statement, Dr Lowe said this:

6 "As a clinical medical student in 1970 to 1972,
7 I was taught about hepatitis A and B. I recall one of
8 our questions in the final examination in medicine in
9 1972 was write an essay on hepatitis. As a house
10 officer in '72 to '74, I was taught the risks of
11 transmission of hepatitis, including hepatitis B, from
12 blood products."

13 It was Dr Lowe who referred in his statement at
14 paragraph 23.1 and who recalled the reference to
15 hepatitis in Colin Douglas' book, *The Houseman's Tale*,
16 a copy of which I have here. That was first published
17 in '75. The author Dr Douglas graduated in medicine at
18 the University of Edinburgh in 1970. His book includes
19 a reference to a clinician colleague who Dr Campbell,
20 the main character in the book, visited. Page 198:

21 "Campbell hurried along to the isolation unit,
22 a building on its own, beyond the coke dumps and the
23 disused tennis courts."

24 He continues in his book, describing the building as
25 having taken over by a specialist medical unit to

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1 undertook to prepare a passage for the report in this
2 sense."

3 The document also refers to a comment by Sir Michael
4 Woodruff, who suggested that, as regards renal units,
5 ideally he would like to have three areas in the unit,
6 white, yellow or confirmed cases and grey for suspects,
7 especially new cases, going on to say that the grey area
8 might use peritoneal dialysis.

9 Within that document there is a question raised, if
10 you care, sir, to look at it, about whether nurses that
11 had been employed in renal units which were found to, in
12 fact, have carried an infection should then be employed
13 in units which were described as "maiden units", those
14 that didn't have or haven't had an infection.

15 So there is clear knowledge within the wider medical
16 profession of the dangers of hepatitis. Of course, you
17 will recall the recollections that have been addressed
18 earlier on, with other submissions, of Dr Winter. I now
19 refer to Dr Tuddenham.

20 Sorry, you have already been referred to the
21 recollections of Dr Winter and, indeed, I have referred
22 to Dr Tuddenham. I now make reference to Dr Lowe's
23 statement at paragraph 7.1, WITN3496013. Dr Lowe said
24 this:

25 "As I stated at the Penrose Inquiry", and he refers

30

1 intensive care and barrier nursing facilities for
2 dangerously infected patients. On arrival, the
3 fictional character in the book, Dr Campbell put on
4 "a disposable mask, overshoes, a gown, a white unfestive
5 paper hat and a face mask". In the book it is Christmas
6 time. The book continues and describes the patient:

7 "Mack was sitting up in his cubicle smiling and
8 faintly jaundiced.

9 "Welcome to the pest house. They tell me I've got
10 the yellow peril and it'll be six months off the booze."

11 "Which of the yellow perils, is it?' Campbell
12 asked, 'Plain or fancy?' There were two types of
13 hepatitis, one of which killed people, serum hepatitis
14 did, and was less common but more likely to occur among
15 hospital staff. Mack said this:

16 "They are running a test now but from the way they
17 are treating me I'd say that it is the real fancy, no
18 messing about, nasty serum stuff. They are taking no
19 chances. You know Ivor, the SHO here, he came at me for
20 blood dressed like a deep sea diver, you know bootlets,
21 gauntlets, a thing like a welder's mask on. It made me
22 feel I wasn't nice to know."

23 Now, that's not the first time that transmission of
24 hepatitis in blood-borne viruses was or had been
25 referred to in a medical comedy. In M*A*S*H, the

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1 American series based in the Korean war, series 1,
2 episode 11, titled "Germ Warfare", in which
3 a transfusion of blood from Major Burns is suspected of
4 having transmitted serum hepatitis to a patient, giving
5 rise to comedic attempts to stop Major Burns associating
6 with Major Houlihan or attempting to operate as
7 a surgeon. The date of that broadcast, that episode,
8 was 10 December 1972.

9 Submissions which attempt to say that the
10 non-existence of the internet and digital library
11 resources until much later in the 20th century hamper
12 our understanding or that we must be wary of
13 hindsight -- reference to the Department of Health's
14 written submissions 1.23 onwards -- those submissions
15 must, sir, we say, be reviewed with care.

16 First, that some of the earliest materials
17 identifying the connection between jaundice and blood
18 products came, in fact, from the Ministry of Health, as
19 it then was, and not, as it seems that some of the
20 closing submissions are attempting to say, from some
21 type of obscure, hard to get at, unrecognisable source.

22 Second, doctors have expressed before this Inquiry
23 their very own real understanding of risk from blood,
24 which may cause a serious and potentially fatal
25 hepatitis from the earliest days of their practice.

33

1 view describing and setting out what it is that they
2 would want to say?

3 If we go, please, now to RLIT000041_0001. Sir, the
4 book on the screen from Relativity is the first edition,
5 1974, of this book which I'm holding in my right-hand,
6 which is the second edition, I think 1984.

7 If I can then go please very shortly to the sixth
8 page, same reference, a very small point. We see first
9 of all that the book is dated '74 and in reference to
10 the letter to Peter Longstaff's parents we looked at
11 earlier, you will see at the top right-hand corner of
12 that, referring to the Attic Lab. This book was
13 dedicated to those individuals and to the Attic Lab
14 where it all began. Take us to page 0079, bottom
15 right-hand corner. Chapter 5 is headed, "Treatment 1 --
16 Therapeutic Materials":

17 "Most of the materials used in the treatment of
18 bleeding disorders are derived from human blood. This
19 is provided by voluntary donors and is collected by
20 a transfusion service which may be local or national; in
21 the United Kingdom the donors receive no payment for
22 their generosity.

23 "The blood is taken at special sessions arranged in
24 localities suitable for the majority of donors in
25 a particular area; these might be in factories,

35

1 Third, it was of such common knowledge that
2 fictional sources, medical dramas, demonstrate that this
3 was common knowledge both in the UK and the United
4 States.

5 It was wrong to leave patients without
6 an explanation about the possible consequences of
7 infection. The fact that we know, as we have gone
8 through, that hospitals themselves clearly viewed the
9 risk of potential harm from hepatitis to be serious, and
10 that they took steps themselves to warn each other of
11 the dangers of blood that is just drawn from people with
12 haemophilia demonstrates, we suggest, a clear double
13 standard.

14 Patients need to be told. The fact that hepatitis
15 was a risk to the patient and a risk of onwards
16 transmission should have been discussed with that
17 particular patient at that time to say, not only is this
18 a risk to you, but there is a potential risk to your
19 loved ones and others. We suggest that that was a clear
20 duty that existed and always existed.

21 But having identified the risk of hepatitis, how was
22 that translated into patient care? Well, we heard from
23 the patients in their evidence about how they were not
24 informed of the risks or that it was minimised. So what
25 contemporary evidence exists from the clinician point of

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1 universities, church halls or recreation centres.
2 Donors already enrolled in the area will often be
3 notified of the session but new donors are always
4 welcomed without prior arrangement. In order to give
5 blood a donor must be an adult in good health and not
6 known to carry a communicable disease ...

7 "After a session the labelled packs of blood are
8 taken in a refrigerated van to the central laboratories
9 of the transfusion service. Here they go through
10 a series of stringent tests to exclude infection,
11 including serum hepatitis, and to make sure that the
12 blood groups on the labels are correct."

13 1984, jumping ahead, same book, same paragraph,
14 "Treatment 1 -- Therapeutic Materials", page 81. This
15 is not going to go on the screen:

16 "Most of the materials used in the treatment of
17 bleeding disorders are still derived from human blood."

18 So 1984, same book/version:

19 "Most of the materials used in the treatment of
20 bleeding disorders are still derived from human blood.
21 This is provided by the voluntary or paid donors and is
22 collected by a transfusion service which may be local or
23 national. In several countries, including the United
24 Kingdom, the donors receive no payment for their
25 generosity. In other countries, most especially in the

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1 United States, donors are paid a modest amounts for
2 their blood plasma, which is then processed by one of
3 the commercial companies."

4 A very similar paragraph we looked at in the 1974
5 version:

6 "After a session, the labelled packs of blood are
7 taken in a refrigerated van to the central laboratories
8 of the transfusion service. Here they go through
9 a series of stringent tests to exclude infection,
10 including serum hepatitis and to make sure that the
11 blood groups on the labels are correct."

12 That's 1984.

13 We say this in our written submission,
14 paragraph 334, page 112, we made reference at that stage
15 in our written submission to the 1974 book but I suggest
16 it applies equally to the '84 book.

17 A reader would be forgiven for understanding this
18 chapter to say that factor concentrates used in the UK
19 were sourced from British volunteer donors, whose blood
20 had been screened to all but exclude the risk of
21 hepatitis. In fact at the point of publication in 1974
22 two commercial products, Baxter's Hemofil and Immuno's
23 Kryobulin had been licensed, both sourced from foreign
24 paid donors and both manufactured from pools well in
25 excess of several donors. Even NHS pools, we say, were

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1 treatment which falls below the standard of a reasonably
2 competent medical practitioner.

3 That is not and cannot be right. If somehow you
4 choose to treat someone without their consent then that
5 means the onus is on you to get it right, not just the
6 treatment itself but the choice of treatment.

7 In taking choice and information away from
8 a patient, in deciding to take their decision for them,
9 you assume responsibility for the appropriateness of
10 that treatment and for the consequences of getting that
11 risk-benefit analysis wrong.

12 This was done, as we know, many, many times in the
13 general treatment of haemophiliacs and the misdiagnosed,
14 many of whom should never have been exposed to the risks
15 posed by blood concentrates. We repeat, lack of consent
16 is not an excuse for lack of care.

17 So, other medical choices. So what were the
18 possible medical choices? Katharine Dormandy,
19 Dr Dormandy ran an apparently successful home treatment
20 programme from the Royal Free using cryoprecipitate
21 until 1978.

22 In his statement, WITN3496013, Professor Gordon Lowe
23 said:

24 "For treatment or prevention of a bleed in such
25 patients, I said that the combination of desmopressin,

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1 several hundred rather than several donations in size by
2 the time of the publication.

3 Now, these books were written for the families of
4 haemophiliacs, for haemophiliacs to understand about
5 their treatment. They were deliberately designed for
6 that purpose. So when you consider everyone's evidence
7 against the contemporaneous materials published by
8 an eminent and very well known haematologist, setting
9 out the advice for patients in his published works, we
10 suggest that doctors routinely failed to advise
11 haemophiliacs as to the inherent dangers of this type of
12 treatment, despite the fact that they and the rest of
13 the medical profession knew of the risks.

14 I started with three particular points. May
15 I emphasise the second one. We suggest that the issue
16 of failure of consent needs to be considered for what it
17 is. If any doctor at any time or date proceeds to treat
18 without consent, that emphasises the burden on the
19 doctor to get it right, and get it right for that
20 patient, and get it right given the state of medical
21 knowledge. Not to get it wrong, not to muck it up.

22 What some have referred to as a paternalistic
23 approach to consent appears at times to have been
24 equated with doctors having a licence to give poor
25 treatment or, as Ms Milligan would have me say,

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1 and the response to injury (which also raises level of
2 Factor VIII/von Willebrand factor), often allowed us to
3 not have to give blood products."

4 In evidence to the Lindsay Tribunal, Dr Brian Colvin
5 discussed how treatment with concentrates was more
6 fashionable than using cryoprecipitate. He stood by
7 this and repeatedly emphasised his view during his
8 evidence to this Inquiry. In his evidence to the
9 Lindsay Tribunal, Dr Colvin said this:

10 "It was certainly my policy to try to give children
11 cryoprecipitate, because children are small and they can
12 be treated with perhaps one or two or three donor units
13 of cryoprecipitate. I think there was a feeling amongst
14 some haemophilia treaters that the cryoprecipitate
15 approach was rather old-fashioned, and indeed in many
16 ways perhaps it was, but I think I was trying to use
17 cryoprecipitate not to prevent HIV infection but to try
18 to limit the amount of non-A, non-B infection in my
19 children's community."

20 An example of what happened instead, of course, is
21 that -- I use -- I made a reference to
22 Ms Colette Wintle, a teenager in 1976, supposed to be on
23 cryoprecipitate, it was typed in her notes, a reference
24 to cryoprecipitate struck through, instead replaced with
25 a reference to Factor VIII.

40

1 Given after that point Hemofil, possibly one of the
2 most dangerous of the products at that time.
3 Another example, Peter Longstaff, Ms Grayson's
4 husband, a severe haemophiliac, was treated successfully
5 throughout his early life with cryoprecipitate.

6 In this Inquiry we have all too often concentrated
7 on the question of consent when in fact we should have
8 been thinking in terms of patient choice. The evidence
9 tells us that haemophiliacs believed that they were
10 being treated by compassionate doctors who only had
11 their best interests at heart. The Haemophilia Centres
12 and their haemophiliac patients became part of each
13 other's lives, and we heard evidence, didn't we, about
14 social events and family events attended by haemophilia
15 clinic staff members.

16 I suggest it must feel to the victims of this
17 scandal, the haemophilia victims of this scandal and
18 indeed others, that there cannot be a greater betrayal
19 of trust, sir, because of what they perceived was the
20 special relationship they had with their doctors. This
21 closeness also attacks the patrician discussions that
22 have been presented to you, as it might be thought that
23 the very close relationship between these doctors and
24 their patients should have demanded truth and clarity in
25 medical advice.

41

1 my practice background. I come from a criminal defence
2 practice background. So, for me, this has been a little
3 like doing a case without looking at the murder weapon.
4 Its very medical appearance is part of its seductive
5 qualities. But for haematologists, the revolution that
6 started with cryoprecipitate was complete. The lives,
7 they thought, and the lifespan, of haemophiliacs had
8 changed. This was referred to at some stages in the
9 evidence as the "golden period", the theory being that
10 no longer would haemophiliacs drop down dead from the
11 near mythological brain bleed.

12 It seems likely that, so entranced with this new and
13 seemingly great treatment, that they ignored the
14 screamingly obvious: this treatment will -- not maybe,
15 but will -- expose the patient to whatever disease was
16 in the blood of the person who gave that blood. And
17 when you start moving to pooled blood, you reach a stage
18 where, the evidence tells us, there was essentially
19 a certainty of infection.

20 Sir, I have a note from Mr Harrison saying this may
21 be an appropriate time to have our break. The next
22 section will take more than five minutes.

23 **SIR BRIAN LANGSTAFF:** This is "Other choices"?

24 **MR STEIN:** I'm moving on to "Experimentation", sir. I'm
25 slightly behind.

43

1 This isn't the situation that we saw in the Carry On
2 films of Dr Lancelot Spratt, wandering around his clinic
3 doing his rounds, that distance between consultant and
4 patient. These are the haemophilia consultants
5 themselves engaging very closely with their patients,
6 knowing that people had families, and indeed meeting
7 their families. And they knew, therefore, that when
8 treating an individual about the risks of haemophilia
9 not only for the transmission to the individual, but the
10 concern that was expressed across all medical literature
11 as to the onward transmission to others.

12 Now, we accept that there is no actual evidence that
13 haematologists had money paid into Swiss bank accounts,
14 or that they sat down with a large brandy in hand and
15 plotted the extermination of haemophiliacs. So what on
16 earth were they thinking?

17 We believe they fell in love with blood
18 concentrates. They were seduced by it. It was easy to
19 use and it was, on the face of it, effective as
20 a treatment.

21 Can we have on screen, please, the image of
22 Factor VIII.jpg, please.

23 Here it is. Teeming with infectivity.

24 I'm not sure in this Inquiry that we have looked at
25 a bottle of the Factor VIII before. And, sir, you know

42

1 **SIR BRIAN LANGSTAFF:** Let's take the break now then, shall
2 we, and come back at 11.40 am.

3 **(11.11 am)**

4 **(A short break)**

5 **(11.40 am)**

6 **MR STEIN:** Sir, may I just make one small correction. I'm
7 very grateful to Ms Milligan for bringing this to my
8 attention.

9 I referred to a reference, which is FACT000005, to
10 the 1943 Ministry of Health memorandum. She expressed
11 to me, and she is right, that the reference should in
12 fact be NHBT0000091_011.

13 Instead, sir, of patient choice, the shadow of
14 experimentation looms large over this Inquiry. The
15 evidence from victims tells us consent was not freely
16 given, but the disturbing evidence that concerns
17 experimentation and clinical studies is obvious and
18 before us. The "only good" letter we examined earlier
19 bears on this issue for obvious reason.

20 We have had examples of this. I'm going to be
21 referring at the moment to the Royal Free.

22 The Royal Free's late adoption of concentrates gave
23 rise, we suggest, to a greater responsibility on behalf
24 of Drs Kernoff and Tuddenham to weigh the benefit versus
25 risk of concentrates to each individual patient.

44

1 It was well known by 1978 that NANB was a particular
2 risk in concentrates. It was not believed at that time,
3 that was what was thought, to be so prolific a risk in
4 cryoprecipitate. We suggest that there is a connection
5 between Drs Kernoff and Tuddenham switching patients to
6 concentrates and at the same time retaining a policy of
7 obtaining blood samples from patients in order to study
8 hepatitis.

9 The late adoption of concentrates at the Royal Free
10 put the physicians there in a particularly advantageous
11 position when in 1982 the risk of AIDS became apparent,
12 because there had only been a relatively short interval
13 since the use of cryoprecipitate had stopped.

14 We suggest that there was another choice available
15 but not taken, that Drs Kernoff and Tuddenham failed to
16 take advantage of at the Royal Free, which was to
17 acknowledge the experience of cryoprecipitate treatment
18 and revert to it, reducing the possible incidence of
19 further infection with AIDS.

20 Professor Lee gave evidence to the Lindsay Tribunal
21 concerning the organisation at the Royal Free, prior to
22 '78. The reference is at LIND0000326_0005.

23 Well, at the Royal Free they went on using it
24 probably for longer than other places, and this was
25 because Katharine Dormandy had this pioneering

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1 by Dr Goldman. As soon as Dr ... Kernoff arrived as my
2 co-director in mid-1978, he took that over ...
3 Dr Kernoff, with his research interest in blood
4 transmitted hepatitis instituted a plasma/serum bank of
5 stored frozen samples, taken regularly from patients
6 attending for treatment."

7 Why was the Royal Free attractive to
8 Professor Kernoff? Logically, given his interest in
9 post-transfusion hepatitis, would it have not made more
10 sense for him to look for a position in a centre with
11 a higher incidence of post-transfusion hepatitis?

12 It is possible that Professor Kernoff's attraction
13 to the Royal Free was the comparative number of patients
14 who had not by '78 been exposed to large pool
15 concentrates.

16 We suggest that the work of Professors Kernoff and
17 Lee in their '85 paper entitled "High risk of non-A
18 non-B hepatitis after a first exposure to volunteer or
19 commercial clotting factor concentrates" would
20 constitute clinical research, in that Professor Kernoff
21 altered the treatment of haemophilia patients with the
22 intention of following them up and establishing the rate
23 with which they became infected with post-transfusion
24 hepatitis.

25 Now, in the early days of the use of blood

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1 experience, I suppose, and was very enthusiastic about
2 cryoprecipitate. She, Professor Lee went on to say,
3 said, "I'm afraid our centres are full of disasters".

4 She in 1978, referring to Professor Dormandy, died,
5 just at the point the new centre had been built, and two
6 co-directors were put in, Dr Kernoff and Dr Tuddenham.
7 They were young doctors and they came in '78 and very
8 rapidly changed everybody to concentrate. There had
9 been some people who had had concentrate before then but
10 I think up until '78, the majority were still probably on
11 cryoprecipitate.

12 Dr Tuddenham tells us that when he came to the Royal
13 Free as the Haemophilia Centre Director in 1978,
14 Katharine Dormandy was terminally ill and the service
15 was then being run by Dr Eleanor Goldman, with the
16 assistance of a senior nurse.

17 Dr Tuddenham goes on to tell us how arrangements
18 changed once he and Professor Kernoff took their
19 directorships. That is in reference WITN3435002_0009.

20 He says:

21 "To begin with obtaining supplies of treatment
22 materials, cryoprecipitate, plasma, NHS concentrates of
23 factor IX or factor VIII ..."

24 Sorry, I will change that in a moment:

25 "... and commercial factor concentrates was handled

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1 concentrates as treatment, and essentially during the
2 time whereby there's evidence before this Inquiry of
3 experimentation, it wasn't in fact that long ago. In
4 1947 we had the drafting of the Nuremberg Code. The
5 Nuremberg Code emphasises that voluntary consent of the
6 human subject is essential when experimenting on them.
7 And I quote:

8 "This means that the person involved should have
9 legal capacity to give consent; should be so situated as
10 to be able to exercise free power of choice, without the
11 intervention of any element of force, fraud, deceit,
12 duress, overreaching, or other ulterior form of
13 constraint or coercion; and should have sufficient
14 knowledge and comprehension of the elements of the
15 subject matter involved as to enable him to make
16 an understanding and enlightened decision."

17 In a moment I will turn to licensing and discuss its
18 role in the facts that you have to consider, but before
19 I do let me summarise what we say about consent, the
20 timely provision of information, experimentation and
21 harm and the consequences that may follow.

22 The criminal law is, in effect, the bottom line of
23 regulation. Criminal law says that if people harm each
24 other then there will be consequences. Doctors have no
25 special immunity. A doctor treating a patient and

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1 touching them for the purposes of a diagnosis and
2 possible treatment does so with the consent of
3 the patient who has come to the doctor for their medical
4 expertise.

5 Well, so far so good.

6 Haemophiliacs suffer from an inherited disorder
7 which means they require expert medical support
8 throughout their lives. If a doctor invasively treats
9 a patient without their consent and harm is caused, then
10 they open themselves up to a prosecution.

11 Now, of course, the CPS in this country or relevant
12 prosecution authorities in Northern Ireland and Scotland
13 will have to consider whether it is in the public
14 interest to prosecute any case, and some cases are
15 clearer perhaps than others.

16 I was discussing this the other day with
17 Clive Smith, the Chair of The Haemophilia Society. He
18 is an experienced criminal advocate as well. And his
19 point, a good one, is that there may be real clarity in
20 cases where patients were not told of their infected
21 status and passed on their infection to their partners.
22 That might mark a high point of criminality.

23 But all treatment without consent causing harm needs
24 to be considered through that, as I call it, the bottom
25 line of regulation, the criminal law.

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1 the use of concentrates. You, sir, have heard and seen
2 a great deal of evidence on the machinations of the
3 licensing regime. This effectively operated as a chain.
4 The Department of Health Medicines Division evaluated
5 the licensing application and sent it to the most
6 relevant specialist subcommittee of the Committee on
7 Safety of Medicines, the CSM, which, in the case of
8 blood products, went to the Biologicals Subcommittee.
9 The Biologicals Subcommittee fed its recommendations to
10 the CSM which, in turn, advised the Minister of the
11 Department of Health, who is the Licensing Authority.

12 Against a backdrop of the decades of awareness of
13 the risk posed by blood products that we have outlined
14 and particularly the risks from larger pools, one of the
15 central questions for this Inquiry to answer is how is
16 it that this country's regulator came to license the use
17 of large pool commercial concentrates in the early '70s?
18 That was a decision which undeniably and irrevocably
19 changed the landscape of risk.

20 The answer, perhaps, boils down to this, as with
21 those administering blood products: the regulators
22 failed if their duty to assess the risk by reference not
23 only to the harm it might cause but also to the relative
24 benefit to be gained.

25 Now, that was supposed to be the essence of the task

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1 Now, it is now 2023, and in some cases it has been
2 many decades, perhaps even 50 years since the individual
3 was infected. Time itself is no barrier to prosecution
4 of cases. You will have seen our discussion within our
5 written submission, sir, of the difficulties of the
6 operation of the old Year and a Day Rule that poses
7 particular problems for allegations of a homicide.

8 Obtaining the interest and engagement of local
9 police authorities is not going to be easy. It is
10 always going to be difficult. They will regard these
11 cases as complex cases. That doesn't mean that they
12 should not consider them but we have to accept that
13 there will be real difficulties in looking at that in
14 the future.

15 One of the factors that, sir, this Inquiry needs to
16 consider, the compensation framework needs to consider
17 in the future, is the lost opportunity for
18 accountability through criminal law and criminal
19 prosecution of individual doctors because of the passage
20 of time and the prevarication by the state and the
21 failure to own up or 'fess up to their own culpability.

22 Let me deal now and turn to licensing. In the
23 creation of this scandal, the perils of a system where
24 doctors decided to make their patients' choices for them
25 went hand in hand with a failure to properly regulate

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1 entrusted to them by section 19 of the Medicines Act
2 1968. They were asked to have particular regard to
3 safety, efficacy and quality.

4 The first product licences issued in respect of
5 concentrates were those for Hemofil and Kryobulin in
6 February and March '73. As we have already discussed,
7 at that time, it had been known for decades that blood
8 products carried a risk of virus, transmission and, more
9 importantly, that the risk increased as pool sizes
10 themselves increased.

11 We know that. As an example, a memo produced in
12 1946 from the Ministry of Health, DHSC01000008_191, the
13 Ministry's consultant adviser on blood transfusion wrote
14 at that time:

15 "Whilst homologous serum jaundice follows the use of
16 whole blood in very few of the recipients, the use of
17 dried plasma is followed by the development of jaundice
18 in about 10 per cent of those receiving it. This
19 incidence is probably halved if plasma is used which is
20 made from plasma pools derived from the blood of only
21 ten donors instead of from large pools derived from the
22 blood of greater numbers."

23 Can I emphasise plasma pools being referred to of
24 ten donors. Anything in that Ministry of Health
25 document above ten was a large pool.

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1 That was 1946. Come '73, the time of the licence
2 approvals, it was also known that imported blood
3 products, particularly those obtained from the US,
4 carried a higher degree of infection. In fact, that
5 very same month, an expert group was convened by the
6 Department of Health to create self-sufficiency targets.

7 The Inquiry's chronology quotes the Archer Report at
8 page 28, which states:

9 "In '73 the Department of Health convened a group of
10 experts to assess the likely future requirements of
11 Factor VIII concentrate. It met on 20 March 1973 and
12 quickly agreed that the UK shall become self-sufficient
13 in the shortest possible time. It estimated that to
14 achieve self-sufficiency would require 400,000 donations
15 of blood annually of which 275,000 should be used for
16 Factor VIII concentrates."

17 That effort was driven, at least in part, by the
18 Department's knowledge that foreign blood products
19 carried a greater risk of infection. That much was
20 admitted in the 2007 Self-Sufficiency Report, since
21 withdrawn as a result of the compelling critique in the
22 dissertation of our client, Carol Grayson.

23 There can be no room for doubt that the specialists
24 who constituted the Biologicals Subcommittee of the CSM,
25 as well as the CSM itself, were alive to these issues.

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1 short of recklessness. We know, sir, that this got
2 worse, pooling and re-pooling. There was a well
3 traversed path of apprehension towards larger pools of
4 plasma and for good reason. On the other hand, there
5 was a complete absence of evidence to justify increasing
6 pool size or testing under control conditions, compliant
7 with Nuremberg, those potential ways forward in relation
8 to possible ways of trying to establish safety, thrown
9 to the wind.

10 That reckless decision would prove to be a gateway
11 to the infected blood scandal. Thereafter, pool sizes
12 continued to sky rocket, climbing even to 50,000 donors
13 and then 300,000 donors, with the advent of re-pooling.
14 Infections, of course, sky rocketed.

15 These are not and were not complicated questions of
16 medicine which are now being interpreted with the
17 benefit of hindsight. This is a question of basic
18 maths. If exposure to one donor's blood poses
19 a percentage of risk, what happens when concentrate is
20 made from the blood of two donors: the risk doubles.
21 Children can do that sum. It should also be remembered
22 that the initial decision to license was not a binary
23 one. The Licensing Authority's choice was not merely
24 between yes to allowing concentrates or no to banning
25 concentrates. It had the power to work slowly and

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1 For example, in its consideration of the product licence
2 application for Hemofil, DHSC0105593_006, at
3 paragraph 26, the CSM noted:

4 "The major disadvantage of currently available
5 commercial preparation, such as Hemofil, is that they
6 are prepared from very large plasma pools and carry the
7 risk of transmitting hepatitis virus. Hyland screen all
8 their donors for hepatitis associated antigen, which
9 reduces but does not eliminate this risk."

10 We know that Hemofil at that time was prepared from
11 pools of at least 1,000 donors. Kryobulin was
12 manufactured from a plasma pool of at least 1,000
13 donors. See, in these terms, reference SHPL0000071_135.

14 A report from Dr Maycock in January 1973 noted that
15 pool sizes for Kryobulin were smaller than those for
16 Hemofil. That reference is MHRA00333322_057.

17 So we ask this question: how on Earth could the CSM
18 approve a jump from ten donors to 1,000 donors?

19 A Ministry of Health document from '63, ten years
20 prior, states that:

21 "All dried plasma or serum issued in the United
22 Kingdom is prepared from pools made from not more than
23 ten donors."

24 That is at JPAC0000162_021.

25 We submit that the leap in pool sizes was nothing

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1 incrementally and to impose safety conditions or
2 qualifications as a precaution.

3 Those conditions could have included, for example,
4 restricting pool sizes; only permitting blood from
5 certain sources; testing and batch release certificates
6 which could be combined with a cautious product rollout;
7 product warnings and guidance. All of those measures
8 could have controlled or mitigated the risk. Instead,
9 what happened? Everything was allowed in; caution
10 thrown to the wind.

11 Our submission on this decision-making is simple.
12 That expansion in donor exposure without controlled
13 measures cannot be justified now and could not be
14 justified then.

15 There was a failure by the Licensing Authority, the
16 CSM and its Biologicals Subcommittee to treat patient
17 safety with primacy. The CSM said in its consideration
18 of the Hemofil application, DHSC0105593_6:

19 "It may be considered that the decision to use this
20 material could be left to the individual clinician who
21 can balance the potential hazard against the anticipated
22 therapeutic benefit to the patient."

23 Similar risk benefit considerations were reported in
24 the CSM's reflections, informally relayed -- this is
25 from Norman Berry to Dr Eibl, and referred to in

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1 SHPL000665_142 at item 2.7, and these were shared in
2 relation to Immuno's 1973 application:

3 "The Committee see the justification of some risk of
4 hepatitis in treating a haemophiliac who would otherwise
5 die from haemorrhage."

6 Yet notwithstanding the CSM view or understanding
7 that the risk should only be entertained for those for
8 whom there might be grave consequences, that
9 qualification or caution did not appear anywhere whether
10 in licensing decisions or in requirements for product
11 literature. It should have done and, as we know,
12 clinicians did not take that approach, and they ought to
13 have done.

14 Now, although licences did not always run back to
15 back or for their entire period of five years, we
16 suggest that it is instructive to look at what was going
17 on and what was known every five years after those
18 initial licences. We fast forward to '78 and using The
19 Lancet alone as a source, although there are many
20 others, in a study by Professor Alter with inoculated
21 chimpanzees, it was concluded that NANB hepatitis seems
22 to be due to a transmissible agent which can persist and
23 remain infectious for long periods, PRSE0004515, and of
24 course a study by Professor Preston and his
25 contemporaries concluded that NANB hepatitis was more

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1 mechanisms.

2 Five years later in 1983, knowledge of the dangers
3 of HIV and AIDS have become part of everyone's lives.
4 What is more, at that stage, the CDC had published its
5 reports which linked the transmission of HIV to blood
6 products. The CDC notified directors of the Haemophilia
7 Centres and advised that patients and parents should be
8 aware of the potential risks. The reference to that is
9 BAYP0000018_119. Why didn't that happen here? Why did
10 the CSM and Licensing Authority not take similar
11 measures? Why instead were licensing continually
12 approved with increasing pool sizes and without
13 adequately controlled mechanisms?

14 The CSM's push for the Licensing Authority to move
15 towards heat-treated Factor VIII came very late in '84
16 and into '85.

17 I refer now to the minutes of the meeting of
18 22 November 1984, DHSC0003947_015.

19 Dr Joseph Smith informed the Committee that heat
20 treatment of Factor VIII, which is used in the treatment
21 of haemophiliacs, abolished detectable infectivity of
22 AIDS virus added to the preparation, therefore companies
23 should be encouraged to apply for the variation of
24 licences to permit widespread use of heat-treated
25 Factor VIII, so that the incidence of AIDS in

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1 serious and progressive than was generally thought to be
2 the case, PRSE0003622.

3 We also know that around that time the yellow card
4 system reporting to the CSM incidents of NANB hepatitis
5 following treatment from various Factor VIII products
6 and discussed in the recently served witness statement
7 of Anne Ryan, exhibits a table and seven such reports
8 from '79. The table, we have reference WITN7183007,
9 another reference to it is at WITN7183006. It is
10 unclear as to why they chose 1979 and what the records
11 from the earlier year show.

12 But those references should have resulted in action.
13 If one considers the 1989 affidavit of the CSM's
14 chairman in a judicial review relating to
15 anti-depressant licences, WITN6406024, Professor Asher
16 says this. This is at page 9, paragraph 15.2, that the
17 yellow card scheme distinguished between serious and
18 minor reactions. Serious reactions were to be defined
19 as those which were fatal, life threatening, disabling,
20 incapacitating, which result in or prolong
21 hospitalisation. Professor Asher said that blood
22 disorders would always be considered serious. Yet the
23 CSM and the Licensing Authority, the Ministry, were
24 still approving licensing and licences with ever
25 increasing pool sizes without adequate control

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1 haemophiliacs might be reduced.

2 The Committee -- this is the final paragraph --
3 requested that the Licensing Authority proposed to the
4 companies concerned that they make early applications
5 for variations to use a dry heating process in the
6 manufacture of their Factor VIII products. Even at that
7 late stage, the Authorities' approach was not to mandate
8 heat treatment, backed by a threat of pulling licences
9 or indeed to pull licences, but instead made proposals
10 to the manufacturers that they make early applications
11 for variations.

12 We suggest that a closer look reveals that the
13 Licensing Authority's approach to those variation
14 applications were slipshod and we say that they were
15 focused on external appearances rather than being
16 genuinely motivated by patient safety. Consider, for
17 example, in this regard, the internal Immuno
18 communications, SHPL00008_026, in which it was reported.

19 "Subject to minor alterations in title and
20 directions circular, we have been awarded a product
21 licence modification. We have, however, been informed,
22 both unofficially and officially, that the information
23 submitted by us for this modification was most
24 inadequate and, but for the panic situation which
25 existed to get everywhere on heat treated material as

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1 quickly as possible, we would have been turned down.
 2 They expected far better proof of inactivation with
 3 evidence obtained against six, seven or eight different
 4 viruses. They wanted greater evidence shown by clinical
 5 evaluation that the product remained equally effective
 6 and with no increase in side effects."

7 Make no mistake, sir -- make no mistake --
 8 a regulator truly motivated by patient safety would have
 9 pulled the non-inactivated products and only allowed
 10 those with adequate evidence of viral inactivation.

11 We repeat the actions of the CSM and the Licensing
 12 Authority were reckless.

13 Although we have presented our analysis by reference
 14 to those five year intervals, it must be remembered that
 15 those intervals, representing theoretical product
 16 licence renewal applications, were not the only or
 17 isolated windows of opportunity. The Licensing
 18 Authority had the power to revoke, suspend or vary
 19 licences at any time if the concentrates could no longer
 20 be regarded as safe or efficacious.

21 Despite all of the information that was known to
 22 those authorities, as this Inquiry has shown, those
 23 powers were never exercised. They should have been.

24 Again, the only reasonable conclusion to be drawn
 25 from that action or inaction is that patient safety came

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1 risks posed by the products and indeed of the developing
 2 science.

3 As we explain in our written submissions, the
 4 statutory regime only required the CSM's input were
 5 a licence to be refused. So the system was this: the
 6 statutory system was for an application to be made for
 7 licensing, that would go to the Medicines Division, and
 8 then if it were or might be rejected or refused it would
 9 then go to the CSM.

10 Although some of the evidence presented in this
 11 Inquiry has suggested that in fact the CSM's views were
 12 routinely sought, the evidence disclosed just two
 13 perhaps three days ago now shows that this was not
 14 always the case. And this was the second loophole.

15 The second witness statement of Dr Diana Walford,
 16 the Senior Medical Officer at the Department of
 17 Health -- the witness statement I refer to is this,
 18 WITN4461158, disclosed on Wednesday -- explained that
 19 in 1977 the CSM and the CSM Biological Subcommittee were
 20 not consulted on Immuno's variation application in
 21 respect of Kryobulin. That had included the fact that
 22 it sought to move from German and Austrian sources of
 23 plasma to those from the US.

24 What's more, it is also apparent from that statement
 25 that Immuno were able to conceal knowledge of the

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1 second and firmly behind commercial continuity.

2 Finally, we highlight that the efficacy of any
 3 regulatory regime also has to be judged by its
 4 workarounds or loopholes. The Medicines Act 1968
 5 created significant loopholes in the licensing regime
 6 which may have contributed to the erroneous decisions
 7 being made and to the extent of infections which were
 8 spread. Can we highlight two important points.

9 First, one of the most significant loopholes was the
 10 named patient basis exception. Now, that allowed
 11 medical professionals to go about purchasing and
 12 importing blood products which had not been granted
 13 a product licence at their whim, or perhaps because of
 14 the effective advertising by pharmaceutical companies.

15 There was no adequate regulatory oversight of the
 16 use of products on that basis until May '84.

17 Sir, as you are aware we say much more on that
 18 loophole in our written submissions. But for the
 19 purposes of today's submission, we say that that was the
 20 "doctor knows best" dogma, robbing a regulatory regime
 21 of any teeth and cutting it off at the knees.

22 Second, there is evidence that licensing decisions
 23 bypass the CSM and the CSM Biological Subcommittee and
 24 therefore evaded the scrutiny of those who might
 25 reasonably have expected to have been in the know on the

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1 American plasmas' higher risk of hepatitis from the
 2 Licensing Authority.

3 Undoubtedly the loophole that was the lack of
 4 routine CSM input contributed to that situation, but,
 5 and this was something that the Inquiry's Rule 9 request
 6 also picked up on, the licensing regime also failed to
 7 impose any legal obligation on a manufacturer to
 8 disclose that information by way of reference in
 9 relation to applications.

10 Those are, we say, issues that arose because of the
 11 opt in and toothless nature of that regulatory regime.

12 New chapter heading. What should have happened?
 13 There was a history of research, sir, dating back to
 14 Pasteur which showed the efficacy of heat treatment and,
 15 in particular in relation to vaccines, its use in
 16 rendering safe plasma products.

17 The effects of heat treatment in rendering safe
 18 otherwise potentially harmful substances is well
 19 established and dates back to the work with bacteria in
 20 the mid-19th century. The discoveries that, first,
 21 there existed viruses as well as bacteria, and
 22 subsequently that these viruses could also be vulnerable
 23 to heat, predate the events giving rise to this Inquiry
 24 by decades. We have set out in our written closing
 25 submission how this knowledge progressed and how,

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1 through the Second World War, albumin was rendered safe
2 through pasteurisation.

3 Given that efforts by Behringwerke in Germany to
4 virally inactivate concentrates had borne fruit by 1978,
5 BPL, Blood Products Laboratory, were dilatory in their
6 approach to developing virally inactivated concentrates.
7 Once a concerted effort was made, from a standing start
8 it took no longer than two years for fractionators to
9 produce effectively heat-treated concentrates.

10 If untreated blood products had been prevented from
11 use, the very market forces which drove their
12 dissemination into this country and into the veins of
13 this community would have meant that the companies
14 supplying this material would have turned their minds
15 and their money to the inactivation of viruses within
16 their products.

17 By the early '70s and the advent of factor
18 concentrates, we find an odd paradox where it is well
19 known amongst those in blood collection and transfusion
20 medicine that the pooling of blood plasma without any
21 viral inactivation technique will increase the risk of
22 virus transmission to the recipient. Yet at the same
23 time we have those with an interest in haemophilia care,
24 whether they be doctors or pharmaceutical companies,
25 racing to produce blood products which were to present

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1 American rivals.

2 There is an extract of the book *Blood on their Hands*
3 by Eric Weinberg and Donna Shaw available on Relativity.
4 We will supply the Relativity reference at a later
5 stage. The book recounts the story of Mr Weinberg's
6 investigation and subsequent conduct of the litigation
7 in America taken by haemophiliacs infected with HIV
8 against the pharmaceutical companies, of which, sir, as
9 you are aware, our client group took part.

10 Chapter 9 of that book from page 94 onwards
11 described Dr Weinberg's first contact and meeting with
12 Dr Edward Shanbrom, the chief medical adviser at Hyland
13 with a responsibility for the first development of
14 concentrates in the United States. Dr Shanbrom is said
15 to have raised concerns about the viral safety of
16 concentrates in 1970 after noticing patients who were
17 HBV antibody positive were nevertheless falling ill with
18 a new kind of hepatitis. Dr Shanbrom is said to have
19 been slowly let go by Hyland as a result of the
20 expression of those concerns.

21 Dr Shanbrom would, of course, ultimately go on to
22 develop a detergent washing system for virally
23 inactivating concentrates which was licensed by the
24 New York Red Cross.

25 Elsewhere, the Inquiry has seen evidence that

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1 a significantly greater risk of transmitting viruses.

2 One might expect that, fixed with the knowledge that
3 increasing plasma pool sizes increases risk, those
4 developing and marketing the products might have taken
5 some time and effort and expense first to attempt to
6 virally inactivate the filth that they were producing to
7 haemophiliacs as a wonder drug.

8 Now, there is some evidence, Dr Foster, I referred
9 to now -- there's some evidence -- Dr Foster said that
10 this wasn't so. He said that Factor VIII protein was
11 considered so heat-labile that the concept of subjecting
12 it to pasteurisation was inconceivable to him.

13 There are problems with that assertion. The first
14 is that heat treatment and other viral inactivation
15 techniques were clearly not considered unthinkable by
16 all fractionators. The chronology of events dictates
17 that at the time Dr Foster and some other witnesses to
18 the Inquiry were still averring that the idea was
19 unthinkable, Behringwerke scientists had clearly had the
20 idea a number of years before and had some success in
21 developing pasteurisation techniques.

22 The second problem is that Behringwerke were not
23 alone in taking steps to virally inactivate products.
24 They were not mavericks at the vanguard of product
25 safety, they just got further than some of their

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1 Travenol was investigating viral inactivation techniques
2 in the '70s, including heat treatment, but that its
3 research priority was slowly downgraded during the
4 course of '78 from a grade A priority to a grade B
5 priority.

6 It is expressly stated within Travenol memos that
7 the research cannot proceed any further without more
8 funding and dedicated research time. References to that
9 are CGRA0000213, onwards 214, 5, 6 and 7.

10 Why wasn't time and resource given to this research?
11 That's because the pharmaceutical companies didn't need
12 to. They were able to peddle their contaminated product
13 with the knowledge, consent and approval of US and
14 UK regulators.

15 Travenol did, in '79, urgently upgrade their
16 research into pasteurisation. But not through motives
17 of trying to protect patients; that was for the
18 commercial reasons. And for no other reason than to
19 protect their market position in light of Behringwerke's
20 development of a heat-treated product.

21 Reference to that is CGRA0000218.

22 I will tie these threads together. There is no
23 scientific or technological discovery which takes place
24 between 1970 and '84 which suddenly enables viral
25 inactivation. It is old science and old technology

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1 which is utilised ultimately to successfully virally
2 inactivate the products: heating a product in
3 a stabilising solution, the same technique applied to
4 albumin for decades. Intellectual curiosity may have
5 been lacking, but the only thing really missing from
6 unlocking a safer treatment was an incentive.

7 It is important that had the UK licensing authority
8 done its job properly and refused to grant licences to
9 these lethal products, a clear and loud message would
10 have been broadcast not just to the pharmaceuticals but
11 to other regulators across Europe and North America.
12 That message would have been that the risk/reward
13 balance did not tilt in favour of reward and that these
14 products were unacceptably dangerous.

15 That, in turn, would have provided the incentive
16 that pharmaceutical companies would have needed to
17 address viral threat properly and sooner. After all,
18 when they are forced to put their minds to the task in
19 light of AIDS, they managed to largely succeed in the
20 space of little more than 18 months.

21 I now turn to AIDS. This is a very short section.

22 The damage had already been done by 1982. The
23 domino effect of the failure to protect people from the
24 dangers of infection with hepatitis meant that
25 haemophiliacs were inevitably going to be infected with

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1 at that time. Clearly, insufficient (sic) was done to
2 withdraw those products. The answer should have been:
3 get them off the shelves, don't use them, dispose of
4 them.

5 I now turn to campaigners. Lawrence, if you would,
6 please.

7 We are going to be looking at some images,
8 photographs of haemophilia protesters, and they start --
9 if you look to the right-hand side first of all.

10 For date purposes, this is in relation to a march to
11 Downing Street on 3 April 2001. If we look, then, at
12 the photograph that appears on the left. If you turn it
13 right way up, thank you.

14 That's Ms Wintle and her husband, Steven. Sir, you
15 can see all around them the signs, what is being
16 said: "Hep C", "death sentence", "RIP", "Help the sick,
17 suffering and bereaved".

18 Next page, please. Again, left-hand side, a
19 photograph of Colette Wintle. She is holding in her
20 hands bags of blood -- these weren't real -- symbols
21 being used to demonstrate the nature of what had
22 happened in the past.

23 If we move on to the next page, please.

24 We see here again Ms Wintle and Ms Grayson and, at
25 the top page and the bottom, at the Downing Street part

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1 whatever viruses were swimming in the vast pools of
2 blood from paid donors in the United States.

3 Essentially, our submission in relation to the
4 transmission of AIDS into the haemophilia community is
5 that this is a domino effect, and what had happened is
6 that the earlier failure to protect people from the use
7 of blood products and the obvious dangers from the
8 viruses contained in those products meant that so many
9 people were already infected by the time the message
10 came through in the early '80s.

11 Dr Franklin, at paragraphs 36 and 37 of his
12 statement, WITN4032001, says:

13 "By 1982 there had been a few cases of transfusion
14 associated AIDS in the USA and also a few men with
15 haemophilia had the condition."

16 Going on to say, regarding awareness of an
17 association between AIDS and the use of blood products:

18 "For transfusion associated AIDS, late 1982 in the
19 USA. For plasma products in patients in the UK during
20 1983. I found out [about that connection, from his
21 point of view] via medical journals, news items and word
22 of mouth."

23 Sir, you have our submissions which set out in
24 detail the chronology of events leading to the awareness
25 of knowledge of the risk of AIDS within blood products

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1 of the march.

2 Thank you, Lawrence.

3 The incredible campaigning work of Carol Grayson and
4 her husband Pete Longstaff, a severe haemophiliac who
5 died of his infections, should be recognised by us all.
6 Carol and Pete did everything possible to bring this
7 dark passage of history into the light.

8 Ms Wintle joined with Carol and, together, their
9 campaigning became their jobs, unfunded. The basics of
10 life and healthcare became subjugated to the campaign.

11 I recall standing with Ms Wintle in the area outside
12 of the tearoom in now, I believe -- I am told by
13 Mr Harrison -- the torn-down building that we used to
14 inhabit for this Inquiry, I was with her, standing
15 outside the tearoom there, and we spoke about her years
16 of campaigning -- and this is not just a reference to
17 her but all of the other campaigners -- the years of
18 campaigning, the lack of ability to pursue a career, how
19 it took over everything, family life, finances.

20 This will have happened to many campaigners. The
21 life of campaigners, sir, is very different to the
22 commercial lobbyist paid for by corporate interests who
23 don't have to fund their own travel, paper, printing and
24 telephone costs. Their and others' relentless
25 campaigning kept the very issues we have examined for

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1 four years in the public eye in the discussion.
 2 Carol and Colette's work has been foundational.
 3 Other campaigners and this Inquiry have followed in the
 4 path they worked so hard to forge.
 5 They were not the only campaigners. But, as we have
 6 heard from the evidence, from politicians, they were
 7 prolific and constant. In the history of this scandal,
 8 Carol Grayson's name and Colette Wintle's name should be
 9 remembered, acknowledged and honoured.
 10 Following the death of her husband, Ms Grayson
 11 started her research leading to a seminal dissertation,
 12 available on The Haemophilia Society's website, entitled
 13 "MA Gender, Culture and Development. Blood Flows Not
 14 Just Through Our Veins but Through Our Minds".
 15 I read only part, chapter 6, the conclusion:
 16 "I believe that my analysis with the SSR (the
 17 Self-Sufficiency Report) reveals that much more could
 18 have been done by the government and medical
 19 practitioners to protect haemophiliacs from the risk of
 20 contamination with HIV and hepatitis viruses at every
 21 stage. Once they became aware that haemophiliacs were
 22 infected, they disempowered patients by withholding
 23 information, denying them informed choice in relation to
 24 treatment, carrying out unethical research and, in some
 25 cases, failing to treat their medical conditions."

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1 HIV clinics, where the ready assumption was always made
 2 that they had been infected through drug use or had been
 3 sex workers. At times the evidence has demonstrated
 4 that women have been relegated to the back row and
 5 excluded from the heart of discussion. You will recall
 6 Ms Pappenheim, at paragraph 11 of her statement,
 7 WITN45040001 referring to the launch of the women's
 8 project. She refers to it as being very important the
 9 charity was recognising -- was seeking to engage with
 10 the women affected by the scandal.

11 But this is what happens, isn't it? If the
 12 Government pushes away or refuses to consider its own
 13 culpability then, in turn, it avoids its own
 14 responsibility to sort out its mess, instead leaving the
 15 debris of victims and the avoidance of support for those
 16 infected both directly and indirectly.

17 During the course of the Inquiry, I was sent
 18 a message by Clair Walton, whom I represent. I read it:
 19 "As an infected widow, I have been out on a limb and
 20 ignored in the community. Most of my adult life, since
 21 23, has been consumed with dealing with the aftermath of
 22 my husband's HIV diagnosis. Caring for my dying
 23 husband, making sense of my own HIV infection, loss of
 24 family life, discrimination, stigma and near-death from
 25 AIDS defining illness, relentless 30-year battle with

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1 We suggest we should all pay attention to what
 2 Ms Grayson was writing there, because she foreshadowed
 3 so many of the aspects that we have been considering in
 4 the evidence over these many years of this Inquiry.

5 The campaigning work by so many didn't just have to
 6 address government but also had to look at times to the
 7 work of the represented body, The Haemophilia Society.

8 Now, The Haemophilia Society we say without question
 9 has become more representative and is trying to work
 10 with the community. But that has not always been
 11 seamless. The letter from Chris Hodgson that was
 12 examined within the Inquiry time, WITN1055079, referring
 13 to the campaign now being more inclusive. Suggesting
 14 that it hadn't been so inclusive in past.

15 Women campaigners and women infected with hepatitis
 16 and/or HIV have always faced stigma and discrimination
 17 and had to fight tooth and nail for inclusion within
 18 campaigns and consideration by government. Clair Walton
 19 and anonymous witness WITN1388 were forced, through this
 20 lack of recognition, to start their own campaign for
 21 those women who were infected with HIV by their
 22 partners, who had of course been infected by blood
 23 products themselves.

24 Non-haemophilic women with HIV were not catered for
 25 by the haemophilic centres and instead were treated at

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1 the MFT over the charge on my home, restricting my
 2 freedom to move away and get on with my life, attempting
 3 to maintain a career I love, pursue a semblance of
 4 normal life, the campaign for justice and recognition
 5 and understanding of the needs or the needs of women
 6 living with HIV."

7 Then she finished that by saying then we get the
 8 THT.

9 Now, the effects of the decades of the delayed
 10 acknowledgement of harm done by the state is that,
 11 instead of considering and dealing with the fallout from
 12 the NHS and Ministry of Health's failures to protect its
 13 vulnerable patients, what we have instead is a failure
 14 to consider how far that harm has extended. Decades of
 15 delays, not just in compensation but in rounded support
 16 for its victims or families.

17 Haemophiliacs who have been infected all face
 18 complicating features of their conditions and the
 19 combination of medications also give rise to adverse
 20 effects through treatment interaction. You will recall
 21 the evidence from the witness before the Archer Inquiry
 22 reference ARCH0000004_0010. The description which
 23 I recall, which stuck in my mind, is being a bit like
 24 being on chemotherapy for the rest of your life.

25 Long-term, an individual infected with HCV and those

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1 co-infected with hep B and HIV may go on to develop
2 various chronic infections. Some of the complications
3 are costochondritis, fibromyalgia, early onset of
4 menopause, deterioration of the spinal discs connected
5 to the anti-viral chemotherapy used to treat chronic
6 HIV.

7 We are also behind, as I recall, in speaking to
8 an anonymous client I represent, also very much behind
9 in our research as to the long-term effect upon an aging
10 population of haemophiliacs with infections and
11 co-infections.

12 The damage to the liver in an infected individual is
13 well known, as is the increased possibility of
14 developing cancer, but the liver damage can also affect
15 blood platelets which, if they reach a low level can be
16 life threatening.

17 The consequences and possible complications which
18 arise from the infection via contaminated blood and the
19 need for support for partners of haemophiliacs and
20 deceased haemophiliacs can be identified and the needs
21 of the limited community of people are known. The
22 partners of deceased haemophiliacs are inadequately
23 catered for within the NHS, as they get older they face
24 continuing, often worsening issues with stress,
25 depression and PTSD.

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1 in some detail in our recommendation submissions.

2 I don't want to overly labour this point but I do
3 want to say that the former MFT, Macfarlane Trust,
4 registrants' objections to the THT are not based on any
5 foundation of prejudice or any sense of "guilty" and
6 "innocent" victims of HIV. Their objections are based
7 solely on the fact that the interests pursued by the THT
8 do not coincide with those of the former registrants
9 and, in fact, conflict with them.

10 That point has been illustrated recently with the
11 THT throwing itself behind a campaign to make every
12 contact count, exceptionally advocating an opt out
13 scheme whereby every time blood is taken in a clinical
14 setting it ought to be tested for HIV, HCV and HBV.
15 Recalling the vast amount of evidence you have heard
16 over the last four years, sir, the idea that people
17 ought to have their blood tested for these viruses
18 without a proper pre-test counselling framework in place
19 is the antithesis of what the former MFT registrants
20 would want to see in its place.

21 At its most fundamental the residual Macfarlane
22 Trust funds represent power, which is capable of being
23 wielded over the former registrants. The former
24 registrants of the MFT Trust, those we represent, want
25 to see those funds surrendered by the THT, divided

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1 I spoke with Amanda Beesley the other day. She
2 spoke about the fact of the way it feels to her
3 sometimes that she's teetering on the brink. She spoke
4 about her well-rehearsed knitting of threads together
5 which might unravel, as being her mental state.

6 The failure by Government to listen to the truth and
7 acknowledge its own responsibility for these decades has
8 multiplied the suffering. That needs to be stated, it
9 needs to be recognised and it needs to be acknowledged
10 by the state.

11 Sir, I now go on to deal with recommendations. So
12 this final chapter in my submissions is "Recommendations
13 and the way forward".

14 Sir, you will have read and seen our submissions on
15 recommendations. They are at page 196 onwards. We see
16 no benefit in repeating those submissions orally.
17 Instead, I'm going to make some submissions about the
18 Terrence Higgins Trust, the THT, Governmental change and
19 then go on to suggest a proposal for you to consider as
20 to the delivery of your report.

21 Terrence Higgins Trust. Without wishing to take
22 away from the important and life changing work that the
23 Terrence Higgins Trust has done over the last 40 years,
24 their involvement with the former Macfarlane Trust
25 registrants is simply inappropriate. We deal with this

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1 amongst the four national haemophilia societies and
2 employed for the purposes of creating monuments to the
3 former registrants. This is the only way that the power
4 residing in the residual funds can be eradicated and the
5 only way in which the former registrants will be freed
6 from the advocacy which has been forced unwantedly upon
7 them.

8 Now, I turn to Government. Regarding Government, we
9 must stop the head banging. The head banging I refer to
10 is the head banging of campaigners and survivors against
11 the administrative and overly bureaucratic castle walls
12 of state, in what has almost become an oft-used
13 hackneyed phrase: speaking truth to power. That only
14 works if power is prepared to listen. Instead, what we
15 have seen and discussed in this Inquiry and other
16 Inquiries is that power only listens randomly,
17 capriciously and, frankly, when it is politically in the
18 mood and has a moment.

19 It is hard to accept, sir, that Government lobbyists
20 paid for by corporate funds who employ basically insider
21 club members, many of them ex-politicians, ministers and
22 even prime ministers, who automatically, it seems, have
23 access when campaign groups have to increasingly get
24 permission from the police to demonstrate outside the
25 hallowed walls, it is not difficult to say that

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1 something clearly is going wrong.

2 Disasters have happened in the past and disasters
3 are going to happen again. Disasters of themselves are
4 not unusual. So why do we find that there is no system
5 to cope? Why do we find there is no system to cope with
6 the victims? Campaigners should not be met with a blank
7 wall of state and the words "the Government line". The
8 Government line, phrase or anything similar, should be
9 treated by current and future ministers with scepticism
10 and questioning and not blind acceptance.

11 A simple improvement, we suggest, would be for all
12 Government lines to be dated so that we know when they
13 started and for ministers to ask, if that is not
14 apparent, for how long has this line been held?

15 In addition to consideration of ours and others'
16 proposed recommendations, you may wish in your report,
17 sir, to comment on the need for an Inquiry
18 recommendation oversight system. We have considered how
19 that might be done.

20 This could be by a dedicated select committee or the
21 use of the standing departmental committees for the
22 relevant ministry, with a duty to maintain a watch on
23 inquiry and perhaps inquest recommendations. Select
24 committees have the power to call for evidence and
25 witnesses to come forward and publicly seek explanations

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1 me "Finish the job" and I always took those to be wise
2 words. Later on in my career, in moments of reflection,
3 I have in odd moments whether she just meant to me,
4 directly, "You finish the job". Nevertheless it stuck
5 in my mind as a phrase and a touchstone for the work
6 that I've done over many a year.

7 Peace in the way I have described it is very
8 difficult to do within the powers of a statutory
9 inquiry, because when you finish the last full stop on
10 the last page of your report and your report is
11 delivered to Government, your powers as an Inquiry Chair
12 are extinguished. This has every potential to leave
13 your report and its findings and recommendations at the
14 whim of Government, and I think that we can establish
15 one thing, Government is not trusted by our client group
16 or indeed this community.

17 So what we ask is this, you consider issuing a final
18 report, setting out your findings on the main evidential
19 points and the conclusions that follow.

20 But deliver part of your report as an interim
21 report, allowing time for Government to complete its
22 internal discussions on the compensation scheme
23 framework, incidentally allowing time for an answer from
24 the Department of Health to your question about what it
25 has apologised for.

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1 for delays in implementation or reasons why individual
2 recommendations are no longer required. This is never
3 going to be a perfect system.

4 For example, we note that select committees have no
5 power to call for evidence from Members of Parliament or
6 ministers, although generally they do secure the
7 co-operation of Government ministers.

8 I turn now to the delivery of your report, I do so
9 gently and with trepidation because I, respectfully, am
10 going to make submissions as to the shape of your
11 report.

12 Can I suggest, sir, that in everything you do and
13 consider, when looking at the evidence in this matter
14 and looking and then thinking about your
15 recommendations, that you aim as far as it is humanly
16 possible at peace and finality.

17 After Penrose, Lindsay, Archer, let's make this the
18 final report on the worst medical disaster in the
19 history of the NHS. So what do I mean by "peace"?
20 I think I mean that we must finish the job or, put it
21 another way, leave no loose ends.

22 I remember now, sir, you may accept many years ago,
23 working as a paralegal employed by a terrific East End
24 solicitor, Ms Cherry McMillen, recently retired as
25 a judge in the island of Guernsey. She always said to

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1 The advantage of taking such a course, splitting
2 essentially the report into a main report with its
3 conclusions, findings and its main recommendations --
4 the answer that would be provided would be the retention
5 of your powers under the Act, so that you could then, if
6 required and if necessary, call for evidence from
7 whoever at that time might be the minister in charge or
8 to recall Sir Robert to answer questions as to the
9 viability and acceptability of the Government's response
10 and proposals as regards compensation.

11 After all, sir, as we have seen very recently, not
12 following report recommendations is hardly a new sport.
13 We note the recent news and discussions about the
14 Hillsborough report and the Home Secretary, Suella
15 Braverman has recently reneged on the Government's
16 commitments given in the light of the Windrush report
17 recommendations.

18 Sir, we make these submissions and we find support
19 for this way ahead in the terms of reference -- always
20 useful -- treatment care and support, number 8 of the
21 terms of reference. This Inquiry is bound to consider
22 the nature and adequacy of the treatment care and
23 support, including financial assistance provided to
24 people who are infected and affected, including the
25 bereaved.

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1 Sir, to achieve finality and to achieve what I have
2 discussed by way of the way forward, you may find that
3 that paragraph would assist you in considering a split
4 way of providing a report, to give Government the
5 understanding of your findings, your consideration of
6 evidence, while leaving open also the ability to
7 consider the way the Government responds.

8 In our submission, this Inquiry will not have
9 fulfilled its terms of reference, with the greatest of
10 respect, until such time it has been established what
11 the Government will do in terms of financial provision
12 for the infected and affected going forwards. The
13 Department of Health's evasive closing submissions lend,
14 we suggest, special weight to the necessity to continue
15 to apply scrutiny to the action of Government in this
16 regard.

17 Before I set out my final and very short concluding
18 remarks, let me use this platform to send a message to
19 the Labour Party.

20 Wes Streeting MP is Labour's Shadow Health and
21 Social Care Secretary and with, Sir Keir Starmer, we
22 suggest that he and they must, as a matter of urgency,
23 commit the next possible Government to the
24 implementation of the Inquiry recommendations and the
25 establishment of the compensation scheme.

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1 (12.48 pm)

(The luncheon adjournment)

2 (1.50 pm)

Closing statement by MS RICHARDS KC

5 **SIR BRIAN LANGSTAFF:** Thank you. You really didn't have to
6 stand up. Ms Richards does.

7 **MS RICHARDS:** I should perhaps explain that the Chair's new
8 location is not because I'm about to start
9 cross-examining him, sadly.

10 I want to start by saying something about the
11 Inquiry's work over the last four and a half years. I'm
12 then going to say something -- a little about the
13 Inquiry's work after today because today is not the end.
14 And finally I will make some observations about just
15 a few of the issues that have emerged from the oral and
16 written submissions that we have been considering over
17 the last few weeks.

18 The events which gave rise to this Inquiry have
19 memorably been described as the worst treatment disaster
20 in the history of the National Health Service. The
21 scope of this Inquiry has been unprecedented in what
22 I would suggest are four particular respects.

23 Firstly, as to the scale of the disaster. The
24 number of those infected runs, as we now know, into tens
25 of thousands, many of whom have died. And as we have

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1 We are, sir, all aware that the politics of the
2 moment are even more unstable than usual, and that is
3 saying something, but the victims and survivors of this
4 disaster must not be left to wonder whether a possible
5 future Labour government might hold up or stall the
6 development of the compensation scheme.

7 My final concluding remarks. Sir, I have to accept
8 that my request for peace is the hardest of goals. But
9 many of those infected and affected simply want peace
10 and the ability, as far as this can ever be achieved, to
11 put this behind them and quietly get on with the
12 remainder of their lives. We ask, sir, that you bear
13 this goal in mind when finalising your report.

14 But, sir, at least for now, you get peace from me.

15 Thank you for listening.

16 **SIR BRIAN LANGSTAFF:** Thank you very much, Mr Stein. You
17 need not have worried, as you said at the start, whether
18 you would do your duty by your clients, plainly you
19 have.

20 I will have something to say perhaps this afternoon,
21 which may touch upon the last matters that you are
22 mentioning, but you will have to wait and hear that if
23 you want to.

24 Before me, we will have Ms Richards but we won't
25 have her now, we will have her at 1.50 pm. 1.50 pm.

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1 been powerfully reminded during the submissions, not
2 least yesterday and this morning, people are continuing
3 to die in consequence of their treatment with infected
4 blood and infected blood products.

5 Secondly, the Inquiry's scope is unprecedented in
6 terms of its geographical scope, covering all four
7 nations within the UK, and giving rise, as you have
8 heard this week, to considerations about the
9 relationship between the UK government and Scotland
10 Wales and Northern Ireland both pre and post-devolution.

11 Thirdly, the scope of the Inquiry is unprecedented
12 in terms of its time frame, exploring over five decades
13 of knowledge, of decision-making, of action and of
14 inaction.

15 Then the fourth respect is this, most Inquiries
16 examine a catastrophic event and the circumstances,
17 which may often be complex, which lead up to that event.
18 This Inquiry's terms of reference have required it to
19 consider the response of government, the NHS and others
20 in the decades following the transmission of infection.

21 Mr Dawson KC yesterday talked about the way in which
22 the harms caused by infection and treatment have been,
23 and I quote from his submissions, "irrevocably and
24 multiply compounded and increased by the way the state
25 has reacted", and he described the compounding of the

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1 harm as a unique and important element of the disaster
2 which you, sir, will have to consider.

3 It is important that the wider public and the media
4 understand that this is not simply an inquiry into
5 matters of history. This is an inquiry into, as
6 Mr Williams KC put it on Wednesday, the here and now.
7 It is an inquiry with ongoing relevance and resonance to
8 decision-making by government and the NHS today.

9 In the last ten days, three reports have been
10 published.

11 On 24 January the Committee on Standards in Public
12 Life published the report that its Chair,
13 Lord Jonathan Evans, told us about when he gave evidence
14 to this Inquiry in November. That report is about the
15 need for active work to ensure that the ethical values
16 reflected in the Nolan Principles become the cultural
17 norm for those in public life. The inference being that
18 there is still more work to be done in that regard. And
19 you may think one only has to read the news to believe
20 that to be the case.

21 The second report published this week is the report
22 from the College of Policing and the National Police
23 Chiefs' Council, entitled *The National Police Response*
24 *to the Hillsborough Disaster*. It is a response to
25 Bishop Jones' report, about which you have heard a lot

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1 to gather a vast amount of material. It has had to
2 obtain, sift and analyse contemporaneous documentation
3 from a wide variety of sources and then use that
4 documentation to obtain statements from a large number
5 of witnesses.

6 It is only right that I should acknowledge that the
7 Inquiry has had extensive co-operation from Core
8 Participants and their legal representatives and
9 I should say that has included the Department of Health
10 and Social Care. We are grateful for the amount of work
11 that's been devoted by witnesses to the task of engaging
12 with and responding to the Inquiry's requests for
13 documents and statements.

14 A few facts and figures then about the Inquiry's
15 work. The number of documents disclosed to Core
16 Participants is, I am reliably informed, over 100,000,
17 comprising over 0.75 million pages of material. We have
18 received over 4,000 statements from those infected and
19 affected. We have received well over 1,000 -- I think
20 the precise figure, in fact, is 1,200 -- statements from
21 other witnesses, from doctors, politicians, civil
22 servants, those involved in the Alliance House
23 Organisations, those working for pharmaceutical
24 companies, and so on.

25 We have obtained material reports from seven

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1 in recent weeks, his report entitled *The patronising*
2 *disposition of unaccountable power*. And that police
3 report accepts that those who lead must acknowledge when
4 mistakes have been made and must not seek to defend the
5 indefensible.

6 The third report just published is a report from the
7 Patient Safety Commissioner for England, Dr Henrietta
8 Hughes. She's just reported on her first 100 days in
9 post. It makes depressing reading. She says this:
10 "Over my first 100 days in the role I have heard
11 a yearning desire for patient safety to be at the top of
12 the agenda. It is clear from what they told me that the
13 focus on the Health Service is on productivity,
14 operational performance and financial control."

15 She said this, and this is a sentence which I think
16 will resonate with all of you, "Medicine is
17 industrialised when it needs to be humanised".

18 She said also this, worryingly:

19 "It is clear that the culture is getting worse and
20 unless leaders set a strategic intention to listen and
21 act we are heading straight back to the days of Mid
22 Staffs and other health scandals, severe harm and
23 death."

24 Turning then to the Inquiry's work. In order to
25 fulfil its wide terms of reference the Inquiry has had

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1 different expert groups and I will refer to some of
2 those in the course of my address. The Inquiry has
3 heard orally from 370 witnesses and has sat hearing
4 evidence and submissions for 286 days, including today.

5 I hope you don't mind if I give you a quick recap of
6 what we have covered in the oral hearings.

7 Following the preliminary hearings in September 2018
8 at Church House in Westminster, we heard the evidence of
9 people who were infected and affected, starting in
10 London at the end of April 2019, we then moved to
11 Belfast, to Leeds, to Edinburgh and Cardiff and then
12 again sat in London in October 2019.

13 In February 2020, the Inquiry heard from the
14 intermediaries who were able to tell us about the
15 experiences of those who had not felt able to give
16 witness statements to the Inquiry but who wanted their
17 story nevertheless to be heard. We heard from clinical
18 experts in relation to hepatitis, HIV and on bleeding
19 and blood disorders, and we heard from the psychosocial
20 expert panel. Mr Dawson told you yesterday of the
21 importance of that evidence from his clients'
22 perspective.

23 That evidence helped all of us understand the
24 multiple and profound ways in which lives have been
25 impacted above and beyond the devastating direct

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1 consequences of infection and treatment. I just want to
2 read one short passage from the evidence of the
3 psychosocial experts. It was on 24 February 2020 and it
4 is page 150 of the transcript.

5 The question which I put was as follows:

6 "One particular feature from the evidence that the
7 Inquiry has heard is that for many people their whole
8 lives have become defined by the condition with which
9 they were infected and treatment for it, for symptoms
10 and so on. But the result is that they have had to live
11 a life completely different from the life that they
12 would otherwise have expected to and they have lost
13 opportunities, been unable to fulfil a potential that
14 would otherwise have been there. How does that bear
15 upon their psychological experience?"

16 This was Professor Weinman's answer:

17 "Hugely, because [he said] going back to what I said
18 earlier about one's sense of self, one's sense of self
19 identity, I think some people have said, you know, if
20 you think of illness as a sort of set of things and
21 one's self as a set of things, for some people, you
22 know, the sense of one's self can be completely
23 obliterated because day to day this is what's happening
24 to you. There is nothing else. So those multiple
25 selves, one's future selves, all those really important

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1 We also began the first of a series of
2 presentations. We started looking at the work of
3 Professor Arthur Bloom, the Cardiff Haemophilia Centre
4 and the Oxford Haemophilia Centre. Such presentations
5 are not a normal feature of the way in which public
6 inquiries normally hold their hearings but it had seemed
7 to us important where there was no living witness that
8 the key facts and documents should be examined in
9 a public domain for all to hear.

10 We heard the first of a number of haemophilia
11 clinicians starting in October 2020 with the evidence of
12 Dr Mark Winter. We heard from a number of other
13 clinicians over the following months and, where we were
14 not able to call key doctors, we continued to examine
15 the contemporaneous documentation in the presentations.

16 We heard from the expert panel of medical ethicists
17 in January 2021. I will come back to their evidence
18 but, again, it is hugely important evidence from the
19 Inquiry's perspective.

20 We heard from Mr Watters of The Haemophilia Society
21 and evidence from those involved in the Alliance House
22 Organisations through February and March 2021. In
23 May 2021 we heard from Health Ministers in each of the
24 four nations, together with those involved in the
25 current financial support schemes.

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1 dimensions become pretty well wiped out.

2 "That is from an experiential point of view but also
3 in terms of people's aspirations absolutely devastating.
4 The idea of having, you know, no obvious future or
5 incredibly uncertain future which is completely dictated
6 by this thing which now defines you is massively
7 impactful."

8 Sir, I know the psychosocial evidence will be hugely
9 valuable to you in your work of addressing part 4 of the
10 terms of reference.

11 Returning to the oral hearings, it had been the
12 Inquiry's plan to start hearing from haemophilia
13 clinicians in the summer of 2020 but as we all know
14 events took a different course and the pandemic
15 intervened. That led to those hearings being deferred
16 to September 2020 but, since that time, the Inquiry has
17 managed to continue to conduct its hearings,
18 notwithstanding the constraints imposed by Covid-19.

19 The September 2020 hearings began with the evidence
20 of Lord David Owen. His important evidence was then
21 followed by an examination of medical and other
22 literature, so as to analyse and importantly expose to
23 public scrutiny what was actually known and what could
24 or should have been known about the risks of viral
25 transmission at the relevant times.

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1 I am sure you will all recall Mr Matthew Hancock,
2 then Secretary of State for Health, accepting moral
3 responsibility on the Government to address the impact
4 of what happened to you. He said this too:

5 "Should substantial compensation be the outcome of
6 this Inquiry, then we [the Government] will provide it."

7 In June 2021, having heard further evidence about
8 The Haemophilia Society, we heard evidence from
9 campaigners and we examined and called evidence in
10 relation to Treloar's. I do not think I am, in any
11 sense, prejudging the conclusions you reached, sir, when
12 I observed that the evidence that we examined and heard
13 in relation to Treloar's was truly shocking.

14 In July 2021, we heard the first of our government
15 witnesses, civil servants and politicians, Dr Diana
16 Walford, Lord Glenarthur and, memorably, Lord Clarke.
17 I am sure you will all understand when I say I am
18 unlikely ever to forget the experience of questioning
19 the latter.

20 In September 2021 we heard the evidence of Lord
21 Fowler, which you may think set a rather different tone.
22 Then between September and November 2021, we examined
23 the actions and roles of pharmaceutical companies,
24 largely through presentations and analysis of the
25 contemporaneous documentation but we heard also from

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1 Christopher Bishop, an employee of Armour.
 2 In November 2021 the Inquiry turned its forensic
 3 lens on the Blood Transfusion Services and that work
 4 continued into February 2022. As well as presentations
 5 on the organisational structures and history of the
 6 blood transfusion services, we examined the work of
 7 Dr Gunson and Professor Cash. We were able to hear from
 8 a number of surviving Regional Transfusion Directors,
 9 fortunately this was an area in which we were able to
 10 hear directly from those involved in Wales and Northern
 11 Ireland, which has not always been the case.

12 That phase culminated in the evidence of Dr Lloyd
 13 the Newcastle Regional Transfusion Director. You will
 14 recall no doubt that in 1991 he had been vilified for
 15 having the temerity to introduce hepatitis C screening
 16 ahead of other Regional Transfusion Directors.

17 In February 2022, we undertook the vitally important
 18 task of examining blood transfusion policies and
 19 practices through presentations and witnesses.

20 We moved in March 2022 to consideration of
 21 self-sufficiency, domestic production and viral
 22 inactivation, hearing from Drs Foster, Snape and Perry.

23 In May 2022 we returned to government decision
 24 making, mostly hearing from witnesses from England and
 25 Scotland, a range of civil servants and politicians,

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1 have died and whose testimonies we have never been able
 2 to gather, those who have been infected but who have for
 3 perfectly understandable reasons not felt able to
 4 participate in the Inquiry, no doubt in part because of
 5 their experiences of stigma and trauma, and those who
 6 may have lived and died unaware of their infection as
 7 a result of blood transfusion.

8 Thirdly, in relation to the oral hearings, there are
 9 key individuals from government, from the medical
 10 profession, from pharmaceutical companies and elsewhere,
 11 from whom the Inquiry has not been able to obtain
 12 statements either because they are dead or because of
 13 impairments of health and age. Bloom, Gunson, Cash,
 14 Lane, Forbes, Willoughby, Galbraith, Acheson; those are
 15 some of the names that came to mind.

16 Had this Inquiry been heard in the 1990s most -- not
 17 all but most -- of those would have been able to give
 18 evidence. However, notwithstanding that disadvantage,
 19 we have, we think, been able to gather and shine
 20 a forensic light on sufficient of the contemporaneous
 21 documentation to enable you, sir, to answer the terms of
 22 reference comprehensively.

23 If I turn briefly to the Inquiry's ongoing work.
 24 The oral hearings come to an end today but the work of
 25 the Inquiry continues. That burden will fall largely on

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1 predominantly Health Ministers but also a former Prime
 2 Minister, John Major.

3 That took us to the end of July 2022 but of course,
 4 also in the course of July 2022, we heard the evidence
 5 of Sir Robert Francis, nearly seven months ago now.

6 Following further government evidence in September
 7 2022, the Inquiry hearings moved into their last phases.
 8 Between September and October we returned to the vitally
 9 important exercise of hearing from those infected and
 10 affected directly.

11 We heard expert evidence from the public health and
 12 administration group, evidence from Professor Richard
 13 Tedder and then, in November, we moved into two weeks of
 14 evidence relevant to recommendations, covering a wide
 15 range of issues and culminating with the evidence of
 16 Professor Sir Jonathan Van-Tam.

17 Three short observations about the oral hearings.
 18 First, I must emphasise that whilst the Inquiry has
 19 heard orally from a significant number of the infected
 20 and affected community, there are many more who did not
 21 give oral evidence but who have provided written
 22 statements to the Inquiry. Their evidence is just as
 23 important -- and I know you, sir, have faithfully read
 24 those statements.

25 Secondly, we must not and do not forget those who

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1 you, sir, and I know you will shortly provide some
 2 further information in that regard. I won't try to
 3 steal your thunder.

4 There are some witness statements still being
 5 received, and hence there will be some continuing
 6 disclosure of documents and statements to Core
 7 Participants, as well as a process of publication of
 8 a large amount of material on the Inquiry's website.

9 It is very much now an exercise of crossing t's and
 10 dotting i's, filling in very small pieces of the jigsaw,
 11 and we do not expect the material that we are continuing
 12 to receive to be likely to alter any of the submissions
 13 that have been made.

14 If, however, there are any particular significant
 15 statements, I undertake to flag that up to recognised
 16 legal representatives, and if they wish to add to their
 17 written submissions, they can, where the Chair considers
 18 it would be helpful, be facilitated.

19 I want to turn then to some observations relating to
 20 issues that have arisen in the course of the submissions
 21 hearings. But I'm going to preface them with a general
 22 observation.

23 Section 2.1 of the Inquiries Act precludes the Chair
 24 from ruling on or determining any person's criminal or
 25 civil liability. But section 2.2 provides that the

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1 Chair is not inhibited in the discharge of his functions
2 by any likelihood of liability being averred from the
3 facts he determines or the recommendations he makes.

4 What that means, sir, is you are free to criticise.
5 You are free to say that wrong was done and to
6 particularise, if this is where the evidence leads you,
7 the respects in which you consider wrong was done.

8 You are free to say that governments or clinicians
9 or NHS bodies or pharmaceutical companies acted
10 unreasonably, or unethically, or unconscionably or
11 failed to act when they should.

12 With that in mind, can I then address three points
13 that have arisen out of these submissions. The first is
14 the nature of the obligation owed by the state or the
15 government to its citizens.

16 Although the Chair is not empowered to determine
17 questions of legal liability, as I have said, he is
18 entitled to consider the nature and extent of the
19 state's obligations and responsibilities to its
20 citizens, and that may provide a useful backdrop to
21 an analysis of what happened and why.

22 Core Participants in their submissions have
23 identified three sources of obligations and
24 responsibilities. The first are international and
25 human rights conventions and instruments. They are

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1 Inquiry's work.

2 One other source of responsibilities and duties
3 identified by Core Participants in their submissions are
4 domestic, legal duties. Mr Snowden's submissions take
5 you, sir, to the National Health Service Act of 1946,
6 1977 and 2006. I don't propose to rehearse those. But
7 you will no doubt need also to consider the position in
8 relation to Scotland and Northern Ireland because those
9 Acts cover England and Wales.

10 But the third source of state responsibility is what
11 might be characterised the moral duty. Lord David Owen
12 when he gave evidence from his perspective as a Health
13 Minister in the 1970s -- and his evidence was given on
14 22 September 2020 -- was asked this by you, sir:

15 "As a matter of principle, do you see it as one of
16 the first duties of the state to look after the safety
17 of its population?"

18 **"Answer:** Yes.

19 **"Question:** So that would extend to the safety of
20 patients receiving blood or blood products?"

21 **"Answer:** Yes."

22 Exactly one year later, on the second day of his
23 oral evidence, Lord Fowler was asked a similar question
24 by the Chair:

25 **"Question:** Would your standpoint have been that

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1 discussed in some detail in Mr Snowden's written
2 submissions and in Ms Monaghan's written and oral
3 submissions, and I don't propose to repeat them.

4 There is only one additional matter which I flag up.
5 Ms Monaghan, in paragraphs 30 to 31 of her written
6 submissions, described one particular protective
7 obligation under Article 2 of the European Convention,
8 that's the obligation to protect life.

9 The obligation she described arose from a decision
10 of the European Court of Human Rights in a case called
11 Osman. It is an obligation often referred to as the
12 operational obligation.

13 But there is a separate and additional obligation
14 under Article 2 that you, sir, may wish to consider. It
15 is referred to in the case law of the European Court of
16 Human Rights as a systemic obligation. It is a duty to
17 make regulations compelling hospitals to adopt
18 appropriate measures for the protection of patients'
19 lives, a duty to have effective administrative and
20 regulatory systems in place, and a duty which
21 encompasses necessary measures to ensure the effective
22 functioning of the regulatory framework, including by
23 way of superficial and enforcement.

24 You may think that those formulations of the state's
25 duty to protect life have a particular resonance to this

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1 keeping the public safe is one of the first if not the
2 first duty of government?

3 **"Answer:** I think it is the first duty of government
4 and so I would take public health as being the first.

5 **"Question:** And therefore everything ought to depend
6 first of all upon does this protect or help protect the
7 safety of the public?"

8 **"Answer:** Exactly."

9 Then Andy Burnham, who gave evidence in July 2022,
10 was asked about his own words in a document called
11 *Glaziers and window breakers*. The reference for the
12 transcript, it doesn't need to go up, is RLIT0001140.
13 It is a document that gathers together the reflections
14 of a number of former Secretaries of State. Mr Burnham
15 in that document had said this, about the job of being
16 Secretary of State for Health:

17 "The job, as I see it, is to get the best possible
18 health care, the safest, highest quality health care for
19 the people of England and to protect them from health
20 risks."

21 In his oral evidence to this Inquiry he said he
22 would absolutely stand by that.

23 Moving then to a second issue emerging from the
24 submissions that have been made by Core Participants.
25 You have heard about hindsight and you have heard

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1 warnings about the risk of hindsight bias. It has been
2 suggested that the decisions and actions should be
3 assessed, at least in the first instance, by the
4 standards and norms of behaviour or conduct at the time.

5 That's a suggestion not limited to the Department of
6 Health and Social Care but you will see it also in the
7 submissions of NHSBT, the Belfast Health and Social Care
8 Trust and others.

9 There are two points I would like to make in
10 relation to that. Firstly, something may be done in
11 accordance with the standards and norms of the time and
12 yet be wrong. A stark historical example but one that
13 was referred to by the medical ethicists during their
14 evidence is slavery. You, sir, are not limited to
15 assessing decisions by reference to the standards or
16 norms at the time. You are entitled to say that what
17 was done was wrong, if that is where the evidence takes
18 you.

19 You are entitled to say indeed that the standards
20 and norms themselves were wrong. The medical ethicists
21 said this in their oral evidence:

22 "And in medicine as in many other spheres of life we
23 can see examples of practices and behaviours that at one
24 particular point were deemed acceptable but subsequently
25 with further thinking sometimes, and it is just with

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1 and judged in this Inquiry: clinicians, civil servants
2 and politicians.

3 In relations to clinicians, the medical ethicists
4 told us about fundamental moral principles or values
5 that were stable and consistent across time. They told
6 us by reference to a 1979 publication, *Principles of*
7 *Biomedical Ethics* about four principles, autonomy;
8 justice; beneficence, in other words the imperative to
9 do good; and non-maleficence, do no harm.

10 The ethicists agree that a basic and fundamental
11 principle of clinical practice is that an adult with
12 capacity should not be subject to medical intervention
13 unless they had given a valid and informed consent.
14 Their evidence explained that the philosophical basis
15 for the idea of informed consent is patient autonomy.
16 That is not a new idea. There was a discussion in the
17 ethicist's evidence about the 18th century philosopher,
18 Immanuel Kant, and Professor Savulescu said this in his
19 evidence on 26 January 2021, referring to Kant's
20 categorical imperatives of autonomy and rationality. He
21 said this:

22 "Because human beings have autonomy and they have
23 rationality, you should always treat human beings as
24 an end and never merely as a means, and how you treat
25 somebody as an end is essentially if you get their

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1 further thinking, it becomes clear that those are just
2 not acceptable and were actually never acceptable."

3 You may recall, sir, that I suggested to the
4 ethicists that context and history might help us
5 understand why something happened, why a practice took
6 place but wouldn't necessarily provide a justification
7 or excuse of that practice having taken place.

8 Professor Savulescu said:

9 "That's exactly right. There is a distinction
10 between two kinds of reasons, explanatory reasons and
11 justificatory or normative reasons."

12 So, for example a culture of paternalism or a dearth
13 of guidance from the Chief Medical Officer or the
14 General Medical Council might be an explanatory reason,
15 it might help explain why something was done the way it
16 was, but that doesn't mean that it is necessarily
17 a justificatory or normative one.

18 The second point in relation to this issue about
19 hindsight and standards and norms of behaviour at the
20 time -- and this was alluded to by Mr Dawson
21 yesterday -- there is evidence before you, sir, that
22 some of the ideas, principles or ethical norms that are
23 most relevant to this Inquiry have, in fact, been
24 incredibly stable across time. I want to take three
25 categories of people whose actions fall to be assessed

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1 informed consent, in a nutshell. So when they
2 understand what you are proposing and freely agree to
3 it, you are treating them as an end. When you don't do
4 that, you are treating them as a means. That's what's
5 so important about obtaining informed consent, is that
6 you are then treating the patient as an end in
7 themselves and not merely as a means to something else."

8 The ethicists also told us about the importance of
9 a series of lectures given by Professor Sir Ian Kennedy
10 in 1980, the Reith Lectures, *Unmasking Medicine*. It is
11 just one of those lectures I want to put up on screen.

12 RLIT0000620, "Reith Lectures 1980: Unmasking
13 Medicine. Ian Kennedy Lecture 4: If I were you, Mrs B".
14 Professor Kennedy said this:

15 "It would normally be accepted that ethical
16 principles, the principles by reference to which we
17 organise our lives and decide what we ought or ought not
18 to do, are not the preserve of any one group. But the
19 doctor may reply that, yes, he does make ethical
20 decisions, but these are medical ethics things and so
21 they are properly for doctors alone. This would suggest
22 that there is a realm of ethics unique to medicine and
23 within the unique competence of doctors to determine and
24 apply. My response is that medical ethics are not
25 separate from but part of the general moral and ethical

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1 order by which we live. Decisions as to what the doctor
2 ought to do must therefore be tested against the ethical
3 principles of the society. He has no special
4 dispensation to depart from our moral and ethical order.
5 It must be wrong that a doctor, by describing a decision
6 as medical, can claim unique competence to make such an
7 decision, even if it touches the basic values by which
8 we live our lives."

9 Then we can go, please, to page 3, Lawrence, second
10 and third paragraphs.

11 Professor Kennedy said this:

12 "Another rationalisation resorted to is the
13 so-called therapeutic privilege. This suggests that, as
14 a matter of good medical practice, circumstances exist
15 in which the doctor may withhold information from his
16 patient, if in the exercise of his discretion and
17 judgment it wouldn't be in the best interests of the
18 patient's health to know. This is clearly a device
19 created by doctors to do what is in the best interests
20 of doctors. It may be justified on some occasions but
21 there is no effort to specify these occasions.
22 Everything proceeds on the basis of the particular
23 doctor's judgment. It all boils down to the doctor
24 being good, gentle and kind. It would be nice if all
25 our doctors were like this. But, just in case, can't we

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1 "For, it is a basic moral principle of our society
2 that we should tell the truth."

3 Those then are some of the standards and norms of
4 the time relevant to an assessment of the actions of
5 clinicians.

6 Turning more briefly to civil servants, the Public
7 Health & Administration Group told us that the Civil
8 Service attributes of integrity, honesty, objectivity
9 and impartiality form the bedrock upon which the Civil
10 Service was built. And that whilst those values were
11 not enshrined in statute until 2010, the Civil Service
12 had been firmly based on them for at least the last
13 160 years.

14 So no need for hindsight in order to understand the
15 values and norms which should guide the behaviour of
16 civil servants.

17 Likewise, in relation to politicians, the same
18 Public Health & Administration Expert Group enabled us
19 to explore the Nolan Principles, the seven principles of
20 public life. You will recall they are: selflessness,
21 integrity, objectivity, accountability, openness,
22 honesty and leadership. And although those were first
23 formally published as such in May 1995, the experts told
24 us that they were the principles that had long
25 underpinned the spirit of public service in this

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1 have some more certain guarantees that our interests, as
2 defined by us, may be allowed to prevail? The device of
3 the therapeutic privilege pays lip-service to the
4 principles of truth-telling and self-determination,
5 while it creates a discretionary exception which is
6 quite capable of swallowing these principles when the
7 doctor decides the occasion requires it.

8 "If we look beneath these rationalisations we see
9 an ethical principle which is certainly not part of
10 received tradition in analysing the doctor-patient
11 relationship. The traditional view is that the
12 doctor-patient relationship rests on trust or at least
13 on agreement. But what we see is an operational
14 principle defined by the doctor and accepted by us by
15 default, which allows the doctor to suspend the trust or
16 rewrite the agreement when in his view this is
17 appropriate. Of course, if the patient breaks his trust
18 or violates the agreement, there may be dire
19 consequences for him, even to the extent of his
20 forfeiting further care. Not so the doctor. He remains
21 arbiter of the relationship, even to the extent of
22 claiming the privilege of resort to an operational
23 principle which is the precise opposite of traditional
24 ethics."

25 Then this last sentence:

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1 country.

2 So, put shortly, the civil servants and politicians
3 whose decisions and actions you, sir, will need to
4 consider were always expected to act with objectivity,
5 with integrity and with honesty.

6 The third issue that I want to say something about
7 relates to the submissions that have been made about the
8 position adopted by some of the public body
9 Core Participants, most notably but not uniquely the
10 Department of Health and Social Care.

11 Much has already been said by, amongst others,
12 Ms Gollop KC, Ms Jones, Mr Williams KC and Mr Stein KC.
13 You have heard in the submissions of Mr Bowie for the
14 Scottish National Blood Transfusion Service and the
15 Scottish Territorial Health Boards that it is indeed
16 possible for a public body to engage even at this late
17 stage in a valuable process of critical self analysis.

18 As to the Department of Health not having a position
19 or a case, Ms Grey was of course right when she said
20 there is no compulsion on a Core Participant to
21 formulate a case before a public inquiry. There is
22 nothing in the Inquiries Act or Inquiry Rules that
23 compel that. But one may ask the question: if a public
24 Inquiry is not the place for candour, what is?

25 For years, of course, the Department of Health and

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1 government and indeed the Devolved Administrations have
2 promulgated positions and views. We have examined some
3 of them. The phrases are familiar to you all: no
4 conclusive proof, best available treatment, no fault,
5 inadvertence.

6 You, sir, may wish to consider the fact that the
7 Department of Health and government have felt able to
8 take a position to advance a case previously on the
9 basis of what might be said to be a limited
10 understanding of the underlying facts, but now, when so
11 much more is known, it has not done so. But that is, of
12 course, ultimately a matter for you.

13 I have already referenced Mr Williams' observation
14 that this is an Inquiry looking into the here and now.
15 The position adopted by any public body, and
16 a disinclination, for example, therefore, to answer the
17 questions posed of the Department by Mr Snowden on the
18 first day of those submissions, is itself a matter that
19 you would be entitled to consider if you wish, sir, as
20 part of your assessment of the response of government
21 under the Inquiry's terms of reference.

22 The other point to bear in mind about the situation
23 of public bodies not engaging in the process of critical
24 self analysis is a point that was made powerfully by
25 Mr Dawson yesterday. He referred to the psychosocial

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1 that would have prevented it. I've already said, had we
2 taken the step we now know would have saved lives we'd
3 have been treated with outrage by the Haemophilia
4 Society and most haemophiliacs by denying them their
5 Factor VIII. There just wasn't the evidence to suggest
6 that.

7 "I don't think the Department did anything wrong,
8 I don't think there was anything the Department could
9 have done that it didn't do. It's the current way of
10 the life now. It's part of the current political scene,
11 that somebody has got to be summonsed, to use the old
12 saying. Someone has got to be found to be blamed for
13 this, and it's all the fault of the Government, really.
14 Or sometimes it's all the fault of the Tory party; it
15 depends who is in power at the time. I don't think we
16 did anything really wrong."

17 Sir, you wanted the evidence which this Inquiry has
18 heard to begin and end with the accounts of those
19 infected and affected. I am going to end by reminding
20 everyone about a particular piece of evidence that was
21 heard during the course of the Inquiry hearing on
22 8 May 2019. The reason why I am going to do so I will
23 explain after I have summarised the evidence.

24 On that day an anonymous witness, Mrs C, gave
25 evidence about her son S. It was the first time she had

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1 evidence and the evidence that a lack of apology, a lack
2 of explanation can itself cause further harm.

3 The psychosocial group told us how that can lead to
4 health care becoming compromised because patients avoid
5 going back into the health care system. They told us
6 people can become stuck with anger, that they can't move
7 on with their lives because nobody has acknowledged or
8 taken responsibility for what has happened to them.

9 So one further question you, sir, will be entitled
10 to consider as part of your analysis if you choose, in
11 terms of analysing the response of government, is
12 whether the stance of public bodies on an ongoing basis
13 has compounded or continues to compound that harm.

14 In that respect, it may be instructive to note that
15 whilst the Department might not wish to take a position,
16 some of the witnesses who they have supported to give
17 evidence have done so. Some of course have accepted
18 where things went wrong. Mr Burnham gave evidence in
19 very powerful terms in that respect.

20 By contrast, however, we have the view of
21 Lord Clarke in his evidence on 27 July 2021, if I may be
22 forgiven for quoting:

23 "I don't think the Department did anything wrong.
24 I've never heard anybody suggest anything that in the
25 real world a minister or a civil servant might have done

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1 ever spoken about these events beyond her immediate
2 family. S was born in 1978. He had haemophilia A. He
3 would go to hospital quite regularly to receive
4 cryoprecipitate. He didn't like it, Mrs C said it was
5 quite difficult, but there was no suggestion from her
6 evidence that treatment with cryoprecipitate was
7 ineffective.

8 In 1983 S's treatment changed to Factor VIII
9 concentrates and he started home treatment -- in 1983.
10 The significance of that date in relation to the events
11 which the Inquiry has been examining needs no further
12 explanation.

13 S was five years old when he began to be treated
14 with Factor VIII concentrates. I asked Mrs C if she had
15 ever been given any warning about the products that her
16 son was being treated with. Her answer shortly was
17 none. She was just told it was an amazing thing and,
18 indeed, it seemed that way to her because it was quicker
19 and it was more convenient than cryoprecipitate.

20 I asked her if there was ever any discussion with
21 her about the particular concentrates being used or any
22 differences between different kinds of concentrates, the
23 answer was no. We don't know what particular
24 concentrates S was treated with but the annual returns
25 for the hospital in question for 1983 and 1984 show the

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1 centre using both NHS Factor VIII concentrates and
2 Armour Factorate for home treatment.

3 A year or two after S started being treated with
4 Factor VIII concentrates he developed a tooth problem.
5 Mrs C took him to the hospital where they called
6 a dentist to come down and examine him and when the
7 dentist appeared, she was wearing what Mrs C could only
8 describe as a "space suit". The dentist didn't want to
9 come too close to this little boy. He was six going on
10 seven and it was as if the dentist didn't want to touch
11 him. Mrs C didn't understand. So she turned to the
12 doctor and asked what was going on and the doctor took
13 her into another room, gave her a blue plastic bottle
14 and plastic gloves and told Mrs C that her boys -- she
15 had another son with haemophilia as well as S -- had
16 been tested for HIV, had tested positive and, in future,
17 when she administered Factor VIII to them she would need
18 to wear the gloves and use the blue plastic bottle to
19 put them in. Then the doctor sent them home and "That's
20 how it was", said Mrs C.

21 The doctor didn't tell Mrs C anything about HIV or
22 the connection with AIDS or the longer term prognosis
23 for S and his brother. Mrs C asked about the risks at
24 home; she had a baby at home. The only answer she got
25 was that the doctor didn't know. Mrs C hadn't known

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1 was not told anything about the side effects or the
2 risks or disadvantages of AZT and it had devastating
3 implications and effects on S's health. She felt he was
4 used as a guinea pig by the hospital.

5 In early 1994 S became very ill. I'm not going to
6 recount the details of his last weeks, it's in her
7 written and oral evidence, but suffice it to say that he
8 was very frightened and he was in a lot of pain.

9 Mrs C told us about a book that S wrote in, a kind
10 of diary, it was entitled "My feelings and my life" and
11 he wrote on the first page "Started 8 February 1994" and
12 he wrote "Finish when all the pages run out". S didn't
13 get to finish the pages. That month, February 1994, was
14 the month he died. He was 15 years old.

15 There was no reference to HIV or AIDS on his death
16 certificate. Haemophilia was on there but not HIV, not
17 AIDS, and that wasn't at Mrs C's request.

18 Because of stigma, Mrs C kept S's diagnosis from her
19 other children. She told them he had had a rare form of
20 cancer but some time later one of her children was told
21 by a doctor treating him at the hospital that his
22 brother S had had HIV and AIDS and died from it. That
23 was done without Mrs C's knowledge and consent, and her
24 daughter was given the same information by their GP.

25 The family was never offered any support or counselling.

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1 that her sons were going to be tested for HIV and she
2 never received anything in writing from the hospital
3 about the tests and the results.

4 About a week later, the GP turned up at the door
5 with someone else, someone to do with education, she
6 thought, and they said they had to go to the boy's
7 school and tell them about the HIV results.

8 There came a time when a newspaper reported that
9 there were brothers carrying the AIDS virus in a London
10 hospital. Their ages and the name of the hospital was
11 given but not their names, but Mrs C knew that this was
12 a reference to her boys. That information had, as she
13 understood it, been leaked by someone at the hospital to
14 the press.

15 The Inquiry was able to track down one of the
16 articles before Mrs C gave her evidence. It was said in
17 the article that haemophiliacs had a higher than average
18 chance of the virus developing into AIDS. Mrs C told us
19 the hospital hadn't told her that.

20 The article said that parents knew of the risks to
21 their children; she said that wasn't correct. The
22 article quoted a spokesman for the Regional Health
23 Authority saying the family was being counselled by
24 senior doctors; they were not.

25 When S was about 11 he was prescribed AZT. Mrs C

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1 S received some money from the Macfarlane Trust
2 during his short lifetime. The last Mrs C ever heard
3 from the Macfarlane Trust was a letter with some money
4 to help with funeral costs very shortly after he died.
5 She learned that S had been tested for hepatitis C and
6 been infected with hepatitis C only years later when
7 a letter came out of the blue from the Skipton Fund.

8 I just want to read two short sentences from Mrs C's
9 evidence. She said this:

10 "S did exist. He had every right to be here now.
11 That was taken away from him. I think people should
12 know what happened to him because it shouldn't have.
13 Nobody's ever told me how this happened, why it happened
14 or just said to me 'We are sorry'."

15 Mrs C's evidence was about S, was unique to S and
16 was deeply personal. But I have recounted it today for
17 two reasons. Firstly, because captured in that one
18 account is so much of what you have all told this
19 Inquiry over the years.

20 So much of what you have told us you and your loved
21 ones experienced, whether infected through blood
22 products or through transfusion, whether infected with
23 HIV or hepatitis B or hepatitis C or all three. The
24 failure to provide information about the risks of
25 treatment to the individual being treated or, in the

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1 case of a child, to the parent or parents. False
2 reassurance expressly or implicitly through the use of
3 phrases such as "wonder drug", about the safety of the
4 treatment.

5 The absence of informed consent to treatment. The
6 absence of discussions about alternatives to treatment
7 with blood or blood products. Testing for HIV or
8 hepatitis C without consent. Failures, gross appalling
9 failures in the communication of diagnoses. The
10 experience of stigma, including at the hands of the
11 National Health Service.

12 The terrible effects of the treatments, particularly
13 the early treatments, whether as in S's case and in
14 other accounts that we have heard, treatment with AZT
15 or, as so many of you have told us, treatment with
16 interferon or ribavirin for those infected with
17 hepatitis C.

18 The unimaginable pain and suffering endured by those
19 infected and witnessed by their families. Deep abiding
20 grief, whether for a life lost or a life whose course
21 has been irrevocably altered. The lack of support,
22 psychological and practical, and the lack of
23 explanation, accountability and apology.

24 All that is in Mrs C's account of what happened to S
25 and all that is in the accounts that you have given the

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1 Was S's treatment the best available treatment in
2 light of the medical knowledge at the time? That's
3 a question, sir, for you to consider.

4 Very finally, in the course of closing submissions
5 thanks have been expressed to the Inquiry and those
6 working for it or on its behalf. Those are greatly
7 appreciated and I can say on behalf, not only of the
8 team I lead but I think on behalf of all those who
9 worked for the Inquiry, that it has been an honour and
10 a privilege and a truly humbling experience.

11 But the true thanks are owed by us and by every
12 Government Department, every Government Minister, past
13 and present, every civil servant, every doctor, every
14 NHS organisation and every other organisation or
15 an individual with an interest in these matters to you:
16 to every man, woman and child who was infected and who
17 suffered. To every family member whose loved ones had
18 died. Every family member who has had to witness and
19 may still be witnessing their loved ones suffering in
20 the most difficult circumstances imaginable.

21 To those who have, with great courage, given oral
22 testimony that has moved us to tears. To those who also
23 with great courage have provided written statements to
24 the Inquiry which have revealed their most personal
25 experiences and suffering. To those without whose

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1 Inquiry over the years.

2 The other reason why I wanted to recount Mrs C's
3 testimony is because I want to remind you of three lines
4 to take that we have heard about and suggest that it may
5 be instructive to view those lines when you reach
6 whatever conclusions you decide to reach, sir, about
7 them through the prism of Mrs C's evidence and the
8 evidence of you all.

9 The UK Government line, and this is a quote:

10 "The Government does not accept that any wrongful
11 practices were employed."

12 The Scottish Executive line, and this is also
13 a quote:

14 "... no reason to believe anyone acted wrongly in
15 the light of the facts that were available to them at
16 the time."

17 And, of course, the line that we have seen repeated
18 so often and it is certainly articulated by the then
19 Prime Minister, Mrs Thatcher, in a meeting on
20 22 November 1989, and the reference -- I'm not going to
21 put it up -- is DHSC0002536_031, that line was then
22 followed in the Northern Ireland Office and the Welsh
23 Office:

24 "All patients received the best treatment available
25 in the light of the medical knowledge at the time."

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1 campaigning, tenacity and determination there would be
2 no Inquiry.

3 You have laid bare the most personal and distressing
4 parts of your lives in pursuit of truth and justice and
5 in the hope that lessons can be learned for the future
6 for the benefit of others and so, with the greatest of
7 admiration and respect to you all, I say thank you.

8 **SIR BRIAN LANGSTAFF:** Well, I say thank you too. I have to
9 say a personal note here, I could not have asked for
10 a better counsel to the Inquiry.

11 What she has said has shown once again the
12 importance of this Inquiry and the way in which there
13 has been a response to that importance by the
14 collaborative efforts, the collective efforts of all of
15 you. Thank you.

16 This is no all probability the last time we shall
17 meet here at Aldwych House. The last time that those of
18 you who have followed proceedings more remotely can log
19 on to hear evidence, see presentations or hear
20 submissions.

21 It may well be some time before we meet again.
22 There's something perhaps -- I'm going off script a bit
23 here -- but there is something almost like an end of
24 term feeling about today and forgive me then for being
25 just the headmaster I have occasionally been and

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1 reminding you, please, particularly since there are so
2 many of you here, you may want to take photographs --
3 you know what's coming -- please be careful when you do,
4 if you do, to make sure there is no one in the
5 photograph who does not wish to be photographed for
6 obvious reasons, some of which you have just heard
7 expressed.

8 But you being here or there throughout four and
9 a half years, through Covid, through lockdowns, through
10 the challenges of ill health, through strikes, despite,
11 in many cases, bereavement.

12 Many of you have contributed through your
13 statements, your evidence, your provision of documents
14 but let me stress that your being here or watching
15 online in such numbers as you have has also been
16 important.

17 Let me tell you why I think it is so important.
18 Nothing concentrates the mind of a speaker than seeing
19 and knowing that they are talking to a large number of
20 people. True, a few played to the gallery -- no
21 names -- but, for most, the knowledge that so many are
22 so interested after so long a time tends to make them
23 realise the importance of what they are addressing and
24 the need to tell it as best they can.

25 It also fully justifies the decision, even if
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1 given everything that we have heard? But it will be as
2 short as I can make it whilst doing justice to the
3 evidence and the submissions which I have heard and read
4 and to the breadth of the terms of reference. And it
5 will be as quick to produce as I can.

6 Now, where there is a particular topic that
7 interests you, I intend that you should be able to go to
8 the relevant chapter to find the answers you are looking
9 for, and I hope that it will be an engaging read.

10 There will, of course, be an overview so that you
11 can quickly get a summary of my findings and
12 recommendations, and so that members of the press can
13 explain what we have collectively learned to the rest of
14 the country.

15 Beyond the writing of the report itself there is
16 a further part of the process which is required by
17 statute, the Inquiry Rules require it, but I would in
18 any event have considered it necessary in fairness. It
19 is that where there is to be explicit or significant
20 criticism in the report -- and there will be
21 criticism -- that the person due to be criticised is
22 told of what I intend to say and of the factual basis
23 underpinning it so that they can respond if they wish.

24 Now, the process is not only fair, but it also
25 reduces the possibility of challenge to the report.
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1 belated, to hold a public inquiry, by definition one in
2 which the public has an interest. Your sheer numbers
3 reinforces the point that the public think this is
4 important and it must help to bring that home to those
5 who will in due course consider my report.

6 Your simply being here has made a real contribution.

7 Representatives of NHS bodies, the devolved
8 administrations, politicians, civil servants, lawyers,
9 clinicians, interested experts, Scottish, Northern
10 Irish, Welsh, have also all contributed in their own
11 way -- I suppose I should add the English -- to what
12 I had asked should be a collective endeavour and, in my
13 judgement, it has broadly been that, even with the odd
14 wrinkle. I would like to thank you all of you for that.

15 As you know, as Ms Richards has kept reminding me
16 over the last half hour, I must now turn to writing the
17 full report. Now, I can't tell you at this stage
18 precisely when the report will be published. I wish
19 I could. But I tell you what I do know, and it is this,
20 the process of writing the report will inevitably take
21 some time. Time to weigh the submissions with the
22 evidence, time to resolve issues where the evidence is
23 not clear cut, and time to make the report as readable
24 as I can.

25 The report will not be short. How could it be,
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1 From the start we have designed the Inquiry's
2 processes to avoid unnecessary delay at this stage. We
3 have seen Ms Richards and her team put areas of
4 potential criticism to witnesses, both for them to
5 answer in their written statements and in hearings.
6 I don't anticipate that many witnesses or organisations
7 will be surprised by the terms in which they are
8 criticised if they are. But I do have to allow
9 a reasonable time for them to consider, in confidence,
10 the criticisms which I propose to make and for me to
11 consider any responses received.

12 As we know, some of our witnesses are old, some are
13 not in good health, and so I must make due allowance for
14 that, particularly if there is more than one criticism
15 to be made. But I can assure you that I will allow no
16 more time than is reasonable.

17 I know that many of you will want to make plans
18 outside the Inquiry and so I can say this, that the
19 report will not be published before the autumn.
20 Ms Richards has persuaded me that July is likely to be
21 too ambitious, and I think she's right, and that later
22 in the year will be more realistic.

23 It won't be August, since Parliament will not be
24 sitting then, so in short, the best estimate I can give
25 you is autumn.
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1 It has always been my intention to be as quick as
2 reasonable thoroughness permits. Time is not a luxury
3 I can squander. I assure you that I will be writing the
4 report as fast as I can and that Ms Richards and her
5 team will be handling the warning letter process for me
6 with their usual efficiency.

7 I can also promise that we will give you plenty of
8 notice about when the report will be published so that
9 those of you who wish to come together and attend in
10 person on that day are able to do so.

11 Let me turn from the autumn to these last three
12 weeks.

13 First, I should say that the written submissions and
14 these three weeks of oral submissions, mainly but not
15 only from those who are representing institutions or
16 groups of Core Participants, they have all been of great
17 value to me. They have helped to highlight what has
18 been most important to each of you. The written
19 submissions have expressed it, the oral submissions have
20 summarised it.

21 I should add that if you had asked me at the start
22 of these three weeks whether each speaker would be able
23 to contain what they had to say within their allotted
24 time slots, you might imagine what I would have said.

25 It is often much more difficult to condense, to
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1 Finally, I want to come back to what I said when
2 I started with these few words. I would like to thank
3 you for the spirit in which you have followed the
4 Inquiry proceedings, in whatever way you have, here in
5 person, online, through the Inquiry emails and wider
6 media. I thank you with sincere appreciation for making
7 this a collective endeavour, for the warmth with which
8 you support one another, and for your kind words about
9 the Inquiry team and its process.

10 Thank you all, individually and collectively. Thank
11 you and goodbye, for now.

12 (2.57 pm)

13 (Inquiry hearings adjourned)
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1 precis what you think and why you think it, it is
2 something of an art. I'm not sure I would have had it
3 as an advocate. But I'm glad to say I would have, in
4 this case, been proved wrong. I would like to thank
5 each and all of those who made submissions orally for
6 respecting almost to the minute the timetable.

7 It was drawn up to ensure that the time available
8 was shared fairly between everyone who wanted to speak
9 and, by keeping within your slots, no one took unfair
10 advantage. So thank you.

11 Many of the submissions in writing or orally asked
12 me to make another interim report about compensation.
13 You heard that general point touched upon by Mr Stein
14 this morning. I will need to reflect on the
15 submissions, especially those that point out that as
16 little time as possible should be lost before finalising
17 arrangements for compensation.

18 I want to tell you that I have written to the
19 Paymaster General to inform him of my intention to make
20 a further interim report about the framework for
21 compensation. I anticipate that I will be in a position
22 to do so before Easter if not earlier, will aim to tell
23 you a week before publication when more precisely it is
24 coming. The report will be shared with our contact list
25 and published on the Inquiry website.
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