

Tuesday, 17 January 2023

(10.00 am)

SIR BRIAN LANGSTAFF: Just before we begin, Mr Snowden, can I just say this. It has been a while since the hearing room here in Aldwych House has been quite so full. Can I remind you, please, to be very careful if you are taking photographs of anyone not to include by accident somebody who should not be in the photograph. Only photograph people, please, with their consent. It is something I will remind you of from time to time, forgive me for reminding those of you who obviously already know it, but just please take care. The reasons are obvious.

Mr Snowden.

Closing Statement by MR SNOWDEN KC

On Behalf of 1,074 Individual Core Participants, Factor 8, Families and Friends of Haemophilia NI and The Fatherless Generation

MR SNOWDEN: Sir, good morning.

By way of introduction, Lord Robert Winston, professor, doctor, scientist, was entirely right to describe the contaminated blood scandal as the worst treatment disaster in the history of the NHS.

Disaster is a good word to connote the severity of what happened but in certain usage it can connote

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theme is that governments have, over the years, delayed, denied and have degraded those who are infected and affected by how they have subsequently been treated.

We will invite you to find in your report, as we have done in writing, that all the concerns expressed by our Core Participants and others, over decades, about the blood products and the transfusions they were given and the treatment they received and how they have subsequently been dealt with will be fully borne out.

We analyse the totality of our submissions, we reduce to one paragraph if we may in this way, we say this preventable catastrophe arose from the combination of pharmaceutical companies' greed and unsafe practices; the skipping of known safety steps for blood products; insufficient regulation, foresight and planning by government; overenthusiasm on the part of clinicians blinding them to the obvious risks and dangers of large pool blood products; failure on the part of the government and clinicians to recognise the long-standing danger of non-A, non-B hepatitis, hepatitis C as it became to be known, and their failure to respond appropriately and quickly to HIV, HTLV-III as it was initially called; and most significantly, failure to apprise the patients, or, when they were children, their parents, of the true state of affairs at the time or own

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something terrible but unavoidable, a natural disaster; that is not what this was, we invite you to find.

This was a scandal, as we and others have long described it, precisely because it was avoidable, it need not have happened, and we will invite you to conclude in your report that it should not have happened.

Language is important and we expect a Prime Minister to be careful with their words, and when she granted this Inquiry in 2017 Theresa May described it as an appalling tragedy which should simply never have happened. Jeremy Hunt, now Chancellor of the Exchequer, agreed when he gave evidence to you on 27 July 2022.

Thousands of men, women and children have died or have had the trajectory of their lives unavoidably altered for the worse. Families have been shattered. This was a brutal, unacceptable, unforgivable and unnecessary travesty visited upon patients in the grossest breach of medical trust imaginable, with truly devastating consequences.

A theme running through our submissions and those of all the other Core Participants who have given you written submissions for the infected and the affected is individuals have been stripped of their dignity. They have been forced to lead lives they did not choose. Our

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up quickly afterwards.

That, in a nutshell, is our summary. Failing to apprise the patients or their parents of the risks and the options denied them the power to exercise their own informed choice over treatment. It turned them into mere passive recipients of what others wrongly decided was best for them.

Those affected and infected have battled for decades to lay bare what we have now heard in the last four years of evidence. But we pause at the end of the introduction to ask this: why, in the United Kingdom, in the 21st century, did it have to come to this? Why has the truth had to be squeezed out of government by campaigners through litigation and through public Inquiry?

Here's an answer. Jeremy Hunt, formerly Secretary of State, now Chancellor of the Exchequer and, we presume therefore, partly involved in decision-making when you report, sir, had reflected on this before he gave his evidence to you, and he said honestly in his oral evidence to you, sir, "I am afraid that institutions and the state close ranks around a lie sometimes and I think that's what happened in this case".

For those who weren't here to hear him, we should

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1 pause and let that sink in. He thinks the institutions
2 of the state closed ranks around a lie. And that is
3 a conclusion we invite you to draw in your final report.

4 Also at the outset, sir, if I may, a few words about
5 the word "liability". I said a moment ago that language
6 matters, and indeed it does. We recognise that in your
7 report you cannot determine civil or criminal liability
8 but we invite you in careful language to appropriately
9 emphasise what we describe as catastrophic failings,
10 woefully inadequate decision-making by government and,
11 in many cases, utterly unacceptable treatment of
12 patients.

13 We say there have been egregious failings of the
14 grossest kind on the part of pharmaceutical companies,
15 civil servants, ministers and clinicians.

16 You will recall and we note in passing here, we will
17 come back to it later if we have time, the unequivocal
18 view of Professor Savidge in his contemporaneous expert
19 report that the treatment of at least one of the boys,
20 of one of the witnesses who gave evidence to you,
21 Susan Hallwood at Alder Hey Hospital was, in his words,
22 negligent, negligent, negligent.

23 Without yourself determining negligence, you, sir,
24 have seen and can record in your report how others such
25 as Professor Savidge described it at the time. While

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1 decades as part of other groups such as Tainted Blood.
2 And we also represent the vast majority of the surviving
3 pupils and bereaved families of those who attended the
4 Lord Mayor Treloar school in Hampshire.

5 Now, some of those present, and perhaps more of
6 those watching online, whether the infected and affected
7 or members of the press, may not have watched every day
8 of the live stream. We all know, here, that a public
9 inquiry is an unusual creature. It is not litigation
10 between two competing parties in front of a judge
11 deciding between them. You, sir, and your team of
12 counsel to the Inquiry, led by Ms Richards KC, have been
13 investigating -- and continue to investigate, as we
14 receive further documents from you even yesterday. We,
15 by which I mean those Core Participants we represent,
16 have the role of being able to help, to assist, to offer
17 evidence, to invite you to look at particular issues.

18 You invited us to give you written submissions at
19 the conclusion of the oral evidence. You asked us not
20 simply to regurgitate or recite back to you the evidence
21 you had heard. You asked us to give you our Core
22 Participants' views on the issues which most concerned
23 them, both on what you should make as findings in your
24 report and what you should make as recommendations, and
25 we have tried to do that.

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1 you may be restricted by the Inquiries Act from yourself
2 reaching a conclusion of negligent, that is how we
3 describe it.

4 The Inquiry has heard the line peddled by
5 governments for decades that this was all done in
6 accordance with the standards of the time and that
7 patients got the best possible treatment. That cannot
8 possibly be sustained after the evidence you have heard.
9 They did not.

10 So let's go back again to the Prime Minister
11 Theresa May in 2017 for a moment of clarity. She said:

12 "Thousands of patients expected the world-class care
13 our NHS is famous for, but they were failed."

14 And we invite you to express those failings in the
15 strongest terms when you report.

16 Sir, after that introduction, let me pause for
17 a moment and step back before we dive in. You know
18 that, with Mr Cummins and Dr Burin, instructed by
19 Collins, I represent more than a thousand of the
20 infected and affected Core Participants. Our
21 Core Participants also include campaigning
22 organisations: Factor 8, Families and Friends of
23 Haemophilia Northern Ireland and The Fatherless
24 Generation. And within those individuals are
25 a considerable number who have campaigned tirelessly for

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1 Having seen the very substantial amounts of material
2 produced by all of the Core Participants, we can see you
3 have received submissions on all of the issues from
4 every perspective. You have several thousand pages of
5 written submissions in total. There may be differences
6 of emphasis and perhaps differences of some detail among
7 the recognised legal representatives who act for the
8 infected and affected, but I discern very little real
9 difference of substance among us.

10 I anticipate that each of those who represent the
11 infected and affected will bring a slightly different
12 perspective to what we say over the course of the next
13 three weeks. For today we won't be repeating everything
14 we have said in writing, we know you have already read
15 it, but, like the approach of counsel to the Inquiry
16 when delivering presentations, we are fully aware this
17 is a public inquiry and a process by which what is said
18 is said in public, so we will touch on or allude to what
19 we wrote and we will spend a little bit more time on
20 some parts of it. So we are trying to do what we did in
21 writing, only with even more focus, emphasising and
22 highlighting in this public forum what matters most to
23 our Core Participants.

24 So our intention today is to first of all summarise
25 very briefly what we've said in writing, emphasising key

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points, to dip in a little more detail into some areas.
We can't do them all but we are confident that you will hear from other representatives over the next three weeks on every area that concerns you.

Significantly though, today should be a chance to respond to what the non-infected and affected Core Participants have said in writing. By that I mean principally the Department of Health, as we call them. Most of the time you will be hearing from me. My junior, Mr Cummins, is going to deal with the section dealing with Lord Mayor Treloar school, probably after the coffee break.

But before we begin, we do want to say, as we said in writing -- to convey the thanks to you and to counsel to the Inquiry publicly from our Core Participants. Some have fought for more than 30 years for this Inquiry, others for shorter times but no less vigorously. The analogy of David and Goliath, which of course is the obvious one and is used in our submissions, is entirely apt. Long campaigning was relentlessly pushed back against again and again and again by governments -- and this is not a party political point, by governments of all colours -- resisting an Inquiry until 2017.

Those campaigning have tried to piece together what

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the topics which we have titled, in our written submissions "People", that is the experience of the infected and affected; "Myths and Lies", which is how we have titled those assumptions, those unwritten presuppositions that have grown up over time around this scandal. We are going to talk to you very briefly about the Government and clinicians' response, about Treloar's and, towards the end, we'll highlight aspects of what we suggest you should find as recommendations and to do with compensation, and then we will end, in time for a further Core Participant to give his submissions this afternoon.

Now, some parts we won't repeat in any detail today, so, if you will forgive me, I am merely going to, largely for the purpose of conveying them publicly, emphasise some aspects of what we have said in writing but won't delve deeply into.

First of all, the HIV Litigation. We, the broad point is, invite you to find the Government's approach was wrong.

You can take comfort in so finding because of the highly unusual intervention of the trial judge, Sir Harry Ognall, into the litigation and the way in which Lord Justice Ralph Gibson expressed his comments in the Court of Appeal in September 1990. Sir Harry Ognall

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some initially believed and, indeed, some who gave evidence to you until very recently believed was simply their own tragic experience. That grew through knowledge of others into an awareness of how widespread this scandal was, with growing outrage, collaboration and campaigning. Even now though, attempts to get hold of records, Freedom of Information Act requests, and so on, are pushed back.

What you, sir, and your team have done and what my Core Participants are enormously grateful for is something like assembling a jigsaw. The better analogy perhaps is it is like assembling a jigsaw whose pieces have been scattered through every room of the house. So you have our thanks for that: for what you have done, for what you will do and, more significantly, for how you have done it.

Let me tell you, if I may, briefly, what we are going to focus on today. I'm going to, in a moment, focus on candour engagement from the Government and the Government's response. Then I'm going to spend a moment, if I may, on the framework, we say, wraps around the duty that rests on the Government and that underpins its responsibility.

Then, I'm going to address you, time permitting -- or we are going to address you, time permitting -- on

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said this:

"A Government which takes upon itself the role of a public provider of medical advice and clinical services is in a very different position to any commercial organisation. It is clearly arguable that their duty to innocent citizens, who suffer injury under the aegis of such treatment, has a moral dimension to it, which should distinguish their assessment of their position from the criteria to be adopted by defendants of a corporate character. Governments owe a duty wider than to shareholders or insurers. It should mean the public may be entitled to expect from government an appraisal of their position which is not confined solely to legal principles to be found in the law of negligence."

In the Court of Appeal, Lord Justice Ralph Gibson said this:

"It appears to be not in dispute that there was, in fact, a failure to protect plaintiffs from the dangers of using blood products, whether imported or supplied in this country, which were infected."

Sir, the broad point, we say, is that those plaintiffs, as they were then, claimants as they would be now, should never have been made to litigate. We are not going to invite you and we don't invite you to go

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through the merits or demerits of the litigation; that will be no part of your report I am sure. But as a matter of principle of approach and of the government's attitude, we invite you to conclude that it was wrong, inappropriate, as Mr Justice Ognall indicated.

We note, a note in passing, sir, what now Sir Rupert Jackson, then Rupert Jackson QC, said in his witness statement before to you. He said it is unfortunate that the government of the day did not face up to its moral responsibility in the same way the present Government has, he said. We wait with bated breath to see whether that will be borne out.

Moving from the HIV litigation to self-sufficiency. Again, in the briefest of summaries, as, sir, I hope you understand, so we can then focus on other points in more detail in due course. What should self-sufficiency have been? We say it is very obvious from the evidence you heard that, through the '70s and '80s, there was a drive to provide as much factor concentrate as possible, in part due to the business and the marketing efforts of pharmaceutical companies, which stood to make substantial profits from their sales.

In part, it was due to clinicians, whose enthusiasm for being able to deliver what they believed were

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sizes, these were all inherent features in the commercialisation of blood and the sale and scale of the manufacturing processes adopted in the US to maximise yield and profit.

They ought -- "they", that is, the Government and clinicians -- ought to have been aware that the viral risks included what was then known as non-A, non-B hepatitis -- we will come back and deal with this in a little more detail later -- which should not even then have been assumed to have been modest, mild, transient or short-term. No other hepatic virus was; why should this one have been assumed to be?

Sir, we therefore say that the proper approach to self-sufficiency ought to have been to have either not used factor concentrates at all, unless and until such time as the viral risks of non-A, non-B could be eliminated, or, at worst, to have reserved concentrates for the very most serious situations and most exceptional cases of clinical need. They should not have been used daily, regularly, "thoughtlessly", is the word we use.

When should that position have been appreciated, the counterfactual scenario, and when, therefore, should self-sufficiency on that basis have been achieved? We, sir, as you know, in writing take it right back to 1967

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transformational products seemed to have blinded them to the risks of those products.

In part, perhaps, it may indeed have been due to the demands of patients who had been told that factor products were miracles, without being told of the risks associated with them.

Whatever the reason for which it occurred, it was felt this perceived level of need -- which the Inquiry knows was reported by UKHCDO clinicians to be rising, year on year, from the late '70s, through the '80s -- it was felt that was legitimate, desirable and unstoppable and had to be met, whether by domestic production or importing commercial products. Our broad point on self-sufficiency, which, sir, you will have seen developed in writing, is that that is an example of the tail wagging the dog.

We propose a counterfactual scenario in which the clinicians and government ought to have appreciated that all pooled factor concentrate carried a significantly higher risk of harm through viral infection than single donor cryoprecipitate. They ought to have appreciated that commercial products made in the United States carried a very significantly higher risk of harm than smaller pool UK factor concentrates, because of the nature of the donors, the source of the donors, the pool

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when Dr Rosemary Biggs, respected doctor at Oxford, wrote to the then Chief Medical Officer, Dr Godber in August 1967. She pointed out that the United Kingdom had pioneered factor concentrate treatment, that there was a shortage of it in England but her concern was that US companies would shortly begin production. Their products would be expensive. Everything should be done to expedite the manufacture of these fractions in England and in Scotland.

She considered that having pioneered the treatment, the UK had the personnel who knew how to make it and had enough plasma. Although she expressed it in that letter as a financial argument, her warnings about the intrusion of United States companies must, to anyone with clinical knowledge, such as the Chief Medical Officer, have been understood to have included concerns over the viral safety of the products, given what was already known about the process of commercial blood donation, collection and pooling in the States. It is possible, we say, that she framed her argument as a financial one believing that was the language the Government would best understand.

We say that was the first call to arms and the self-sufficiency on the terms we have described it should have been considered, thought about and

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implemented in or not very long after 1967.

We have urged on you in writing the retrospective view of Dr Cash. Sir, you will, I know, have seen that, you will have remembered the article and you will have recalled how it was addressed during Inquiry hearings.

He considered that there were a series of errors and we urge you to consider them all in respect to self-sufficiency. But he described it this way: he said the United States, US-imported products between 1972 and 1982 were "dirty blood, a sewer of viruses", and that comes from a medical professional.

Moving from our summary of self-sufficiency to viral inactivation. Today is neither the time nor the place to explore the details of our case on viral inactivation. We set that out in writing and we commend that to you.

In respect of pharmaceutical companies, we summarise again very briefly what we have said in writing in chapter 11 of our written submissions.

The main impression that the Core Participants will have taken from the evidence relating to pharma companies during this Inquiry is, in fact, their failure to participate, despite the fact that, we say, it must be clear that they knew about the transmission of hepatitis through blood products in the decades before

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what we have written. Today is not the moment to go in detail through it but two points to pick out, really, from it if I may.

First, is that, so often, you will have seen in documents and even heard from witnesses language which suggests that patients were commoditised for the purposes of testing.

They were treated as a group. They were treated as a clinicians cohort, rather than as individuals. They were, in a sense almost traded with other clinicians conducting trials to be offered for those clinicians' trials.

We also flag up, as a second aspect of the testing, Dr Craske's persistent and long studies. Knowing what he and other clinicians then knew or ought to have known about non-A, non-B hepatitis, we say it is simply unacceptable to have carried out long testing programmes to see how individuals responded to hepatic risk. The simple point should have been they shouldn't have been carried out at all.

Finally, in way of brief summary of what we say, I'm not going to dwell at any greater length on consent, communication and information sharing, which is how we described chapter 15 of our written submissions to you. We simply summarise it in this way: the evidence you

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the '70s. They knew about the virtually universal contamination of products with non-A, non-B hepatitis in the '70s and '80s. They were aware, as aware as doctors, clinicians and regulatory bodies, of the developing position with AIDS and the fact that it may be transmitted by blood and blood products, and they failed to give any or any adequate warnings in respect of their products. But we observe that those companies have, we understand, watched but not actively participated in any meaningful way in this Inquiry, and we invite you to reach your own conclusions about what we don't hesitate to describe as a cowardly stance.

Transfusion, sir, again ever so briefly. We have addressed that at chapter 12 of our written submissions. We commend those to you. The short sentence is this: as one witness has told you, the safest transfusions is the one not given. The overall approach to transfusion, we say, should have been to have considered the risks and to have reduced blood use many decades before steps in that direction were taken.

We have also set out some submissions in respect of what you have heard described throughout this Inquiry as "PUPs", previously untreated patients and, in respect of other nonconsensual testing trials, studies and experiments, again, sir, we commend to you chapter 14 of

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have heard about the communication of adverse diagnoses and, as well as that, that withholding of information on diagnosis and risk demonstrates every variety of bad practice. The evidence you heard about how teenagers, children, their families and spouses were told of fatal diagnoses demonstrates an astonishing lack of care and that diagnoses were communicated callously.

You have heard, sir, that they were communicated in hospital corridors by nursing staff, they were accidentally overheard, they were communicated months or years after being known, they were discovered sometimes by stickers on fridges or notes being left lying around.

We chose not, in writing, to summarise, and I won't again orally, any further the evidence of the infected and affected because, sir, I know you have that in mind but we simply say this, we invite you to draw the conclusion that the infected and affected suffered every conceivable example of unethical practice about communication or the absence of communication.

Sir, that's a summary of the things I'm not going to dwell at any further length on, with an eye on the time and hoping that we are heading in the right direction. What I would like to do, if I may, is take you back to the preliminary hearing, under the rubric of candour and engagement from the Government.

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Sir, if we go back for a moment to September 2018 when you gave us the opportunity to make opening statements at the preliminary hearing in Westminster Hall. We will suggest that what we then began to outline to you, and others did too, has been entirely borne out by your Inquiry and what evidence has been unearthed over the last four years.

We suggested that complete trust placed by men, women and children in their clinicians and in the State has been broken, in that they were, without consent, given products and blood, the risks of which were not explained. They were given no alternatives, no choices. That, we say, has been borne out by the evidence you heard.

We suggested to you then, even on the dearth of evidence we had, that they had been subjected to clinical tests and trials without proper consent or proper knowledge and that again is borne out by the evidence you have heard and we invite you to so find.

We suggested then that doctors were, at best, mistaken and, at worst, took steps which were substandard and unacceptable. That also is borne out by the evidence you have had heard, some of which evidence shows catastrophic errors of judgement, ignorance of accepted methods of treatment and even ignorance of

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needed at all, still less when compared with the risks they carried. We said then and we continue to say, and I will develop later this morning, that the existing treatment of cryoprecipitate was significantly safer.

Again, we suggested the shift from single blood donors to buying commercial factor concentrates brought with it entirely foreseeable and hugely increased risks of viral transmission and infection, and that the consequences of those viruses were appreciated in the 1970s and before. We will come back again to that later today.

Let's turn, if we may, to what I said at the preliminary hearing about candour and engagement. Lawrence, I wonder if we could have COLL0000025, please, page 3. Sir, you will recall we took you to the report of the Right Reverend James Jones, the former Bishop of Liverpool, into the experiences of the families who had been involved in the Hillsborough disaster, and we suggest that his conclusions are all the more resonant today, having heard the evidence from the infected and affected, which you have heard over the last four years.

May we look at page 7, please, where, sir, you will see if we go to the third paragraph please. He said this -- and, sir, this touches, first of all, on candour but, secondly, on how you yourself will in due course

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material being disseminated by the UKHCDO.

We suggested to you then that the Government response was disingenuous and inadequate and, again, we submit that's borne out by the evidence that you have heard. You have seen, and we'll come back later this morning to deal with, inconsistencies in the ways in which civil servants dealt with information and their communications with ministers.

You've seen how assessments of clinical risk and danger, most acutely in relation to the risks attendant on HIV, were either unintentionally or intentionally misexpressed so that an impression of far lower risk was conveyed than was really warranted. We suggested then that politicians responsible for health took wrong decisions in conjunction with their civil servants and have since been covering up. Again, we suggest that is borne out by the evidence you have heard.

I chose to address you at the preliminary hearing on what I then called the narrative of necessity and I suggested you should look at it with real scepticism. That is the account which has developed that factor concentrates were a wonder product that simply had to be developed and deployed, that they were life saving, that haemophiliacs would have died without them. Whereas, we suggest then and we suggest now, that they are not truly

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express your report and your conclusions:

"In this report I do not pretend to speak for the families. But I have listened to what they have said to me. I urge you [the Prime Minister and Home Secretary to whom he is writing] to help ensure that those responsible for our national institutions listen to what the experiences of the Hillsborough families say about how they should conduct themselves when faced by families bereaved by public tragedy."

The situation is clearly analogous to that which we are in today. Could we turn over to the bottom of page 8 and the penultimate paragraph:

"The Hillsborough families [he said] are not the only ones who have suffered from [what he called] 'the patronising disposition of unaccountable power'."

A term which resonates with the experience of the Core Participants in your Inquiry. He said there:

"The families know that there are others who have found that when in all innocence and with a good conscience they have asked questions of those in authority on behalf of those they love the institution has closed ranks, refused to disclose information, used public money to defend its interests and acted in a way that was both intimidating and oppressive."

Again, sir, we say that clearly resonates with the

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experience of our Core Participants here.

Could we please turn to page 13, internal page 7. Sir, you will recall that in the opening in the preliminary hearing I took you to this, which is what he proposed as a charter for families bereaved through public tragedy and we laid down the challenge to Government bodies to comply with that in your Inquiry. They said they would and we are entitled, therefore, to scrutinise whether they have done and do. You will see there that he invites the public body to:

"... commit to ... becoming an organisation which strives to:

"1. In the event of a public tragedy ... support the bereaved and to protect the vulnerable.

"2. Place the public interest above [its] own reputation.

"3. Approach forms of public scrutiny -- including public inquiries and inquests -- with candour, in an open, honest, and transparent way ...

"6. Recognise that we are accountable and open to challenge. We will ensure that processes are in place to allow the public to hold us to account for the work we do and for the way in which we do it."

So at the outset, sir, I'm going to look at the Government's response, first at what they have done

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approach has been to brush away concerns and to give no detail, in effect saying: Don't worry, we're treating this seriously, we'll do the right thing.

And they have said to a community of people to whom the government had self-evidently not done the right thing for decades, so it is something of a hollow promise.

We have been told that the government can't say anything about the shape or scope of the compensation scheme which Sir Robert proposed, which you and counsel to the Inquiry have scrutinised, which we as legal representatives for the infected and affected have scrutinised, on which we have spent days of time. Yet we are told that multiple departments of government have been beavering away for months, but, strikingly, no sign of involvement of the infected and affected and no clue of what they have been working on, save again to say: Don't worry, we are doing the right thing.

The question of recommendations and compensation is a huge part of your work, of the work of this Inquiry.

Sir, we ask how difficult can it really be to see that a public inquiry is precisely the forum in which the government's past performance should be called into question, and there should be all the more reason to be open, frank, candid, helpful and proactive about those

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during this Inquiry and what the Government has said in Parliament and elsewhere, and done or not done in respect of the recommendations of Sir Robert Francis as to a compensation framework; and, secondly, what they have said in their submissions now.

I will deal with the first, more briefly perhaps, than I intended.

How Government has acted so far. We say that candour is not simply giving up or surrendering documents or providing witnesses. We say that it is being fair, open minded and treating the Core Participants in this Inquiry with respect, and that that has not been done.

Sir Robert Francis, sir, as you know, was required by the Government to produce a wholly independent report into a framework for compensation. He felt it vital to say the infected and affected should be involved in and have confidence in that process and we say that is what has been missing so far in the Government's interaction with campaigners and with the infected and affected during the latter course of this Inquiry.

I don't hesitate to describe the government's approach in this respect as the combination of the two words "patronising" and "condescending" that we have used elsewhere in our written submissions. Their

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very significant issues of compensation, redress and other recommendations.

We'd been promised the government would respond to his report with a response. That is, setting out the government's view. Before Sir Robert Francis gave evidence, they didn't. They haven't since.

In terms of timescale, sir, you know the government got Sir Robert Francis' report in March of 2022, almost a full year ago. We were told by the then Paymaster General that they would publish the government's response alongside Sir Robert Francis' report. That then changed, in a letter to the all-party APPG, to the government publishing its response in time for you, the Infected Blood Inquiry and Core Participants, to consider that government response before Sir Robert Francis gave his evidence. That didn't happen. Another broken promise.

The government only published his report three months after they got it and four weeks before he gave his evidence. Again the Paymaster then, the Paymaster General, said the government was considering his recommendations and it was most important that the government could reflect on his evidence and that of others. We pause for a moment and wonder: Who?

We are not told.

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1 Finally, after a Westminster Hall debate, we have
2 a statement in the House of Commons. And I emphasise
3 this again only because it is such a key part of the
4 work of your Inquiry and is so concerning, as you will
5 appreciate, to the Core Participants, the infected and
6 affected.

7 The statement in the House of Commons was a formal
8 statement on 15 December 2022 from Jeremy Quin, current
9 Minister for the Cabinet Office and Paymaster General.
10 That, funnily enough, was the day before the deadline
11 for closing submissions to be lodged with you. We say
12 colloquially the government has form for that. It
13 announced parity in the vaguest of terms just before
14 Matt Hancock gave evidence to you, and it increased
15 payments, press release, just before the first day of
16 the victims' evidence in 2019. Those, we say, are signs
17 of a government not willing to act proactively for the
18 benefit of the infected and affected. What do we know
19 from December and the House of Commons? We know
20 precious little actually, and I'm doing this to
21 foreshadow how little we can add to it from the
22 government's response to you in this Inquiry.

23 We know that the government for the first time
24 recognises a moral case for the payment of compensation.
25 We see that the government say they want to be prepared

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1 hold them to account?

2 Sir, we see a real risk that this Inquiry -- sir,
3 you have set yourself a mammoth task, we know that --
4 will necessarily take some time to report. And your
5 conclusions may then not be swiftly or properly accepted
6 or implemented. That will all take time. But time, as
7 you know from the beginning of our written submissions,
8 is something that many of those most grievously injured
9 and affected simply do not have.

10 So at the very end of our written submissions and at
11 the end of today I am going to make two suggestions
12 about how to deal with that uncertainty which bedevils
13 the Core Participants, and with the delay likely to be
14 inherent -- likely, I say, from the way the government
15 have behaved so far. We will suggest two things.
16 First, that you might take the approach of issuing
17 a further interim report recommending further interim
18 payments now. Secondly, perhaps more dramatically, the
19 possibility of an early interim report in which you set
20 out a full -- your recommendation as to a full
21 compensation scheme, so that before the Inquiry closes
22 finally you will have set out your views on
23 an appropriate compensation and redress. That could
24 then be responded to by the government before the
25 Inquiry finally wraps up. And you would then preserve

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1 to act quickly when you report. It tells us they have
2 committed to use the Sir Robert Francis study to prepare
3 for the outcome of the Langstaff Inquiry. One asks
4 rhetorically: What does that mean?

5 Sir Robert's report is detailed but not complete.
6 It is a framework, it is not the finished article. So
7 where, we ask, is the difficulty in saying in principle
8 whether it is accepted in full or in part or which bits
9 or which aspects or which heads of loss? Or, even at
10 the basic level, Sir Robert's proposed uprating and
11 harmonisation of annual payments. It is not clear still
12 whether the government proposes to include or would
13 commit to including parents who have lost children or
14 children who lost parents within the scheme.

15 We simply cannot explain why we are in the dark.
16 They have made interim payments but one asks again
17 rhetorically: Interim to what? They haven't told us
18 what comes next. The only impression we say can be
19 taken is they don't want their views on compensation,
20 most of which must surely be formed by now, to be
21 subject to scrutiny, question and analysis in as public
22 a forum as this Inquiry. Is that good faith? Is that
23 candour? Come back to Bishop Jones, is that supporting
24 the bereaved, protecting the vulnerable, approaching
25 public scrutiny with candour or allowing the public to

30

1 the ability to call before you the authors of the
2 government response so that we can then all publicly
3 scrutinise in the way that they promised we would at the
4 outset.

5 Let me move from that, if I may, to the government's
6 position in its written submissions to you. That
7 discussion of candour and openness leads directly to
8 this topic. First of all, we describe it as sitting on
9 the fence or, more colloquially, having their cake and
10 eating it. Sitting on the fence is committing to
11 neither option. Having your cake and eating it is
12 enjoying both.

13 The blood transfusion services have given you
14 a detailed response throughout parts of which they
15 accept they could have done this sooner or that later,
16 they could have done this in a different way, they may
17 not have done. There has been a detailed analysis and
18 a presentation of their case. That is what they say.

19 The UKHCDO have given you essentially a very long
20 chronology, although we say it is curiously sparing in
21 places. There is simply one paragraph identifying the
22 critical Heathrow meeting and saying no more about it
23 than that. And they offer you no help on conclusions.
24 But our most significant issue is the response of the
25 Department of Health and the government.

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With the greatest of respect for their advocates, their submissions seem to seek to face two ways at once, and it is, we say, wholly inconsistent with adopting a position of neutrality or sympathy. On the one hand they say the current government has no case or position -- that is page 15 of their submissions -- and that it is entirely for you to make your mind up. But then they devote 600 pages to restating and seeking to justify the position of government witnesses and the politicians who gave evidence.

We pause to observe that, sir, you will recall, almost all of the witnesses, for instance Baroness Hooper springs to mind, say that they themselves actually have no recollection at all of any of this, and what they have done is simply been provided with a lot of documents by the government legal department and then produced a detailed statement crafted from those records.

Sir, the distinction, we say, between the current governments and previous governments is both artificial and spurious. It is and always has been the government -- or the Department of Health, under whatever name it traded -- throughout the years through which you are concerned. It has been a continuous entity.

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wrong. What the things are that should not have happened. All we can see on the analysis we have done is they accept that it was wrong to have lost individuals' medical records and it was probably wrong not to have held an Inquiry sooner, although it was reasonable not to have done so in the circumstances. That is, with respect, we say, hopeless.

We know that David Cameron apologised at Prime Minister's Questions in March of 2015, after the Penrose Report, using similar sorts of language. He said at the end of what he said:

"To each and every one of those people I would like to say sorry on behalf of the Government for something that should not have happened."

Reading these submissions, one wonders what he was apologising for. It is not as cheap -- it cannot possibly be as cheap or as meaningless an apology as, "I am sorry that you are upset". It just can't be. An apology is only an apology if it accepts that something was indeed wrong or should not have happened and that the person responsible for that wrong accepts what they did and knows what they did.

So what, in these submissions, does the government accept responsibility for?

We aren't told.

35

We ask where is the self scrutiny or the reflection or any sign that they have listened or taken account of their evidence in their submissions? There is none, because they seek to steer between saying, on the one hand, "We present no case", yet on the other dissecting the evidence.

We, it's fair to say, expected something candid. We expected a position from the government. Perhaps that they knew this by then, or they should have realised that by then, or perhaps done better in this respect, or that they support their position in other respects by other reasons.

Now, Ms Grey KC accepted at the preliminary hearing, she said:

"... on behalf of my clients, I [say these] words, the acceptance that this should not have happened, is an acceptance that things went wrong. Things happened that should not have happened and so, on behalf of my clients, I say, unreservedly, that we are sorry. We are sorry that this should be so, that this happened when it should not have done."

What things? What is the "it"?

You can search their submissions, as, sir, I know you will have done, and we found no significant concession or acceptance or identification of what went

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The government's submissions attempt to hold the utterly unsustainable line that they support and endorse the Inquiry but at the same time have no case. How can that be?

SIR BRIAN LANGSTAFF: To be fair, they did say they had a case or a position which was that wrong had happened.

MR SNOWDEN: Yes, but we are not told what the wrong is. We don't know the respects in which they accept things were wrong. Which makes it very difficult indeed for us to address you today in respect of our case. We have all heard the evidence. We are telling you the conclusions we invite you to draw from it. They don't. They simply say: We have no case and this is what the evidence said.

So, sir, I do it this way, if I may. I express the hope that we will hear from Ms Grey tomorrow in relation to, for instance, compensation or recommendations. Because we note that at paragraph 1.11 of her submissions she accepts that those ministers she represents, the current DHSC ministers, will be involved in decision making on recommendations. She is in a position to comment.

So what we do is this, we invite Ms Grey tomorrow to answer for us and for you and so that those who represent the infected and affected, who will speak after me over the next three weeks, know what the

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1 position is.

2 Question 1: What did David Cameron apologise for in

3 2015 and Ms Grey continued to apologise for on their

4 behalf in 2018? May we have the detail?

5 2: What things do the government accept happened

6 that should not have happened? Let's have the detail.

7 Let's see what is accepted.

8 3: What things does the government accept went

9 wrong? Again, let's have that detail.

10 4: Can she confirm, as Matt Hancock said to you when

11 he gave evidence in his role as Secretary of State for

12 Health, that the government will implement whatever

13 recommendations for compensation the Inquiry makes?

14 As part of that, can she confirm whether

15 compensation will extend to parents who lost children,

16 children who lost parents, and carers, all categories of

17 people who have been excluded from the support scheme so

18 far?

19 5: And let's take a detailed example on which they

20 were silent, on what date does the DHSC accept that its

21 predecessor knew that non-A, non-B was a condition which

22 could have serious and long-term consequences? Let's

23 know what they say.

24 And finally 6: When and on what date does the DHSC

25 accept that its predecessor knew that pooling plasma

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1 It would have been right ten years earlier, in 1997.

2 The suggestion that it is right now but was reasonable

3 not to have done before is not really understood by us.

4 It cannot be right -- and, sir, you know from your

5 long judicial experience that in Common Law it is not --

6 to allow a party responsible for a delay to profit from

7 it. In other words, the government can't be allowed to

8 say that it should have the benefit of any doubt or

9 uncertainty in what is now old evidence, missing

10 documents and faded recollections when it itself caused

11 that delay.

12 We suggest that not only would that be abhorrent on

13 the facts of this Inquiry, it would also set the most

14 unfortunate precedent, because most public inquiries

15 consider whether the emanation of the state is at fault

16 for something; it cannot be right that the same state

17 which decides whether an inquiry should be held at all

18 should receive any evidential benefit from delaying the

19 holding of that inquiry.

20 Their submissions invite you to keep the events in

21 perspective. The events of the day. The standards of

22 the time. Sir, we simply say in response to that that

23 we invite you to consider that that is no problem. That

24 is what judges do all the time. Part of my practice has

25 involved litigating over industrial disease cases, where

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1 increased the risk of post-transfusion hepatitis?

2 Those will all have been things it would have been

3 enormously helpful to have known before today. So we

4 could see where there's common ground. So we can see

5 where there are issues and we can address them.

6 Sir, that's the challenge, with the greatest of

7 respect, for my learned friend, for Ms Grey, for

8 tomorrow.

9 What else do we say about the government response?

10 Well, sir, you have read the first 20 pages of it.

11 Apart from the recitation thereafter of what the

12 witnesses say, there are some areas which we can

13 identify as submissions and which you have asked us and

14 other Core Participants to respond to. That's part of

15 the purpose of standing here on my feet speaking to you

16 today, is to respond to what each of us has put in

17 writing. There are some areas where the government

18 actually advances a case and asks the Inquiry to take

19 a particular approach. What do we say about them?

20 First of all, there is considerable reference to delay,

21 to the passage of years and the fading of memories, and

22 an urging upon you of caution.

23 Now, we pause to say for a moment that's hardly fair

24 because that's their fault. If it is right to grant

25 an Inquiry in 2017, it would have been right in 2007.

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1 one looks at the evidence, the standards, the procedures

2 of 30, 40, sometimes even more years before. It is

3 a task that falls regularly to judges. You are no

4 stranger to it and so we are confident you will do it

5 well. So that is the short response to that

6 encouragement from the Department of Health.

7 Finally, they urge upon you by reference to a case

8 called Gestmin -- and now is not the time or the place,

9 again, for legal analysis of propositions of law -- but

10 I urge upon you to consider the passage of time on

11 recollection and accuracy. In a sense, as I understand

12 their submission, it is to be more lenient on their

13 witnesses who had no particular recollection or told you

14 they had no recollection on certain issues.

15 Now, with the greatest of respect, again, we say the

16 analysis of that case is mistaken, in that it cannot be

17 elevated to some binding principle circumscribing how

18 you should approach the evidence.

19 Sir, there are more than I will mention but a number

20 of recent authorities providing a riposte to the

21 overplaying, as we say it is, of the Gestmin case. Most

22 significantly it is a case called Solicitors Regulation

23 Authority v Day, 2018, where Lord Justice Davis says:

24 "Gestmin, helpful though it is in providing

25 guidance, does not demand rigid and unqualified

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acceptance by the court of the literal meaning of a word in a contemporaneous document if the true analysis of the circumstances in which it was used, including [where it appears and so on] suggests that it was the wrong word to use ..."

So there is no rigid principle that you must approach evidence in a particular way. Similarly, Lord Justice Floyd in a case called *Kogan v Martin*: "Gestmin is not to be taken as laying down any general principle for the assessment of evidence. It is one of a line of distinguished judicial observations that emphasise the fallibility of human memory and the need to assess witness evidence in its proper place alongside contemporaneous documentary evidence and evidence upon which undoubted or probable reliance can be placed. Earlier statements of this kind are discussed in Lord Bingham in his well-known essay *The Judge as Juror* ..."

I will take it no further than that.

Sir, insofar as there is a submission to respond to, this is our response to it. You are not bound to do anything other than the normal job of a judge, to see things in their context, to assess all the evidence in its proper surroundings.

Sir, that's all I intend to say about the

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the framework for moral duty, looking at, first of all, the constitution of the NHS. We look at the World Health Organization constitution and other things.

It may be helpful -- yes, if time permits, we will look at the World Health Organization constitution, which is COLL0000020.

Sir, I put it on screen now, I will take us only to a couple of pages because it hasn't been touched upon by the Inquiry before and, insofar as ministers accepted responsibility, I think it is important for us to see where that acceptance may stem from.

You will see, sir, this may be familiar to you, I know it will be because you have read our submissions, the World Health Organization came into being immediately after the Second World War in 1946.

We see that the document I'm taking you to is the records, the final minutes and acts, what was done at the International Health Conference in New York in July 1946.

Can we look at page 5, please, top left, please.

You will see, six lines down:

"The Conference, recognising the vital importance of health as a factor in the promotion of 'conditions of stability [remember this is just after the Second World War] and wellbeing' for the nations of the world,

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government's response. What I'm going to do is to move very briefly, I hope -- let me check our timing -- very, very briefly to consider the framework for a moral duty or a duty on the government.

Sir, you have seen how we set this out in our written submissions. Former minister after former minister gave evidence before you and there was an acceptance that the government owed and had breached a moral duty. For instance Matt Hancock on 21 May 2021. He referred to the errors that led to this harm on people's lives but a sense that redress was not properly considered. Ms Richards asked:

"Do you consider -- and this is a question addressed to you, Mr Hancock ..."

You will recall that Mr Vineall sat beside him.

"... that there is a moral responsibility on Government to address the impact of what's happened to those infected and affected?"

Mr Hancock:

"Yes, I do."

Now, we suggest, and other Core Participants suggest more, that there is indeed a legal duty, but we know that you won't find civil -- you are precluded from finding civil or criminal liability, so we leave it there for now, but in our written submissions we develop

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included 'health' among the fields of co-operative endeavour with which the United Nations system should concern itself."

If we can then -- we will skip through some of the rest but we will look, if we may, please, at page 100, where we see in the top half of the page:

"Text of the Constitution of the World Health Organization."

Sir, we commend this to you, insofar as you feel you need to undertake an analysis of the duties or responsibilities of a State, the State, our State, being developed and being rolled out through clinical and governmental services.

Sir, you will see there:

"Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity."

This is the Constitution of the World Health Organization to which, as a nation, we signed:

"The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."

The final of those small indented paragraphs:

"Governments have a responsibility for the health of

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1 their peoples which can be fulfilled only by the
2 provision of adequate health and social measures."

3 Sir, that's our starting point: on the international
4 stage, there is a responsibility on the Government to
5 secure the complete physical, mental and social
6 wellbeing, not merely the absence of disease or
7 infirmity.

8 May we look, please, at COLL0000021. Again, we see
9 the front page, just for the moment. This is the NHS
10 Constitution for England. Simply touching on and
11 developing, if I may, what we say in our written
12 submissions, there is a constitution. It has been
13 revised periodically. It will continue no doubt to be
14 revised periodically but, insofar as there is
15 a constitution, we say it represents and must represent
16 what always has been understood to be the role of the
17 NHS and its duties, in the broadest sense.

18 It also, this constitution, refers not only to
19 duties and rights but pledges, which it recognises go
20 above and beyond legal rights. Sir, what I hope I'm
21 illustrating or laying out for your consideration is
22 a structure by which, as a nation, we have taken
23 responsibility for procuring these aspects of our
24 citizens' health and wellbeing and then, on a closer
25 level, within the NHS.

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1 very briefly to three short documents in respect of
2 candour and engagement, when a government has breached
3 its basic duty of supporting our health and wellbeing.

4 Can we go to JEVA0000096, please.

5 This is a note, sir, you will see, from the bottom
6 of the page, 26 September 1985, written by someone in
7 the Department of Health, notes about a diary meeting.
8 Middle paragraph:

9 "My own feeling on this is that the Prime Minister
10 should [steer] clear of AIDS (!), even when it is
11 a question of opening laboratories to help innocent
12 victims. I think this is ... something for Norman
13 Fowler. If she is going to do a medical visit, I should
14 prefer to suggest opening a hospital, or a home for
15 children with incurable diseases, etc. Furthermore,
16 I do not think we could entertain the idea of a visit to
17 Elstree shall (where the lab is) [and we all know what
18 they're talking about there] without existing it with
19 something else."

20 So, sir, what we have here is, at a stage at
21 which -- a critical stage after AIDS has become
22 apparent, we have a reluctance to be involved in
23 scrutiny or to engage openly or to be seen to be
24 associated with things which might be considered to have
25 gone wrong.

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1 If we look at page 3, please, we see at the top of
2 the page there:

3 "The NHS belongs to the people.

4 "It is there to improve our health and wellbeing,
5 supporting us to keep mentally and physically well, to
6 get better when we are ill and, when we cannot fully
7 recover, to stay as well as we can to the end of our
8 lives. It works at the limits of science -- bringing
9 the highest levels of human knowledge and skill to save
10 lives and improve health. It touches our lives at times
11 of basic human need, when care and compassion are what
12 matter most."

13 Sir, you will see -- I won't take you to the rest of
14 it -- but over the successive pages there are pledges
15 and expressions of rights. We say, first of all, that
16 this represents, and has always at the material times
17 this Inquiry is concerned with, represented a pledge,
18 a commitment and an obligation of one sort or another,
19 whether truly legal or whether moral or both, on the
20 part of the Government and the NHS, to safeguard the
21 population in the broadest sense of that word.

22 We say, as you will have seen from other aspects of
23 the NHS Constitution, which I won't take time on at the
24 moment, if you fail you come clean: a duty of candour.

25 In that respect, I would like to take you, if I may,

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1 Can we have, please, DHSC0003961_011.

2 This, sir, you will see is a letter of
3 2 November 1987, written from -- you will see the name
4 at the bottom -- John Major, then Chancellor, to Tony
5 Newton, Minister of State in the Department of Health
6 and Social Security. You have seen this in the course
7 of the evidence that you have received in this Inquiry
8 but it relates to the suggestion that the Minister
9 should meet with campaigners from The Haemophilia
10 Society in 1987. Sir, again, you will see there the
11 penultimate paragraph:

12 "I therefore suggest that you and John Moore should
13 listen only at this stage, and that the most you should
14 say is that you will consider the points made by the
15 Society, with no implication that the Government will
16 take action."

17 Sir, that's not engaging. That is not accepting
18 responsibility. That is not engaging with candour.

19 Finally, on this topic, may we look at COLL0000023,
20 please. This is the then Prime Minister Margaret
21 Thatcher herself, on 28 June 1990, writing to David
22 Watters of The Haemophilia Society, and this is perhaps
23 one of the first occasions on which a request for
24 an Inquiry was rebuffed:

25 "Thank you for your letter of 1 June asking for

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1 a special inquiry into the haemophiliac claim for
2 compensation."
3 Bottom paragraph on that first page, please:
4 "I am, therefore, not clear precisely what question
5 you envisage a special inquiry would be asked to
6 examine. If an inquiry were to attempt to establish
7 whether there had been any negligence, either in general
8 or for particular categories of claimants, it would need
9 to sift through exactly the same kind of evidence as the
10 present legal action. It is not clear that this would
11 either lead to a quicker outcome or one more generally
12 accepted as fair. If, on the other hand, the inquiry
13 were to consider whether, in this special case,
14 compensation should be given without proof of negligence
15 that would open up some very broad and difficult issues
16 and could indeed require reopening the whole question of
17 no-fault compensation. Again, it is not clear that this
18 would result in a quicker outcome than the court
19 action ...

20 "I am sorry if this is a disappointing reply."

21 Sir, we put those before you, that accumulation of
22 material, some of which you have seen before some of
23 which you haven't, to, we hope, make good our contention
24 for the underpinning of the duty that politicians have
25 accepted rests with them; the duty that they now have

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1 **MR SNOWDEN:** I should have anticipated the question you
2 always asked, I expect it might be ten. Let me see if
3 I can deal with it in ten, if you would be prepared to
4 do that.

5 **SIR BRIAN LANGSTAFF:** Let's do that, I think, and I see
6 a general nodding.

7 **MR SNOWDEN:** Very good. Sir, what we are doing then is we
8 are moving to the next of the substantive topics which
9 my Core Participants, our Core Participants, asked us to
10 address and it is what we set out for you in chapter 2
11 in our written submissions, under the heading of
12 "People", focusing the outset on the infected and the
13 affected.

14 We gave you some numbers at the beginning of that
15 paragraph and the numbers themselves, as the statistics'
16 experts recognised, are blunt and brutal and seem
17 callous when articulated because, beneath each number,
18 there is a life that has been changed or lost.

19 You have the numbers and you know the numbers that
20 are there. Sir, we know that you endeavoured, towards
21 the end of the evidence of the statisticians, to elicit
22 from them a figure for the total number of deaths caused
23 by the infections. My recollection of that exchange
24 between you and they was that they promised to undertake
25 some further analysis. You considered some numbers,

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1 and accept to compensate; and the paucity of response to
2 it to date.

3 Sir, one final point and that simply is this, and it
4 is a legal point, so I mention it only briefly, as it is
5 not my intention to lecture today. We say, in our
6 submissions, that not only is this a commonsense
7 approach, that if you are responsible for something and
8 it goes wrong, you say sorry quickly and you make
9 amends, but you are responsible for it.

10 We say it also chimes with judicial authority, for
11 instance, the position of rescuers at Common Law. Sir,
12 you know what I mean and I don't need to deploy it any
13 further than that. Put simply, you are liable if you
14 make someone else's predicament worse and we say that is
15 what the Government, through its Civil Service, through
16 the Department of Health, through the clinicians, have
17 done in this case: they have made the position, the
18 predicament of the haemophiliacs and others worse.

19 Sir, I'm not going to say more about that aspect.

20 Sir, I have an eye on the time, I have been learning
21 from watching Ms Richards how one stands here and what
22 one is supposed to do. I'm about to start something
23 which I think will take more than five minutes. Would
24 you like to break now?

25 **SIR BRIAN LANGSTAFF:** How much more than five minutes?

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1 possibly more than 1,000. They weren't terribly happy
2 going up to 3,000.

3 I don't think sir, that you've received -- certainly
4 if you have, forgive me, I'm not aware of you having
5 received any further material from the statisticians on
6 the numbers but clearly it will be important to know and
7 to note when they do.

8 **SIR BRIAN LANGSTAFF:** I don't think they are finding the
9 task easy but I know no more than that.

10 **MR SNOWDEN:** Thank you. In that case, sir, I say no more
11 about numbers. What I will do in the eight minutes that
12 now remain -- my promised eight minutes -- is this:
13 I will simply deal with common themes that we wrote for
14 you of how men, women and children were dealt with.

15 The first major theme was the wholesale lack on
16 their part of knowledge of the true risks of their
17 treatment or of informed consent. Now, we touched on
18 that a little before. But, sir, it is to remind you of
19 this evidence, not to go through it in detail, and it is
20 not my intention in this section to go through evidence
21 in detail but to remind you of the themes we invite you
22 to draw.

23 Not one single patient or parent that you heard from
24 gave evidence of full and informed consent to treatment.
25 That would have involved an explanation of the risks

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1 inherent in their treatments and the risks of not having
2 their treatment and being able to balance those risks
3 for themselves.

4 We invite you to draw from the breadth of that
5 evidence conclusions that in all or almost all cases the
6 risks of treatment with pooled factor concentrates were
7 not communicated to parents or patients as they should
8 have been.

9 You also heard evidence that there was a dearth of
10 any record in their medical notes of the communication
11 of risk or the recording of consent and that sits with
12 the evidence that they, the infected and affected, gave
13 you. You heard some clinicians explain that they
14 believe they would have sought consent or it was their
15 usual practice to explain risks and obtain informed
16 consent but we say, one after another, we invite you to
17 conclude, that all the factual witnesses who was
18 patients or parents of child patients gave evidence that
19 the risks weren't explained, that no one pointed out the
20 dangers or the balance of one treatment against another.

21 We invite you in the broadest terms, careful not to
22 trespass on areas you have told us not to, about drawing
23 conclusions on particular witnesses, but in the broadest
24 of terms, we invite you to prefer the evidence of the
25 parents and the patients particularly because many of

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1 were a trusting community of patients, whose trust, we
2 say, regretfully was abused. Of course, initially,
3 there were close bonds with and considerable respect for
4 and trust in their treating clinicians, some of those
5 still endure, of course. In part, we have said, and
6 I have seen others have in their written submissions
7 invited you to draw out the broad theme from that, that
8 that is, at least in part, because of the hereditary
9 nature of the disorders, the fact that familiarity with
10 the medical environment, familiarity with medical
11 treatment, and regular contact with and reliance on
12 medical professionals. So there is a whole association
13 that goes with the diagnosis of a bleeding disorder.

14 In part, it is because almost all of those who were
15 diagnosed with bleeding disorders would have been
16 diagnosed as children, so would have grown up familiar
17 with being in a medical environment and trusting their
18 clinicians and also because this was not a single event
19 illness, is how I've described it in writing. It is not
20 like breaking your leg, it is not like suffering a heart
21 attack. This is a condition that leads to a lifelong
22 relationship between patient and clinicians and that
23 also engendered the trust and familiarity.

24 Sir, we invite you to find that they were a trusting
25 and reliant community of patients. Some witnesses

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1 them, when they watched television programmes or heard
2 things on the radio or read things in the newspapers,
3 gave you evidence that, at that point, they went and
4 asked the clinicians what was happening and, at that
5 point, they say they were knocked back and they were
6 told "Nothing to worry about".

7 But they wouldn't even have done that, surely, if
8 those risks had been explained earlier. So that, we
9 say, is, in the broadest of terms, a piece of consistent
10 evidence as to the lack of explanation of risk of
11 treatment.

12 Another common theme taken from this is -- and you
13 heard curiously from some clinicians and, even more
14 curiously, from Lord Kenneth Clarke in his oral
15 evidence -- an attempt to pass responsibility by saying
16 the haemophilia patients were "experts in their own
17 condition" and so they can be assumed to have had all
18 the knowledge they needed. Again, the broad theme we
19 invite you to draw from that is the obvious one: they
20 may well have known about their haemophilia but what
21 they didn't know were the risks of new, novel, unusual
22 treatments if they weren't explained to them. That
23 aspect they had no knowledge of at all.

24 Secondly, we invite you, on the broad themes, to
25 draw the conclusion that those with bleeding disorders

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1 described it, indeed, as being like part of the family.

2 The third aspect we invite you to draw broadly from
3 the evidence is one I have entitled "Paternalism" and it
4 explains itself, I hope. Sir, you have read it in
5 writing and you have heard repeated evidence from the
6 infected and affected of patients and their families
7 being treated in an unacceptably paternalistic manner,
8 even by the standards of the '70s and '80s, by their
9 clinicians. The concept that doctor knows best, doctor
10 doesn't need to explain, more or less "Just do as you're
11 told", and we say that is most starkly illustrated by
12 the approach at Lord Mayor Treloar's School, which is
13 going to be considered later this morning.

14 Another aspect we have invite you to draw is what
15 I call "Condescension" and in this we group the infected
16 and affected being badly let down by the design and
17 operation of the MFT and all the other Alliance House
18 schemes. Set up as charities with limited resources and
19 an understanding that they had to preserve their budgets
20 and funding, they were in general terms -- again, I am
21 conscious of your encouragement to draw out general
22 threads, rather than specific witness evidence -- in
23 general terms they were condescending towards,
24 disparaging and sceptical of applicants, rather than
25 generous.

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Applicants were left to discover for themselves what might be applied for, rather than they being sought out and found and approached by any of those trusts or schemes. Decision-making processes, rights of appeal: all opaque. They were not generous, sufficiently generous, in support of those upon whom it had been intended they should confer benefit.

Now, you heard evidence of dying children not being allowed to have the cost of a toy; "We will tell you if you need double glazing"; taking stairlifts away days after somebody had died; investigating what their partners earned: all demeaning and condescending, and we ask you to draw that out as a theme of how the infected and affected were treated. We develop it more in writing, sir, and you know that.

The fifth theme to draw is one of stigma. Again, we could take hours talking about this and we won't because we all know what you mean. You have heard truly awful, graphic accounts of patterns of stigma, abuse, misunderstanding and isolation forced on those who were infected and their families, in part by ignorance, perhaps in part by fear, in part stoked by societal attitudes of the time or the media.

You have heard descriptions of violence and abuse, of families having to move to escape being known, of

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find this was an almost universal practice.

Eighth theme: inappropriate communication of diagnoses. Now, again, we have touched on that already and there is probably little more to say about it, save that, even more brutally than being told a diagnosis or being told that a diagnosis was not as bad as might be feared, when your friends and your school friends have received worse diagnoses, you are told "You are lucky". That can't be right and you have heard that from more than one witness. So the wholly inappropriate communication of diagnoses.

The ninth theme is one of isolation and obstruction. Again, that harks back to the David and Goliath analogy, pressing for public inquiries, campaigning and campaigning and campaigning and campaigning.

The tenth theme is one of being "misled and fobbed off", I've put in my submissions. I don't think I've ever have done that in writing in front of a court but I hope, sir, you will forgive me for using that expression. You know what I mean. Fobbed off by the Government, consistently rejected and knocked back in their search for answers and their fight for a full and proper Inquiry. You will remember, I am sure, Mike Dorricott and his family in Leeds, who met, I think it was Jeremy Hunt -- forgive me if I'm wrong about that,

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children being insulted at school, of infected individuals feeling driven to a life of isolation and solitude, not even telling their close relatives, of parents feeling they must tell their friends their child has cancer, rather than HIV. It is a very, very, as you know, considerable aspect of their treatment and we invite you to make clear and strong findings about it.

Very briefly, as I now have two minutes of my promised ten left, if you indulge me, I will have the advocate's extra one minute and I hope will be done.

You remember we used three Ds at the beginning, the third of which was "degrading treatment", the broad theme of the evidence of the infected and affected people is of falling under suspicion and repeatedly having to explain themselves, DSS fraud investigations, those sorts of things, which are, in the context, truly extraordinary, because the funds which are being investigated by one Government body are being provided by another Government body. It makes no sense. It should not have happened.

The next few themes I can take swiftly because we have discussed them to an extent already. The theme of testing, repeated evidence of patients being tested without knowledge or consent, blood being stored, without consent, for further testing. We invite you to

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but a politician -- sympathetic hearing, said would sort it. Mike died a year later with no answer in his lifetime. People are persistently fobbed off.

Sir, at the conclusion of that chapter on people, what I have done is, as you I think invited us to, identify the impact on the infected in terms of physical, emotional, psychological symptoms. I'm not going to repeat that, you have it in writing. I said in writing, as I say again, it seems brutal to simply list the effects, the consequences and the symptoms. In doing, so we don't for a moment diminish their awful severity but, on the contrary, by the time you have a list that starts at A and ends at Z, and goes into the AAs, there is a very significant impact and, sir, you know that.

That I think brings me to the end of that section. I'm sorry, I have indeed, as feared, overrun my 10 minutes by two. But if now is a convenient moment.

SIR BRIAN LANGSTAFF: Entirely acceptable.

We will take a break now and we will come back at 11.55 am, that I hope gives you all a chance to refresh yourselves and be back. 11.55 am. Then I think we hear from Mr Cummins, do we?

MR SNOWDEN: Sir, I'm afraid you're going to hear a little bit more from me and then Mr Cummins.

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1 (11.23 am)

2 (A short break)

3 (11.55 am)

4 **SIR BRIAN LANGSTAFF:** Yes.

5 **MR SNOWDEN:** Sir, yes, I'm going to pick up with where
6 I left off.

7 The next section we're going to deal with is one
8 which in our written submissions we used the curious
9 title of "Myths and Lies", and it was chapter 3 of our
10 written submissions, which, again, I know you have in
11 mind, sir, having read it. Not everybody here will
12 have, and I'm going to explain what we mean by that in
13 this way.

14 40 years or more have passed since some of the key
15 events this Inquiry is considering, and we and my Core
16 Participants believe that over that period of time,
17 either intentionally or unintentionally, certain
18 inaccurate and untrue points of view and assertions have
19 taken root and become entrenched as established
20 thinking, sometimes seemingly unchallenged as gospel
21 truth. And those are the sorts of things that we refer
22 to as myths and lies in this section.

23 Sir, as you know, the Inquiry has already
24 scrutinised many of these, not only the truth with the
25 benefit of hindsight, but by assessing what was known at

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1 have taken hold is that factor concentrates were
2 essential. Again, sir, that is harking back slightly to
3 what I called the narrative of necessity in our opening.
4 We will come back to look at that in a little bit more
5 detail in terms of consideration of the respective
6 merits and demerits of cryoprecipitate as against factor
7 concentrates.

8 There are some substrata to that, that factor
9 concentrates were essential, one is the oft-repeated
10 story that haemophiliacs would die if not given
11 concentrates. And you saw that played out in the
12 evidence of Lord Glenarthur, Lord Clarke and others,
13 whose understanding was any move away from concentrates
14 would be fatal for a very large number of haemophiliacs.

15 Another aspect of the cryoprecipitate story is that
16 it is often said that it wouldn't have been desirable to
17 go back to it. Patients didn't want to go back to it.
18 You heard that from some clinicians, although whether
19 based on fact or based on supposition it's not clear and
20 wasn't clear in their evidence. The suggestion that
21 cryoprecipitate was too old-fashioned, too cumbersome,
22 fraught with problems or that it simply couldn't be
23 done, that we wouldn't have had the processes to make
24 it.

25 So that is part of the cryoprecipitate bundle of

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1 the time when these assertions were first made.

2 Our Core Participants asked us to identify a number
3 of these so that you could focus on them, deal with them
4 specifically and, again, if you forgive the vernacular,
5 call them out for what they are.

6 It is important to our Core Participants as part of
7 the function and purpose of this Inquiry that the record
8 is set straight on these issues unequivocally and
9 finally.

10 Again, sir, I approach this on the basis that you
11 invited us not simply to regurgitate evidence to you but
12 to focus on the conclusions we invite you to draw. So
13 just to summarise or identify the sort of things I mean
14 as myths and lies, I will list them, and then we are
15 going to look at two of them in a little bit of detail,
16 and then in 16/17 minutes' time I will hand over to
17 Mr Cummins.

18 The sorts of things we are talking about, sir,
19 I know you will have read, are the often promulgated
20 story -- you heard it from Lord Kenneth Clarke -- all
21 this was just unavoidable. We are very clearly inviting
22 you to conclude that that is simply untrue and
23 inaccurate. It was not unavoidable. It was not in line
24 with the best possible standards of the time.

25 Again, other examples of other myths and lies that

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1 myths and lies.

2 Others, though, are that patients themselves were
3 aware of and chose to run the risk of concentrates. We
4 talked about that already, so that scarcely needs to be
5 said to be dismissed.

6 That there was "no conclusive proof" of the link
7 between blood, blood products and HIV infection. Now,
8 that is a very big story which, as you know, you heard,
9 and it was examined in detail by counsel to the Inquiry
10 with Lord Clarke and others, as to how that line to
11 take, of no conclusive proof, was maintained for so long
12 and in such a misleading way.

13 Tying in partly with what I suggested was the first
14 lie or myth, that this was all unavoidable, is that
15 the -- another one is the risks of viruses in
16 concentrates weren't known. Those two tie together and
17 I will deal with those together in a moment. Another
18 oft-repeated one is that there would have been
19 insufficient blood donors to have done anything else.

20 We see that, and into an assertion at several
21 stages, that there were fear that we could not restrict
22 the groups of those who could donate when surrogate
23 screening was being considered for HCV and so on.

24 Lord Owen, his evidence to you was that, as far as
25 he was concerned, he believed sufficient voluntary

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donors would step up. And there is, in fact, no -- we say no cogent evidence at all to support the suggestion that there would have been insufficient blood donors had a different course been taken.

Other myths and lies: it has not been possible to offer compensation because legal liability has not been admitted. Suggested that we couldn't do it because legal liability had been admitted in the Republic of Ireland. But Mr O'Mahoney, in his evidence, told you that was not so; a proper compensation scheme was set up there despite the non-admission of legal liability at the time.

Further myths and lies: haemophiliacs were fully compensated by the combination of the settlement of the HIV Litigation and the funding of the MFT. We know that simply not to be true. A simple cursory look at the figures, and your record of the evidence shows that.

Another, that no-fault compensation simply could not be paid for fear of setting of precedent. Again, Lord Waldegrave, David Mellor and others expressed the view that no-fault compensation could indeed have been paid. Lord Waldegrave explained that it might have been in the government's interest that it was capable of moving with the times, understanding concerns and making an exception to a general rule.

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the hepatitis risk. So the basis of any assertion that there was no risk obvious or it was all unavoidable, depends on using a product which is derived from large pools. If you don't do that, the risk is gone. So that's the foundation for that argument.

We then would take you through a series of steps, all of which I am sure, sir, you will be familiar with, so I simply say them so they are recorded on the transcript as being the way in which we see the knowledge of non-A, non-B developing and of its seriousness.

The next step we would particularly refer you to would be Rosemary Biggs' letter of August 1967, we've mentioned it earlier, warning that the market would be flooded with US commercial concentrates from more than a million donors a year -- I don't think that is an individual pool; I think that might be the totality of the donors in the States -- and that if we in the UK did not get our house in order we would be obliged to buy it from the States. It was extraordinarily prescient in 1967. It is, in fact, one of the underlying keys to the scandal of what happened.

Next we would take you to -- and, again, sir, I am sure you will have all the references; if not, we will provide a short list of them in due course -- an

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One more, before I come back to the detail of two of them, is that throughout the last year, or two or three or four, that the Inquiry has been going, the government has been providing support for all the affected and bereaved. Sir, again, you know, but we invite you to record specifically, that is simply not the case. Parent who lost children, children who lost parents, adult carers for their own parents, for example, are all excluded from current support schemes or at least from the majority of them.

I'm going to dip back, very briefly, into two of the myths and lies. The first is the combination of the lie that this was all inevitable and that the risks and viruses weren't known. Now, again, sir, I'm very mindful indeed of not regurgitating back you to the evidence that you have heard.

Sir, others have tracked it through perhaps in a little more detail than we did in our written submissions, so it's simply to summarise the position for those listening in this way. We go right back to 1946 -- sir, as you will no doubt recall yourself -- the British Medical Journal article linking serum hepatitis and pool sizes. Nothing has changed in the science since 1946. The science has always been that for jaundice or hepatitis, the larger the pool the greater

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April 1974 letter from Judith Pool at Stanford Medical Centre in California, to the United States Government, when they were considering relaxing their National Blood Policy. She described it as a new National Blood Policy that in no way requires or even encourages volunteer blood for this purpose but assumes the continuation of what she described as "dangerous, expensive, wasteful and unethical purchase of plasma by pharmaceutical houses to provide this therapeutic material".

Even in 1974, clear references to the danger of going down this route. We then have, sir, as you well know, the Prince paper in The Lancet, in August 1974, identifying non-A, non-B. Linking of significantly greater incidents of non-A, non-B to blood from commercial sources.

We have, in January 1975, again, from Stanford University Medical Centre, Garrott Allen's letter of 6 January 1975. Simply, if I may, to read out loud, so that, again, we are in the public domain, he says this, in the midst of his letter -- he is talking about a particular product, Konyne, Factor IX product produced by Cutter. He says:

"As you know, Cutter's product Konyne, for Factor IX deficiency, has proved extraordinarily hazardous, 50 to 90% rate of icteric hepatitis developing from it. About

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1 half of these cases prove fatal. Cutter's source of
 2 blood is 100% from skid row derelicts [he says]."
 3 **SIR BRIAN LANGSTAFF:** As a matter of interest, what am I to
 4 make of the opening three words "As you know"?
 5 **MR SNOWDEN:** Yes.
 6 **SIR BRIAN LANGSTAFF:** Is that the same as an advocate
 7 saying, "You must have read this, sir, you must know
 8 this", which may or may not be true, or can I infer from
 9 that that Maycock did indeed know?
 10 **MR SNOWDEN:** I think you can infer because I talked about
 11 Judith Pool, a moment ago in the letter from April the
 12 previous year, April 1974. Judith Pool was, I think,
 13 undertaking research in Stanford or had been based in
 14 Stanford and researching in Britain. In this letter
 15 from Garrott Allen, he talks about his understanding
 16 from Dr Pool about the preparation. He says:
 17 "It has been many years since I last corresponded
 18 with you ..."
 19 So it can't be an immediately preceding piece of
 20 correspondence. The "as you know", I suspect, was
 21 speaking of that which would have or should have been
 22 common knowledge at the time.
 23 **SIR BRIAN LANGSTAFF:** So it is either specific knowledge to
 24 Maycock or, more likely, you submit, likely to be him
 25 reflecting common knowledge?

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1 "Non-A, non-B is not necessarily a benign infection.
 2 The most effective means of preventing it is the
 3 substitution of blood derived from volunteer sources for
 4 commercial blood. The exclusive use of volunteer blood
 5 has been shown to reduce markedly the incidence of
 6 hepatitis B and non-A, non-B."
 7 I won't take you through them all, but we come
 8 through the Hoofnagle article in '77 to Professor
 9 Preston's paper in the Lancet of '78, on which we have
 10 spent some time in the course of the Inquiry. I won't
 11 show it but, sir, again you know, and those listening to
 12 the Inquiry know that Professor Preston identified
 13 a wide spectrum of disease found including chronic
 14 aggressive hepatitis and cirrhosis, which he said
 15 probably related to factor concentrate therapy, so that
 16 is by September 1978.
 17 If I may, if I can find it, one of the witnesses who
 18 gave evidence to you, Dr Mark Winter, whose evidence was
 19 given on 1 October 2020 was asked by Ms Richards:
 20 "Do you accept that in 1979 patients should have
 21 been told there was a possible risk of chronic liver
 22 disease from the treatment they were receiving?"
 23 **"Answer:** I really do accept that, yes, and I think
 24 it would help to reinforce the point, which for some
 25 patients, you will understand, they were reluctant to

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1 **MR SNOWDEN:** Yes, I do. Of course, the significance of it
 2 is not only the writing of the letter but to whom it is
 3 written. It is written to Dr Maycock at the Blood
 4 Products Laboratory, connoting not just this author's
 5 experience but the experience of somebody very prominent
 6 in the United Kingdom.
 7 Moving from that letter, if I may. The process
 8 progresses through Dr Craske's Lancet article in 1975,
 9 where he says:
 10 "Treatment with Factor VIII concentrates exposes the
 11 patient to a higher risk of contracting transfusion
 12 hepatitis. Cryoprecipitate, in which each bag is made
 13 from one or two donations, carries a relatively low risk
 14 of hepatitis. [Distinguishing here] commercial
 15 Factor VIII concentrates which are prepared from pools
 16 of 2,000 to 6,000 litres of plasma, obtained by
 17 plasmapheresis from paid donors, would be expected to
 18 carry a much higher risk of transfusion of hepatitis."
 19 Again, the picture is building, sir, as you know
 20 through 1975. As far as we can discern from the NHSBT
 21 submissions, they accept -- the note is
 22 paragraph 7.19 -- that in the '70s and '80s, medical
 23 students were aware of non-A, non-B.
 24 Purcell, we move on to February 1976: Purcell and
 25 the Yale Journal of Medicine:

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1 follow, that they really needed to take the issue
 2 seriously and, for some of them in particular, that
 3 meant moderating alcohol intake."
 4 Not only awareness of the condition but of how to
 5 best deal with that medical condition.
 6 Could we show, please -- I'm going to look at two
 7 articles briefly -- BART0002487.
 8 In this, if we can go to page 2, please and under
 9 the heading 2, "Types of therapeutic material
 10 available".
 11 Again, sir, this is a document with which you will
 12 be familiar with but we say it's well worth looking at
 13 again. This is Professor Kernoff writing to Dr Colvin,
 14 on 27 April 1979 identifying clinical and moral reasons
 15 to prefer the NHS product.
 16 You will see how non-A, non-B is described in the
 17 middle of this paragraph, starting "Since":
 18 "Since the amount of concentrate being made by the
 19 NHS is at present quite inadequate to satisfy needs, the
 20 shortfall has to be met by buying commercial
 21 concentrate. Not only is commercial concentrate
 22 expensive, but there are both clinical and moral reasons
 23 for preferring the NHS material. The clinical reason is
 24 the growing awareness of the probability that commercial
 25 concentrates have a higher risk of transmitting non-A,

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non-B hepatitis than NHS material. This is a serious disease with long-term consequences which, as far as is known, it is at present much less common in the UK than in those parts of the world -- particularly the USA -- where donor blood for commercial concentrates is collected. We may, therefore, be introducing diseases which are not yet endemic in the UK."

Then a moral reason is given. Sir, it is simply again to remind you -- you don't need reminding -- but those Core Participants watching or attending, this is the original source of the expression and knowledge of serious disease with long-term consequences being expressed between two clinicians in 1979.

Finally, on this topic, could we look at WITN0282008 please. This takes us to September 1980. It is a memo from Dr Walford in the Department of Health. We don't need to look at it but we can see that from the second page. She talks about the severity of non-A, non-B hepatitis in the third substantive paragraph starting "I must emphasise".

She says this in September 1980:

"I must emphasise that 90% of all post-transfusion (and blood product infusion) hepatitis in the USA and elsewhere is caused by non-A, non-B hepatitis viruses which (unlike hepatitis B) cannot at present be detected

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gave their own hospital convenience too great an emphasis. We note also that other recognised legal representatives suggest that commercial ties to pharmaceutical companies, either consciously or subconsciously, influenced clinicians' decisions to remain on concentrates and not revert to cryoprecipitate.

We invite you to conclude that cryoprecipitate was, in fact, effective, it was preferred by prudent clinicians. It probably is worth showing one document even for the sake of taking a minute over it, DHSC0043164_068 at page 4 please.

This is part of, sir, we talked about it earlier, and you'll no doubt recall it, Professor Savidge's report on one of Susan Hallwood's boys. It's simply the middle paragraph there:

"In the late 1970s and early 1980s, the majority [so not simply the 1980s] of UK paediatricians treating infants and children with severe haemophilia considered cryoprecipitate obtained from single blood donations to be the therapeutic product of choice, but if not available NHS factor VIII concentrate should be used."

So an extremely reputable clinician identifying not only his use but suggesting his knowledge of others' use in that way, which itself indicates that it was

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by testing donor blood."

This is the significant part:

"This form of hepatitis can be rapidly fatal (particularly when acquired by patients with pre-existing liver disease) or can lead to progressive liver damage. It can also result in a chronic carrier state, thus increasing the pool of those with viruses in the community."

This is September 1980. This is the Department of Health itself, the recognition of the utmost seriousness of the condition of non-A, non-B hepatitis.

Sir, that, we say, entirely counters the lie that all this was inevitable and that risks weren't known. The second lie to deal with very briefly is the one in relation to the suggestion that factor concentrates were essential because haemophiliacs would die without concentrate, reverting to previous therapy through cryoprecipitate was neither desirable for the clinicians nor for the patients and the cryoprecipitate was too old-fashioned and cumbersome to be used.

We have dealt with this in our written submissions but, broadly speaking, we suggest this, that pharmaceutical companies push the convenience aspects of concentrates and gave them too great an emphasis for both patients and hospitals. Some clinicians themselves

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desirable for clinicians, it was desirable for patients and it was not too old-fashioned or cumbersome to be used. I had hoped to be able to show you on screen three papers falling in the period between the 1960s and the early 1970s in which the authors recognised the use of cryoprecipitate as being both effective and efficient. We have realised we don't in fact have those loaded onto the system, so I can only apologise for that and I will provide you of course with references for them in due course.

Simply so that you know what they are, they are those papers which we have referred to in paragraphs -- paragraph 98 -- no, yes, paragraph 98, pages 28 and 29 of our written submissions. A series of papers in the UK and the British Medical Journal, including one in September 1967 in a Canadian journal, emphasising that a cryoprecipitate could be used effectively at home and prophylactically, even for a 19 year old with serious haemophilia.

British Medical Journal of December 1967, noting it had been possible to teach the patient, a 21 year old with less than 1 per cent clotting factor, to administer his own cryoprecipitate and, "from intermittent doses, on alternate days, it would appear the course of his disease has been reduced from one causing major to one

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causing minimal incapacity", was the view of the author. Indeed, an American paper, in the late 1960s, considered it to be safer than pooled products, a paper by Cooke and others, identified it as being as effective as commercially available concentrates, to be prepared easily and economically and that paper contrasted its risk with the risk from commercial concentrates made from pools of 500 to 1,000 units, which the author said appeared to be heavily contaminated with the virus of serum hepatitis.

So we have a series of respectable, reputable medical papers which, far from giving any credence to the lie that cryoprecipitate was unhelpful or unworkable, said quite the contrary. In terms of the possible effect of cryoprecipitate on life expectancy, or rather of stopping concentrates on life expectancy -- again, sir, you have heard evidence on this which we know you've digested, you were interested in the statistics, we all remember that -- you have, in the fractionators report, again simply to note but not to show the document, for the sake of time, EXPG44 at page 59, the expert fractionator's report to you identifies that when cryoprecipitate was introduced the life expectancy of haemophiliacs increased threefold.

So the game changer, if I may use that expression,

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have given us some snapshots of other countries, we deployed some evidence in our written submissions or we referred to some evidence about what was being done in Finland. Can we just look at one of those documents please, can we have RLIT0000469. It is simply to pause -- yes, we have that.

The broad point in relation to Finland is this. They made a decision to retain patients on cryoprecipitate, specifically not to use factor concentrates until they could be virally inactivated. Recognising that, in terms of therapy, that might be mildly less effective but putting patient safety, in terms of not exposing them to viruses, ahead of a modest change in efficiency of the concentrate or cryoprecipitate.

We have the document thank you, if we go to the -- page 3 please, bottom of the left-hand column. It is an article, sir, which we simply commend to you to read in due course. It is almost certainly referred to in the presentation on what was being done in other countries but, at the bottom of the left-hand column, four lines up from the bottom of the second paragraph:

"An intermediate purity Factor VIII concentrate was developed and tested in patients in the latter part of the 1970s. However the large pool preparation was not

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for life expectancy was not factor concentrates, it was cryoprecipitate.

In that regard, there were also useful articles, which you saw in the course of evidence and therefore I won't repeat, from Dr Biggs in 1977 and Dr Rizza in the British Medical Journal in 1983 both talking about the increases in life expectancy. The point we will invite you to take away from the comparison of those two articles though is, again, the myth or the lie that it was said that the real risk to haemophiliacs, if concentrates were stopped, would be cerebral haemorrhage.

The proportion of haemophiliacs suffering or dying from -- having cause of death of cerebral haemorrhage, in fact, seems to be greater in the later paper from Dr Rizza, in the cohort receiving concentrates, than in the earlier cohort receiving cryoprecipitate. There doesn't seem to be a statistical change of the proportion of cerebral haemorrhage deaths, if you will forgive me for being as blunt about it as that.

Two points, and then I will handover to Mr Cummins.

The first is in relation to, slightly in advance of receipt of the Inquiry's presentation yesterday, on what was being done in other countries, in which your extraordinarily helpful team of counsel to the Inquiry

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introduced to clinical use because of the increased risk of viral infection, ie hepatitis. The low prevalence of antibodies against HIV in Finnish patients with bleeding disorders, astute conditions which already prevailed during the hidden phase of the spread of the virus. In Finland, the national self-sufficiency for blood product has been decisive for the present favourable situation."

So we simply say, rhetorically, if it can be done in Finland why not here?

Sir, we will come to it in due course but I am going to handover to Mr Cummins in a moment. This history of the myth or the lie relating to it being impossible to stop concentrate treatment and revert to cryoprecipitate puts into the sharpest focus the decision of the 13 July 1983, the meeting of the Committee of Safety on Medicines Biologicals Subcommittee, where we say what can only be described as an extraordinary decision made to continue importing US concentrates on the basis that reversion to cryoprecipitate wouldn't work. We say that simply can't be substantiated from the material before you.

More to the point, on that meeting as well, we note Lord Fowler's evidence given to you on 22 September 2021. If the CSM proceeded at that meeting, on the basis of wrong evidence from one man, whom we would

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1 identify, of course, as Professor Bloom, that is
2 unnecessarily and wrongly elevating the risks of
3 stopping concentrate treatment and reverting to
4 cryoprecipitate, it would be a matter of the gravest of
5 concern to him, Lord Fowler.

6 Sir, that deals with, I hope, some of the myths and
7 lies. Unless you feel it necessary I don't suggest you
8 do anything other than remain where you are and
9 Mr Cummins will take my place for the next 40 minutes or
10 so.

11 **SIR BRIAN LANGSTAFF:** Thank you.

12 **CLOSING STATEMENT BY MR CUMMINS**

13 **MR CUMMINS:** Thank you, Sir Brian.

14 It is proposed, sir, to take you back to school now.
15 So I will start by asking the class to sit up and try
16 and pay attention, if I may.

17 Before we do, on behalf of the cohort of Core
18 Participants from the Lord Mayor Treloar school, we
19 would like to thank you, Sir Brian.

20 We are grateful to you and Ms Richards KC, and
21 indeed the Inquiry team, for all the effort and
22 endeavour you have put into this Inquiry. We are also
23 grateful to the support and administrative staff and the
24 technical staff and, indeed, for the psychological
25 support you have made available to us all during this

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1 junior, Dr Achas Burin, for her empathy and her
2 intelligence, and last but not least the very nice tall
3 chap, who doesn't have a title but I'm asked to be
4 condoned for appropriate humanity.

5 Sir, if I may then return you to school and to the
6 evidence that we have heard, evidence from a history of
7 boys and young men suffering haemophilia against
8 a backdrop of mainstream education with enforced
9 absences, some inconsiderate, incidences of bullying,
10 some occasions where they'd been marginalised at times.
11 They were offered the chance to undertake a private
12 boarding school education, with specialist medical care
13 as part of that package, to promote educational
14 improvement. That was an offer that sold itself to many
15 of them, was an offer, for the unsuspecting parents,
16 that seemed a godsend at the time.

17 Sir Brian, you may recall the Prince of Morocco, in
18 Shakespeare's *The Merchant of Venice*, when he chooses
19 his casket and he opens to read the scroll inside that
20 says, "All that glisters is not gold; often have you
21 heard that told". That was the position they were in.

22 Lawrence, can I ask you to put up HSOC0022908.

23 I've asked for this document, which is from
24 Sister Turk's article in *The Haemophilia Society*
25 Bulletin from 1981, the reason I've asked this -- and

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1 Inquiry. It would be remiss not to express our
2 gratitude. Even if we have all had to wear face masks
3 during the course of it, we have understood why.

4 So a huge thank you for your investigations, your
5 persistence, returning jigsaws from various parts of the
6 house, your accessibility and understanding, and most of
7 all your desire to get to the truth of what has happened
8 so many years ago.

9 I'm also asked by them to thank three other groups.
10 First of all, the other Core Participants. It has been
11 a privilege to meet you all, share experiences with you,
12 indeed, on occasions, tears and support. It is
13 an indication of the scale of this tragedy, the numbers
14 infected, the lives and families affected has been truly
15 staggering. They ask me to express the fact that we
16 know none of us are in fact alone in this and,
17 regardless of what campaign group you may be affiliated
18 to or not affiliated to, the united front that's
19 occurred when we have all come together in the face of
20 a common sorrow has been amazing, so thank you for all
21 your support.

22 I'm also asked to thank the solicitors Collins,
23 Dani Holliday and Des Collins and their staff, and last
24 but not least their counsel, Steven Snowden KC, for his
25 approachability, dedication and professionalism, and his

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1 page 4, please, Lawrence, thank you -- is a reminder of
2 what Treloar College was supposed to be about.

3 If we go to the right-hand column, second main
4 paragraph down, we see there:

5 "Treloar College provides medical and educational
6 facilities for handicapped children including
7 haemophiliacs ..."

8 If we go towards the bottom of that, second
9 paragraph below, Lord Treloar:

10 "... used his influence to launch a national appeal
11 to provide medical care and educational facilities ..."

12 We see in the paragraph below it was open
13 since 1904. If we then go down to paragraph starting:

14 "Over the years the types of handicaps have
15 changed ..."

16 You will see in there:

17 "In 1970 boys suffering from haemophilia were
18 admitted to the College and Treloar Haemophilia Centre
19 was [created] ..."

20 Then, bearing in mind this is 1981, the next
21 paragraph:

22 "During the last 10 years the haemophilia unit has
23 grown from a modest side ward in the paediatric unit to
24 a full and busy department including a separate
25 haemophilia laboratory ..."

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1 I pause there. That is one of the turning points in
 2 this tragic history.
 3 "... 3 medical officers and 4 nurses catering for
 4 the needs of 40-50 college pupils and 25 out-patients."
 5 If we then go over to the next page, please,
 6 Lawrence.
 7 On the left-hand side, top paragraph, you will see
 8 there was traditional education but also specialist
 9 practical education: computer studies, business courses,
 10 secretarial courses, horticulture.
 11 The paragraph below, there was also a wide variety
 12 of sports on offer.
 13 Then if we go down to the bottom of that:
 14 "As well as the teaching staff, there are teams of
 15 physiotherapists and remedial gymnasts, house parents
 16 and care staff and an occupational therapist ..."
 17 **SIR BRIAN LANGSTAFF:** Excuse me for having one of those "Who
 18 are the Beatles?" moments, but what is a possum machine?
 19 **MR CUMMINS:** I think you will have to ask someone who knows
 20 that answer. I can find out over the lunch and see if
 21 one of the cohort can assist us with that, or I will
 22 Google it.
 23 **SIR BRIAN LANGSTAFF:** Thank you.
 24 **MR CUMMINS:** So this is the dream that's sold. Clearly
 25 educational and medical needs were being provided hand

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1 a normal state school where he had a supportive worker
 2 that looked after him."
 3 This is odd. It is not said that they knew anything
 4 about Treloar College or even that they had applied to
 5 it. One can almost see Harry Potter's owl, Hedwig,
 6 dropping off the envelope and the invitation to them.
 7 The question maybe is: Was this boy targeted? That is
 8 the obvious inference that could be drawn from that.
 9 Thank you, Lawrence.
 10 Now, as indicated, the opportunity seemed amazing to
 11 them and their parents, and in fairness, from the
 12 evidence that we have heard, there was a plus side to
 13 this ledger. Some credit is actually due. The boys did
 14 receive a reasonable education. When they left, those
 15 who could were employed until their illnesses prevented
 16 it. And I say those who could, because others were even
 17 denied that opportunity: age 17, cast onto benefits
 18 because of the infectious illnesses that were inflicted
 19 on them.
 20 The boys did have some members of staff, educational
 21 and clinical, who appeared to have their welfare and
 22 development at heart. They also made friends and forged
 23 bonds for life, although, as we have heard, in many
 24 cases some of those lives were cut short. But for all
 25 these credits, this was not Hogwarts. This wasn't

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1 in hand. This was the unique selling point of the
 2 college that was sold to the parents and the boys.
 3 One thing you may have to think about is whether or
 4 not this was the same objectives of the clinicians, and
 5 what the awareness of the staff were as to what may have
 6 been behind the curtain of The Wizard of Oz. But this
 7 is what the parents and boys were told and it all
 8 sounded fantastic for them.
 9 I'm going to ask Lawrence, if I may, WITN1428001.
 10 It is a witness statement from one of the parents and
 11 I am going to ask you to take us to paragraph 8.
 12 Now, the evidence we've heard is of school offers
 13 frequently being proposed to the boys by their medical
 14 clinicians in concert with the college itself,
 15 presumably the school's admission and the local
 16 education authorities. So there was that overlap of
 17 invitation. But we also had this paragraph from one of
 18 the parents. You can see there, in relation to her son,
 19 at the age of nine he had an offer and a placement at
 20 Treloar College, Alton:
 21 "We did not make an application to the school. We
 22 just received a letter stating that they would like to
 23 offer my son a place. They had a Haemophilia Centre and
 24 therefore were able to administer Factor VIII and to
 25 attend to medical needs. Prior to this he went to

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1 a happy ever after adventure. This is Hampshire in
 2 England in the '70s and '80s, where the sewer of viruses
 3 referred to earlier also flowed.
 4 This evidence suggests that from the '70s a creeping
 5 nightmare was to unfold for these boys, their families
 6 and their loved ones which still persist today.
 7 We are grateful for the evidence that we have heard
 8 and, through the shock and tears and anger at parts of
 9 that evidence, we have obtained some clarity and we have
 10 had some questions answered. I would like to put to you
 11 12 questions and answers from what we have heard which
 12 reflect what I have been instructed by that cohort.
 13 It has been touched on by Mr Snowden earlier. One
 14 question that they had was: was this in fact
 15 an unavoidable accident? Well, from what we have heard,
 16 we would submit no, it wasn't. That's a lie that has
 17 been told to them over the years. We know the college
 18 did not seek to avoid hepatitis. In fact it went
 19 looking for it in trials.
 20 The second issue is, what did the clinicians know?
 21 From the evidence that we have heard, the answer would
 22 appear to be a lot more than they were saying or letting
 23 on.
 24 The third question that was asked by them was: did
 25 they actually know about these risks of hepatitis in the

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1970s? As alluded to, undoubtedly so, because that's what the trials were conducted for.

Fourth question arises is: what were the teachers and staff doing when the clinicians were undertaking these risky trials? The answer would seem to be: they turned a Lord Nelsonian eye to it. Was this wilful or convenient? Either way it was wrong.

Could the risks have been reduced? The answer to that is: almost certainly. We have seen in one of the trials batches were restricted and products were restricted. If they could do that in trial, why could they not do that as part of best treatment?

The sixth question arises: was there an excessive use of prophylaxis? Well, certainly so. I would submit to you, sir, that from some of the trials these boys were wilfully given the full cocktail.

Were the boys used as human guinea pigs, is something that's often asked. Undoubtedly so would seem to be the answer now.

When did they know about the risks of HIV? Well, the evidence shows that at the very latest the clinicians at the college knew about this in January 1983. And as has been touched on earlier by Mr Snowden, the Heathrow meeting in January '83 would seem the long stop, if not earlier. As for the school

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survive, are coping with ongoing infections on top of their haemophilia illness.

I pause to just think about those statistics for a second. It has been commented that only King Herod had a higher attrition rate of child mortality than what happened at that college.

Those boys were told they were lucky. Mr Snowden touched upon that. Now, they have a clear conflict with this. Yes, they feel fortunate to still be alive, but lucky? Winning the lottery is lucky, not having a serious illness inflicted on you at a young age which shapes the rest of your life. Having the uncertainty of a stolen future, is that lucky? They resoundly say no.

It has been mentioned to me by one of the Core Participants that they were meant to leave school with education certificates in their backpacks, with a future ahead of them, but instead they left with a death certificate.

Despite the investigations, an anger still pervades as a consequence of the impacts of what's happened to this cohort. They're left with a strong sense of being exploited by the clinicians, who couldn't wait to utilise what they deemed to be a unique environment: a coagulation laboratory and large numbers of patients available for daily clinical observations. We have read

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staff, we would submit to you at the very latest the risk of HIV was known in May 1983, and I will refer you back to an article from The Guardian in due course.

The ninth question that has been ventilated is: given what the clinicians knew in early 1983 about HIV, what therapeutic treatments that were used -- was that appropriate? The answer seems to be, there: almost certainly not. There were lower risk options available to them.

I will in due course take you to the UKHCDO returns for 1983 which, in light of what was known, are staggering.

Tenthly, what's the school stance been then and since? The evidence would suggest one of denial. Even in the closing submissions they are still hiding behind the clinicians, they are not accepting their responsibility. And this has led to number of these boys feeling that sense of betrayal persist.

Sir, you will be aware of the level of past fatalities. It is at least 74. And I say at least because one cannot keep tabs on the entire group and cohort, but it is at least 74 out of 122.

Now, if one bears in mind that 50% at the school were essentially haemophiliacs, we have lost at least 60% of those already. And those who are left, those who

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that several teams in many of the documents. For anyone who wanted to undertake research and study, it was manna from heaven.

They also feel anger and that it is unfair that the man who presided over this tragedy was rewarded with an OBE in 1990. There is anger at the way they have since been treated by the government, the Alliance House organisation, the denials of the college and having to fight every step of the way to get an inquiry and to get some recognition.

There is anger for the lives lost of their peers. That real sense of betrayal by the school, the doctors and the adults they are entitled to trust, they let them down and they let their families down and they still continue to do so.

We have heard from some a feeling of guilt, survivor guilt, a feeling they shouldn't still be here but they are. But that anger fuels their fight for those who are not here and they shouldn't have had to carry that burden.

It is absurd when one reads the submissions, closing submissions from the college, that they refer to as stained glass window as a suitable memorial. They overlook that this window is actually down a dingy corridor in the old small physiotherapy room, hidden

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1 away where one might even need permission to see it.
 2 There are no individuals named or identified. No
 3 account of the tragic events that led to their deaths.
 4 There is no recognition that these pupils died not
 5 from their initial ailments or disabilities but because
 6 of the treatment they received at that school.
 7 They ask for a true memorial in an accessible place
 8 where families and friends can visit, that acknowledges
 9 and explains the wrongs that occurred and recognises the
 10 names of those lost. That is the bare minimum. So it
 11 is no wonder their anger persists today.
 12 If one takes a step back, I'm going to ask you to
 13 consider two aspects on the evidence we have heard. The
 14 first is the child vulnerability. Bear in mind the age;
 15 these boys were teenagers or pre-teens. They were alone
 16 or, if lucky, they might have had a sibling there. But
 17 we have heard the tragic evidence of John Peach, one of
 18 the parents who lost both his sons, those two siblings.
 19 They attended the college suffering an illness,
 20 haemophilia, which can be debilitating in its own right.
 21 They were placed in a different environment, with
 22 different children around them, sleeping and eating in
 23 different rooms. They were away from home, their
 24 families and their usual support mechanisms.
 25 We have heard evidence that they would see their

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1 The parents of the pupils legitimately expected the
 2 staff to act with full responsibility and obligation.
 3 It's submitted as part of that role for caring for the
 4 boys' welfare they should have been expected to appraise
 5 themselves of their medical welfare. They should have
 6 been asking about the risks of proposed treatments and
 7 not just relied on the clinicians in an unchecked
 8 fashion.
 9 Mr Macpherson, the headmaster, we give him credit
 10 for coming and giving evidence. Others haven't. He
 11 did. In his evidence he agreed to acting in
 12 loco parentis. You will see that in his transcript on
 13 internal page 83.
 14 He also accepted he would sign consent forms for
 15 various activities and medical procedures, and the
 16 Inquiry has shown one consent form for us from 1976.
 17 Lawrence, may I trouble you with TREL0000165_053.
 18 If we see at the top of that page:
 19 "I hereby authorise the School Medical Officer ..."
 20 I pause there. That is the equivalent of the GP
 21 that's employed by the school:
 22 "... whenever he deems appropriate, to discuss with
 23 one or more Governors and/or the Headmaster or in the
 24 absence of the Headmaster his deputy or my child's
 25 Housemaster information containing the health of the

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1 parents maybe once or twice a term on leave weekends
 2 over those three-month terms, and with time that
 3 diminished. They were initially isolated and wholly
 4 dependent from a young age -- completely dependent -- on
 5 the school and the adults there.
 6 That leads to the second aspect I would ask you to
 7 consider, the whole concept of loco parentis. You will
 8 be aware that since the late 19th century common law has
 9 determined that a school master is bound to take such
 10 care of his pupils as a careful father would. Well,
 11 obviously that was a comment of its time; it has since
 12 been expanded to parents, and we all have to acknowledge
 13 everyone needs their mum.
 14 It is significant as well that this was a boarding
 15 school. As identified above, it increased the
 16 vulnerability of those boys at a boarding school rather
 17 than returning home each evening.
 18 The school, the headmaster, the employed medical and
 19 educational staff were standing in the shoes of those
 20 parents. They were not there to assist the clinicians
 21 nor the pharmaceutical companies or any medical or
 22 scientific research. The first priority should have
 23 been the pupils' best interests. The school was there
 24 to oversee the welfare of the boys, and in that the
 25 evidence indicates they failed.

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1 said pupil ..."
 2 We can see how widespread that net is cast in terms
 3 of consent. It permeates from the top to the bottom of
 4 the school staff. It's express authority to consent,
 5 acting under the advice of the college medical officer.
 6 It demonstrates the links in the chain, the number of
 7 tentacles, and that the staff at the school are as
 8 involved as any NHS medical staff.
 9 Contrast that, when questioned by Ms Richards,
 10 Mr Macpherson later seeking to recant from this
 11 position. You will see that in the transcript on
 12 page 85. In fact I think it may have been questions
 13 from yourself, sir, where he said:
 14 "If it was a purely medical problem, then either
 15 Pat Tomlinson, who was the medical officer employed by
 16 the school, or the haemophilia people would ask the boys
 17 to come and would talk to the pupils."
 18 Now, sir, the Inquiry is entitled to ponder the
 19 question, why were staff not attending those meetings as
 20 well? Not acting in a parental position? You are
 21 entitled to recognise that from the 1970s
 22 Dr Rainsford -- and I will return to that shortly -- was
 23 employed by the Trust, he was the consultant
 24 haematologist. And in light of that express written
 25 consent, solicited by the school, you are entitled to

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consider, in that light, submissions that it was not the school's responsibility and all treatments were down to the clinicians alone, and you are entitled to determine that wasn't the case and that such an assertion is really a colander, riddled with holes.

Thank you, Lawrence.

Two questions arise from this scrutiny: should teaching staff at a boarding school disengage from medical aspects of their pupil's welfare? Are they allowed to wash their hands in terms of medical treatment issues?

Well, one would not expect the boys' parents to behave like that. And if they are standing in the shoes of the parents, nor should we expect that from the school.

Should they have asked questions on the boys' behalf? Well, if the school was not looking out for these boys on questions of appropriate medical care being proposed, then who else was going to do that? Who was the check and the balance?

If the answer is that no one was doing that, then the school has allowed the clinicians free rein over these boys. We mentioned the staff, we have seen the Head Masters, the House Masters, there is reference earlier to the nurses and the physiotherapist, speech

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He is asked about Dr Aronstam and his work there and his reply on that, from line 18 down:

"... he was -- I think at the sharp end of introducing better treatment for haemophilia, and he was to a certain, I suppose, experimenting, in a way, with the use of Factor VIII."

Who is he experimenting on? We know it is the boys. So he has some oversight, Mr Macpherson, and he knows that Dr Aronstam is experimenting -- sorry, Dr Rainsford. It is the employed, rather than the NHS consultant.

If we then move over to page 4., internal page 16.

He is then asked about any meetings he had with the medical staff. He starts at line 7, in the bottom right-hand corner, and corrects himself to say Dr Aronstam on line 10. He highlights there a weekly chat, coffee, once a week, regular meetings just to say "How are things?"

"But sometimes we would sit and discuss something at length ..."

Then on page 5, internal page 17, top left, when asked what he meant by "discuss" his answer at line 11, is to say:

"He would be telling me that this is what they were doing. Because, I mean, I had no -- I had nothing to do

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and occupational therapists and also that college medical officer.

Now, under any chain of command, one might expect reports back to the House Masters and into the Head Masters who, in turn, would have to report back to the trustees and the governors.

Lawrence if I could trouble you for INQY1000134, please. This is the transcript of Mr Macpherson's evidence.

Now, if we go to page 2, first of all, within that or page 1 of the document, internal page 2 of his evidence, you will see the exchange in terms of the Haemophilia Centre:

"Did you or the school college or the trust have any oversight?"

SIR BRIAN LANGSTAFF: That's top right?

MR CUMMINS: Yes, sorry.

SIR BRIAN LANGSTAFF: Top right, line 15?

MR CUMMINS: Yes.

SIR BRIAN LANGSTAFF: So the answer is at line 15.

MR CUMMINS: Yes. He says.

"Answer: Yes, we did -- it [would] probably ... never work today, but we were very fortunate."

He clearly had some oversight. We then move to page 3 of that document, internal page 12, bottom right.

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with making any decisions in the medical side of running things. But I was usually made aware of what was going on and I was kept informed. I think very well by the staff."

That begs the question of what was the purpose of weekly discussions and keeping him informed, if he was never going to act on it or be a safety net for the pupils and their parents? On page 6, straddling internal pages 23 and 24, he agrees he was told about the risk of hepatitis associated with treatment received by Dr Aronstam and the nurse or the sister and says he had concerns about it and it was a big worry.

You will see the "big worry" halfway down page 24, line 12. Bear in mind that the evidence we have heard, Ms Richards took us through it, was the outbreak of hepatitis in 1974/75, early on in his tenure.

Why wasn't he getting involved? Why wasn't he asking questions in that context of an outbreak in the past and having concerns raised to him about hepatitis?

When asked about the issue of AIDS on page 7, straddling 26 and 27, he said he would have been told about it by Dr Aronstam and at line 22:

"We had to discuss it and discuss what we were going to do about it. We had numerous discussions at governors' meetings."

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1 Pause there. It appeared that the earliest
2 governors' meeting discussing AIDS that was presented
3 dated from October 1985. Pause there for one second:
4 1985.

5 When asked about that, he indicated he first knew
6 about it only then and that the school was working on
7 the issue immediately. We see that on page 28, line 9:

8 "So if, for example, we see it being discussed by
9 the governing body really I think properly for the first
10 time in 1985, is the right inference to draw from that
11 that you have been alerted to the problem only
12 relatively shortly before that?"

13 **"Answer:** Yes, I think so", is the reply he gives.

14 When pushed on that, he is then asked over
15 the page, 28 to 29 if he believes that that was
16 the first time he knew about it, and he
17 replies:

18 "So are you saying that he knew about it [he being
19 Dr Aronstam], he knew about it for a while and kept
20 quiet about it?"

21 His answer is:

22 "Well that's one of the matters the Inquiry will
23 have to consider, I can't help you with that."

24 Now, is that deflection on his part? Is there
25 another option, perhaps, that they both knew about it

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1 "Our [parents] are hysterical, said Dr Tony
2 Aronstam, a consultant haematologist ..."

3 **SIR BRIAN LANGSTAFF:** What's the date of this?

4 **MR CUMMINS:** This is 4 May 1983.

5 **SIR BRIAN LANGSTAFF:** Thank you.

6 **MR CUMMINS:** "... a consultant haematologist and director of
7 Treloar Haemophilia Centre at Alton, Hampshire. 'Every
8 report brings haemophiliacs crying to us'.

9 "He stressed that the illness that affected 10
10 children at Treloar in 1981 -- which prompted
11 a Department of Health warning about the risk of
12 hepatitis infection from imported Factor VIII and
13 a warning to health ministers ..."

14 You may consider that where a school is being named
15 in a national newspaper with quotes from its director,
16 a head teacher might know about that or make it his
17 business to find out about it in case there are any
18 questions coming his way from the governors. Lastly, if
19 I may take you to RLIT0000666 and page 13 therein, top
20 of the page, please.

21 This is Dr Aronstam's book from 1985 and you will
22 see in the acknowledgements there he specifically
23 acknowledges Alec Macpherson, head teacher of Lord Mayor
24 Treloar College, "whose understanding of our problems
25 has made our work so much easier".

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1 and both decided to keep quiet about it? There is
2 a clear inference from this evidence of delay and denial
3 by him, which we would say is a dereliction from his
4 moral duty and legal obligations.

5 We know from the evidence as well that he had
6 stepped into the arena in respect of the banning of
7 football from haemophiliac boys. When there had been
8 an increase in bleeding for them, he stepped in to ban
9 them from engaging in the activity. What then of the
10 other staff? What was their knowledge? What could they
11 have picked up or what can we infer?

12 If I can go back to HSOC0022908. This is The
13 Haemophilia Society bulletin again. If I can take you
14 in that to the middle paragraph just below -- page 5.
15 Just below the emblem in the middle. There is
16 a reference there to a sick bay area:

17 "... 10-bedded admission ward for haemophiliacs
18 unfit to ... school. One of the teaching staff is on
19 duty throughout the day, thus lesson continuity is
20 maintained."

21 Now, any staff attending may ask the question "Why
22 is [GRO-A] in the sick bay, what is his treatment and
23 how long is he going to be here for?" If I can take you
24 to MDIA0000022. This is an article from The Guardian,
25 MDIA0000022, middle paragraph:

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1 It is not a huge leap for this Inquiry to infer
2 either that medical staff, the NHS, would talk to the
3 employed college medical staff, who may in turn talk to
4 teaching staff.

5 It renders any assertion or denial of no knowledge
6 of HIV until 1985 highly unlikely.

7 If you are content for me to press on, mindful of
8 the time.

9 **SIR BRIAN LANGSTAFF:** How much more have you got?

10 **MR CUMMINS:** A lot more than I anticipated, is the answer.

11 **SIR BRIAN LANGSTAFF:** Funnily enough, I thought that might
12 be your response. We will take a break now, shall we?

13 **MR CUMMINS:** It is not as easy as it looks, despite

14 Ms Richards' effortless manner in which she does it.

15 **SIR BRIAN LANGSTAFF:** I shall leave you to work out how to
16 do it as efficiently as you can when we come back.

17 Shall we say 2.00?

18 (1.03 pm)

(The short adjournment)

20 (2.00 pm)

21 **SIR BRIAN LANGSTAFF:** Yes.

22 **MR CUMMINS:** Thank you, Sir Brian. We just finished before
23 the break looking at the role of the headmaster and
24 other members of staff at the school. I'm going to
25 briefly touch upon other characters and personae at the

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1 time.

2 Dr Rainsford, you are aware, joined the school from

3 1968 onwards. We have heard how he set up the research

4 coagulation laboratory at the school, funded by a grant

5 to the school.

6 I'm not going to call it up but I will draw your

7 attention to WITN7547002_004. That's a letter on

8 14 February 1969 from the school warden to two parents

9 referring to the hiring of Dr Rainsford, who was to be

10 "concerned with the welfare of the boys suffering

11 haemophilia" and will "co-operate with and advise staff

12 of the Treloar Hospital regarding their treatment, to

13 work under the direction of Dr Biggs".

14 Another document I seek to highlight for you which

15 is touched upon in our written submissions is

16 SWCX0000003_008. This was the grant application to

17 extend the grant used to employ Dr Rainsford. And

18 I flag it up merely for you to note that it is a joint

19 application being made on 1 August 1975 by both the

20 chair of the school and the NHS orthopaedic surgeon.

21 Essentially to submit it would appear that both sides of

22 the coin knew what was going on in terms of any research

23 and trials.

24 If I could then, Lawrence, WITN7547002_0002.

25 This is a letter from September 1967 to the same

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1 potentially in mind.

2 I think I have already addressed Dr Tomlinson, so

3 I won't trouble you any further with her role, but

4 I will say a few words about Dr Aronstam if I may.

5 You will recall, sir, that he undertook his

6 dissertation studying the boys at the college over

7 a five-year period. You will recall from Ms Richards'

8 comprehensive detailed presentation that he was heavily

9 involved in many research projects and trials throughout

10 the 1970s and 1980s.

11 You will recall as well, at TREL00000_113 -- thank

12 you, Lawrence -- that he obtained a generic consent form

13 which didn't identify any specific products or any

14 specific risks or any rights of the patients, just

15 participation with unspecified factor concentrates. He

16 essentially gave himself a free hand.

17 You will also recall, at HHFT0001201_004, that he

18 undertook trials to make comparisons between different

19 competing commercial products, Armour and Hemofil. You

20 will also recall his interactions with the

21 pharmaceutical companies. RLIT0000104, in the

22 acknowledgement section, confirms grants were provided

23 to the college to fund research by Armour

24 Pharmaceutical.

25 HHFT0001201_003 sets out for you Armour being

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1 parents.

2 I think somebody needs to turn their phone off.

3 Thank you.

4 It is the first paragraph. Halfway down. I draw

5 your attention, beginning:

6 "There are nearly 40 haemophiliacs in the College,

7 and we have long felt that they provide an opportunity

8 for research, which should not be missed and which, we

9 hope, will result in improved methods of treatment."

10 **SIR BRIAN LANGSTAFF:** (No microphone).

11 **(Pause)**

12 Yes.

13 **MR CUMMINS:** Thank you.

14 This is from the school warden to those same

15 parents.

16 Then if we go down, essentially, mindful of time,

17 the comments of the warden indicate the school's

18 knowledge that medical research was a feature from 1967

19 onwards. That's when the lab was operational, together

20 with the school's and the clinicians' perception that

21 the boys attending that school were potential research

22 cohorts for them.

23 This is a slightly different USP of the college, or

24 unique selling point, than that that was sold to the

25 parents and the boys, with different objectives

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1 involved in the protocols for research as well as

2 reimbursing costs incurred upon receipt of an invoice

3 when the research funds were exhausted.

4 You may recall in December 1980, at BAYP0000021_063,

5 the minutes of a Cutter Laboratories board meeting which

6 recorded that Cutter were looking into providing some

7 form of financial support for a research fellowship to

8 Dr Aronstam after its representatives had made promises

9 to him to that effect to try to boost their sales. And

10 you will recall from the presentations the Speywood

11 trials of Humanate products, with boys selected who then

12 became infected from HIV. In essence, Russian roulette

13 was played with their lives for pharma's benefit. The

14 Inquiry may wish to question how were any of those

15 interactions genuinely in the best interests of the boys

16 as opposed to the interests of those pharmaceutical

17 companies?

18 The Inquiry looked at Dr Aronstam's book in some

19 detail. RLIT0000666. And at page 0107 therein it

20 identified the onset of infectious diseases, of

21 hepatitis and AIDS, from concentrates, arising from

22 prophylaxis use. Dr Aronstam therein says that the

23 patient should discuss this with their own doctors.

24 Well, the evidence we have heard, it was submitted that

25 Dr Aronstam did not even attempt to pay lip service to

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1 having any discussions with his patients, obtaining
2 informed consent, and that prophylactic use of plasma
3 products could be unacceptable. That is not
4 a conversation he ever had.

5 There is a fair bit we could say of Dr Aronstam but
6 I am going to potentially highlight two matters: the use
7 of prophylaxis at the college and also his attendance at
8 Excelsior Hotel at London Heathrow.

9 I will turn to the first of those. There are three
10 elements I would seek to flag up for you. The Inquiry
11 has investigated proposed trials in 1977, following
12 a previous trial between '76 and '77.

13 Three aspects of that. When that proposal was
14 produced before UKHCDO in January 1977, you will note
15 there Professor Stuart expressing some concerns about
16 the large scale use of prophylactic treatments. That is
17 in PRSE0002268 at 0010.

18 I take you back to The Haemophilia Society Bulletin
19 in 1981 of Sister Turk. HSOC0022908.

20 In terms of prophylaxis, she identifies there that
21 it was used extensively at Treloar's for a variety of
22 reasons, and she gives a list of some of those reasons:
23 treatment of target joints, that's understandable
24 potentially; short-term use when school examination
25 periods occur, perhaps less understanding you may feel;

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1 were heat-treated products available in the US from
2 March 1983.

3 The second limb from that is that the incidence of
4 AIDS was discussed at length at that meeting: its
5 incubation periods, its association with blood products
6 and in particular US concentrate products.

7 Lawrence, if we could have HCDO0001686_001. Turn to
8 the first page, please. We are going up, in the bottom
9 right-hand corner, 0001.

10 Bearing in mind that occurred in January 1983, we
11 have here the UKHCDO returns for Treloar's for 1983.
12 You see that "Total Amount of Material Used during
13 1983". Of significance here is there were safer
14 products available, not least cryoprecipitate.

15 **SIR BRIAN LANGSTAFF:** What's the mark over the "3"? After
16 198, there is some sort of pencil mark been put over
17 that.

18 **MR CUMMINS:** That has just been highlighted?

19 **SIR BRIAN LANGSTAFF:** No, the top left-hand corner.

20 **MR CUMMINS:** That is just the date. It seems to have been
21 smudged or something.

22 **SIR BRIAN LANGSTAFF:** Thank you.

23 **MR CUMMINS:** But we know it is 1983 because if we drop down
24 to "Total Amount of Material Used", this is during 1983,
25 and then we have the three asterisks. So we know it is

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1 short-term use on long journeys are undertaken, so half
2 term and at the end of term holidays.

3 Pause there for one moment. They are being given
4 these for those journeys. That means they are given
5 these at least six times a year for the purposes of
6 being on a journey.

7 And the last element she identifies is: prior to any
8 discos, visiting rock concerts or football matches. She
9 then adds this may seem rather "irresponsible". You may
10 feel that is potentially an underestimate.

11 Contrast that with the treatment sheet we saw of
12 Mr Warwick, which identified 25 consecutive days in
13 May 1982 in use of prophylactic Factor VIII without any
14 bleeds. You will find that at WITN1592023_0001.

15 The context of which was that his home treating
16 clinician had been assured that he would remain on
17 Kryobulin, which clearly he wasn't.

18 The second limb identified was Dr Aronstam's
19 attendance at the Excelsior Hotel at London Heathrow on
20 24 January 1983. This has been touched upon by
21 Mr Snowden this morning.

22 From his attendance there we know two aspects. One
23 is that the Immuno company were discussing with those
24 clinicians the prospect of virally inactivated products
25 at that meeting. We have also heard evidence that there

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1 for that year.

2 Simply highlighting for you that cryoprecipitate was
3 zero use. Which is perhaps the safest of the options
4 open at that time.

5 You will note from these figures, NHS use of
6 Factor VIII concentrate totals 858,581. Factor IX,
7 right at the bottom of that list, would appear to be
8 217,000 -- it stretches across -- if we add those up.

9 Having totaled those up, the total units used is
10 3,371,560, of which cryoprecipitate was 0 per cent. NHS
11 Factor VIII and Factor IX, because of course Factor IX
12 was used at the college as well, was 31.9 per cent, it
13 works out at, and commercial concentrates, 68.1 per
14 cent. So it is roughly 32 per cent NHS, 68 per cent
15 commercial, of which 0 per cent cryoprecipitate.

16 That is in the same year that Dr Aronstam has
17 attended Heathrow. The same year where he knows,
18 unquestionably, what the risks and the hazards are, and
19 his reaction to that was to distribute therapeutic
20 materials in that vein.

21 There are a number of trials that we have heard
22 about in Ms Richards' presentations throughout 1970 and
23 1980s. I'm not going to go through all of those. I'm
24 simply going to highlight some for your consideration.
25 Prophylactic trials of factor concentrates, you will see

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a UKHCDO meeting discussing such on 27 October 1972 at HCDO0001015. I flag that up. You will see in that meeting there were concerns and objections potentially raised -- you might term those disquiet -- on pages 5 and 8 by other clinicians on ethical and practical grounds.

At page 12, therein, you will note it had been stressed that the needs of the Haemophilia Centres have been stressed to the Regional Health Authorities and the board of governors. So the school clearly knew about that. But there's no indication of what the haemophiliac needs of the afflicted boys were as opposed to the needs of the Haemophilia Centres.

Then turn to the 1975 commercial concentrates and hepatitis trial. If we may have AMRE0000011_006. If we read the first paragraph at the top:

"Lord Mayor Treloar College is a unique establishment since there are more than fifty boys suffering from various coagulation defects (namely haemophilia, Christmas diseases and von Willebrand's disease) in residence at the College for approximately 264 days each year. These boys usually come to the College at the age of eleven and leave at the age of sixteen to eighteen years of age. They are, therefore, under continual medical supervision for nine months of

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place provides an ideal opportunity to study this complication of treatment."

You may feel that this trial was a wilful infliction of harm of hepatitis on the subjects of that trial, namely these boys. The evidence we have heard has fuelled the survivors' reflection or perception that their treatment was a form of research for the benefit of others rather than for their own best interests and, despite suggestions to the contrary, it is clear that neither they nor their parents ever gave informed consent to any research of that nature, let alone being informed of those risks.

If I may conclude many questions have been addressed, thank you very much for that. The clinicians and the school need to accept its failings and, until they do so, shame on them. The Government needs to stop with their denials and delays and degradation mentioned by Mr Snowden of the infected and affected. I would like to finish with a brief paragraph from one of the surviving Treloar's boys.

I believe this was written at the time of the Archer Inquiry and it still holds today. In it he says:

"So where were our advocates and advocacy? Where were our protectors? Where were our safety nets before we hit the ground only to be buried in that ground both

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the year and often for many years."

If we turn over the page. If we go to the second paragraph from the bottom please:

"The present arrangements at the College are particularly suitable for a specific type of research into haemophilia and other coagulation disorders, namely the study of relationship between laboratory findings and close day to day clinical observations. It is the only establishment in the United Kingdom which can provide the opportunity and the facilities for extensive clinical trials of various kinds of treatment which cannot, at present, be conducted anywhere else."

This is the unique nature of the college which was pursued by those clinicians. If we turn over to page 4 please, Lawrence. If we go to the bottom paragraph, starting:

"The existence of commercial concentrates of human Factor VIII has led to the much more liberal use of fractions prepared from large donor pools in the treatment of haemophilia. The consequences for the patients of this increased treatment are improved protection from crippling deformity and much extended horizons of possible activities. But the danger of contracting the blood-borne viruses causing hepatitis is also increased. The residence of these boys in one

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metaphorically and literally in the ashes of the school mates we lost, survived only by the doused embers of those ashes? Our flames cannot burn bright as once they would have done.

"Why did no one blow the whistles outside of the sports fields whilst we were turning jaundiced, later to be infected with hepatitis and HIV? There wasn't anybody for us. Our subsequent reality became a bleached white Milton steriliser reality. We were left amongst the school bags, young boys with death sentences handed out to us like exam grades instead. All we wanted was that brighter future promised to us when we entered the school gates."

Thank you, sir Brian.

SIR BRIAN LANGSTAFF: Thank you Mr Cummins.

MR CUMMINS: I will then hand back to Mr Snowden.

Further closing submissions by MR SNOWDEN

MR SNOWDEN: Sir, back to me. I take the place of, as he has described, the tall handsome one who now sits down.

I hope, in the remaining time we have available to us, to say something brief about Government and Civil Service and clinicians, chapters 3 and 4 of what we have written, then to deal briefly again if I may, as is appropriate, with recommendations touching again on inquests and what we say about compensation. So I will

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1 be as brief as I may through each topic.
 2 First, dealing, if I may, with Government and Civil
 3 Service clinicians. The common strand that runs through
 4 them of course is their response to hepatitis non-A,
 5 non-B, which we discussed earlier on but also their
 6 response to HIV. Again, as I did with non-A, non-B I'm
 7 not going to take the time to take you, sir, through
 8 a series of documents with which you are already
 9 familiar, but to bracket the dates so that we can then
 10 see how the civil servants and clinicians reacted within
 11 that bracket of dates.

12 Insofar as we have useful or rather cogent dates, we
 13 start in 1982 with the MMWR report in the States of
 14 three cases of pneumocystis in United States
 15 haemophiliacs who had had commercial concentrates.

16 Now, that provokes -- we are going to look at one
 17 document swiftly, if we could please, PRSE0003007.

18 This was the initial reaction in the Department of
 19 Health to that news of what were clearly ultimately
 20 identified as AIDS symptoms in haemophiliacs. You will
 21 see it is a memo of July 1982.

22 **SIR BRIAN LANGSTAFF:** That date is at the bottom is it?

23 **MR SNOWDEN:** Yes, bottom left. 16 July 1982. It is headed
 24 "American Factor VIII":

25 "You will wish to know that [blank]our [blank] in
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1 division, when the published study is available --
 2 I understand that one of your sections scans the
 3 technical literature for such material -- may have to
 4 consider revoking licences of certain manufacturers. Of
 5 course it may turn out that none of the Factor VIII
 6 involved is supplied to this country."

7 So two things we see simultaneously, one is the
 8 defensiveness which unfortunately appears to be the line
 9 which continues thereafter. The second: would have been
 10 a good idea had it been followed through. Closer
 11 scrutiny, greater attention and ultimately preventing
 12 the import of those products.

13 So that's the mid-part of July 1982. Sir, you know
 14 the chronology then moves on through the end of 1982 and
 15 reports and the first references to the baby in
 16 San Francisco, for whom, at the age of 20 months, there
 17 could be no explanation other than blood-borne viral
 18 transmissions, given that that baby had had multiple
 19 transfusions and then developed T cell immunodeficiency.

20 By January 1983, sir, you will be familiar with, we
 21 have looked in the Inquiry at numerous times at the
 22 Desforges article and the New England Journal of
 23 Medicine, where the author observes:

24 "Unfortunately the data are consistent with greater
 25 potential for AIDS in the population treated with
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1 Blood Transfusion, has received information from the
 2 American Bureau of Biologics via [blank] at NIBSC that
 3 there may be considerable publicity in the next couple
 4 of weeks concerning the safety of American Factor VIII."

5 There's then a layman's explanation, which, as it
 6 turns out, is not entirely correct, as we now see
 7 development and aetiology of AIDS and HIV. But we see
 8 two reactions at this early stage. One is the reaction,
 9 as I would characterise it, of the civil servants, which
 10 is the "This is going to be problematic, are we in
 11 trouble?" You see that in the third substantive
 12 paragraph:

13 "From the DHSS point of view, we can defend the
 14 National Blood Transfusion Service's own record.
 15 Someone taking drugs (gay or not) would not be bled
 16 provided that the injection marks showed."

17 The first response shows a defensive one. We invite
 18 you to conclude, as we do through our written
 19 submissions, that characterises some of the civil
 20 servant's response through the greater part of this
 21 period. There is almost, as an afterthought at the end,
 22 a glimmer of hope which sadly is never pursued. From
 23 the middle of that same paragraph, you will see:

24 "However, about half of the Factor VIII bought from
 25 commercial companies is imported from the USA. Your
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1 concentrate. Physicians involved in the care of
 2 haemophiliacs must now be alive to this risk.
 3 Preventing the complications of the present treatment
 4 may have to take precedence over preventing the
 5 complications of haemophilia itself."

6 Again, we pause there and say, if only that course
 7 had been followed. Again, it was prescient but it was
 8 January 1983.

9 We then move through the response of both Government
 10 and clinicians in the UK. We have in May 1983, skipping
 11 a number of stages, sir, with which you will be familiar
 12 and I won't trouble you again, because you know the
 13 evidence, but in May 1983, Professor Bloom of Cardiff
 14 writes in The Haemophilia Society's Bulletin or
 15 newsletter saying:

16 "The cause of AIDS is quite unknown and it has not
 17 been proven to result from the transmission of the
 18 specific infective agent in blood products. We are not
 19 aware of any proven case in our own haemophiliac
 20 population. While it would be wrong to be complacent it
 21 would be equally counterproductive to alter our
 22 treatment programmes radically. We should avoid
 23 precipitate action."

24 We pause to observe that "precipitate action" is
 25 precisely what was required. It would not have been
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considered precipitate had one taken into account the learning over the previous six, seven or eight months, even in the context of its time. What is also striking, sir, and you will be familiar with this, of course, is when Professor Bloom says "We are not aware of any proven case", only two months previously, on 17 March 1983, Professor Bloom had -- on 22 March he had completed a form identifying that on 17 March he had considered that Kevin Slater, of whom the Inquiry has heard, the first patient to have developed AIDS as a haemophiliac -- Professor Bloom attributed AIDS symptoms in that patient to his treatment.

It simply can't be reconciled what Professor Bloom said at those stages. We move from 1983 through the Galbraith letter, which again we are all familiar with. Again, one can spend an awful lot of time on it and its particular consequences but, in this context it merely sets the scene that by May 1983 the only, a very respected and the only one to comment -- the epidemiologist was calling for the temporary withdrawal of US products -- not an absolutist position but a temporary withdrawal -- until risks could be clarified.

That advice, disregarded in due course. By June 1983, sir, again you will be familiar -- we won't

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if you'll forgive me going to show one more document. MACK0000307 and page 002.

Sir, this again is a document we will all be familiar with having been in the hearings. It is the Council of Europe recommendation, R(83)8. Lawrence, if we can go to the bottom of page 2. Thank you very much.

You will see that, after setting out the basic principles, as they are described in the middle of that page, to minimise the hazard of transmissible infectious diseases, then the bottom paragraph:

"Recognising the necessity to provide pertinent information to blood donors, attending physicians and selected recipient groups in order to avoid, as far as possible, donations by persons in risk groups ..."

Then come over to the top of the page. This says The Council of Europe:

"Recommends the governments of member states:

"I. To take all necessary steps and measures with respect to [AIDS] and in particular ..."

Then we have the three bullet points:

"to avoid wherever possible the use of coagulation factor products prepared from large plasma pools ..."

The second bullet point:

"to inform attending physicians and selected recipients, such as haemophiliacs, of the potential

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show on the screen for the sake of time -- Dr Walford's briefing note. Perhaps it is instructive just to read a few parts of that. So Dr Walford in the Department of Health, by the middle of 1983, appreciates that, in a note headed, "AIDS a new disease", appreciates that mortality rate is at least 40 per cent, there's no known cure, she identifies some of the risk factors -- she uses the collection of Hs which we are all familiar with, homosexuals, heroin addicts, Haitian immigrants and haemophiliacs. But, in that very same note, so in the middle of 1983, haemophiliacs, she says:

"It's thought the greatest risk to haemophiliacs at present is from the use of Factor VIII concentrate prepared from American plasma."

She identifies that certain commercial manufacturers are proposing to introduce heat-treated Factor VIII concentrates but there's no evidence whatsoever that such material reduces the risk of causing AIDS.

Back to the previous page. Sir, again, you will be familiar with the document and I won't show it. But she says:

"The cause of AIDS is unknown but the evidence does suggest that it may be a virus."

So we have a suggestion on which, at that point, no further action is taken. We come to June 1983 and I am,

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health hazards of haemotherapy and the possibilities of minimising these risks ..."

3 is:

"to provide all blood donors with information ...so those in risk groups will refrain from donating ..."

We pause there to observe that although the Government response in a memo of July 1983 from Mr Cummins is summarised, perhaps this is where things -- we may find an explanation here for how many ministers thought they had complied with the recommendation of the Council of Europe but had not in fact, because Mr Cummins inaccurately summarises these three, I will call them requirements or recommendations, as follows. He talks about -- we can leave this on the screen, please, while describing the memo. He says:

"From time to time we submit to ministers international instruments which involve DHSS interests. It is normal practice during the preparation of these documents to ensure the UK is not committed to policies which would not otherwise be followed. So there is correspondingly no action to be taken."

It sounds very *Yes, Minister*. We will only say yes to something that doesn't require us to do anything.

But he describes this document in this way. He says:

"On the basis of present knowledge, it is assumed

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that AIDS is transmissible by blood and the recommendation aims to ensure that appropriate precautions are taken in the preparation of certain blood products and that specific groups and recipients, such as haemophiliacs are accordingly reassured."

One can see immediately from the text that is still on the screen that's not what it says. It says "avoid wherever possible". It says "inform" the recipients of the "health hazards and the possibilities of minimising these risks".

So, sir, what we have is a recommendation of the Council of Europe to which it seems it was thought that consent had been given because it wouldn't really require anyone to do anything, and then a civil servant describing that it doesn't require anyone to do anything. Which is absolutely not what it says on its face.

Notwithstanding that, and many other steps in the chronology, but from June 1983 we move on until eventually, in November 1983, we come to, as we all know, Kenneth Clarke, as he then was, describing in a statement to the House of Commons that there is "no conclusive proof" of the link between products and HIV.

So there's the extraordinary window of relevance.

Sir, I imagine numerous pages and chapters of your

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And we say -- identify that amongst the factors that contributed to the ignorance of government were that blood policy was merely one of a large number of portfolios of responsibilities. It appears not to have been seen until AIDS became more prominent as an area of priority.

There is a high turnover of ministers, which means, in effect, fresh learning and an absence of scrutiny from ministers of what civil servants were doing.

We say you can discern through the evidence you have heard in general a deference to the medical part of the dual hierarchy in the Civil Service, in that those who were medical officers, their views largely were treated as gospel and not challenged. And consequently there was a great deal of dependence by ministers on officials and very little scrutiny or very little ability to scrutinise the submissions being made by the officials to the ministers.

So that is the sense in which we use ignorance.

We also, though, use it in the sense of what I can cheekily call "pass the parcel". We say at paragraphs 141 to 142 and 143 of our submissions, Lord Clarke blamed the medical advice the Department received for the misleading phrase "no conclusive proof". He says it is his officials who have misadvised

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report are going to be devoted to the developments between the end of 1982 and the end of 1983 and into 1984, but that's the timespan into which I want to make two or three observations about the approach, first of all, of ministers and politicians and civil servants, and then, secondly, about the approach of clinicians.

So, against that background, we, sir, in our written submissions, at chapters 2, 3 and 4 -- no, try again, 4 and 5. Chapter 4, we described politicians. We use three words to describe the attitude of the politicians and the interaction between them and their civil servants. We described it as ignorance, arrogance and dependence.

In respect of those, sir, we sort of explain that as follows: in terms of ignorance we are not necessarily calling any politician stupid. We are talking about ignorance of fact, of pertinent information. The way we describe it in our written submission is: a number of factors combined to ensure that information was siloed within the hierarchy of government so that its absence went unnoticed. This in turn meant that unavoidable and unjustifiable delays occurred with accountability, and that egregious decisions were not brought to light. So the ignorance of -- the ignorance of the right hand from what the left is doing, put another way.

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him. They kept the pertinent information from him.

Dr Walford, one of those officials, says about the Galbraith letter, the important one we talked about, about the temporary withdrawal of US concentrates imports. Dr Walford said:

"I didn't see that the paper had been copied to anyone in the Medicines Division, so I don't know if Medicines Division was aware. But I would certainly have said that would be the place it should have gone, and ministers should have been told what the outcome was."

Howsoever it happened, we're playing a game of pass the parcel. The minister says he didn't know because he wasn't told by his officials. The officials say they didn't know because it was sent to the wrong department or passed elsewhere.

So that is the concept of ignorance.

In terms of what we describe as arrogance, sir, we talk about in our written submissions, and I will expand on it only slightly now, an inability of self reflection about their own ignorance in the sense nobody minded, nobody seemed terribly troubled that they didn't know these things at the time. The business of government could carry on perfectly well in the minds of many ministers without having to consider whether errors of

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1 judgment were being made.
 2 We say there is also the general sense in which
 3 arrogance is used. Core Participants will have been
 4 astonished and hurt by statements from some ministers
 5 delivered during the course of their evidence to this
 6 Inquiry.
 7 One example from Lord Clarke. Asked by Ms Richards:
 8 "The Inquiry has heard evidence from ... families,
 9 patients, clinicians, which it might be said paint
 10 a fairly overwhelming picture, of people not having
 11 risks drawn to their attention."
 12 Lord Clarke:
 13 "Well, they must have been [pretty] switched off"
 14 Astonishing arrogance here in a public Inquiry.
 15 And howsoever one characterises it, arrogance or
 16 want of care as to tone, Sir John Major using the
 17 expression "incredibly bad luck", which we all recall.
 18 So, again, we talk about those as aspects of
 19 arrogance, and in terms of the sense of dependence which
 20 we say characterises what went wrong in the relationship
 21 between ministers and their officials.
 22 In our written submission we simply say this: the
 23 views of Committees were rarely presented with
 24 differences of opinion -- so you know and you've heard
 25 that -- differences of opinion retained in the minutes.

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1 it?' And we say, 'I'm afraid we don't think there's
 2 anything you can do unless you want to stop taking
 3 Factor VIII'.
 4 A combination of ignorance and arrogance.
 5 When pressed then by Ms Richards about, well, why
 6 not stop taking Factor VIII in those circumstances
 7 Lord Clarke replies in this way. She asks whether -- he
 8 says whether [you] mean stop taking Factor VIII:
 9 "Taking less wouldn't do any good.
 10 "Well, the physicians, if they were remotely keeping
 11 up to date with things, must have been aware that there
 12 was this mounting concern. So they all had specialist
 13 doctors who were treating them. They didn't just give
 14 themselves Factor VIII. I don't think, I don't know.
 15 Personally, I have to admit I don't know how you take
 16 Factor VIII. So I'm -- I apologise if you're given
 17 a pill which you take home, but they all had highly
 18 specialised physicians treating them."
 19 A clear example of a combination of ignorance and
 20 arrogance in all senses.
 21 And again, when pressed a little later in the
 22 evidence by Ms Richards:
 23 "And do we correctly understand from something you
 24 said earlier that you were not aware of a treatment
 25 called cryoprecipitate?"

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1 Add this to the reliance of ministers on their civil
 2 servants and the picture is one of a government with few
 3 outside influences.
 4 Witnesses unequivocally accepted that ideas could
 5 get entrenched in governments. Both officials, such as
 6 Rowena Jecock, who gave evidence, and ministers,
 7 including John Major, concluded that the Civil Service
 8 is the corporate memory of a department and that this
 9 places a higher burden on officials to provide full and
 10 accurate briefings. In the face of the ignorance, the
 11 arrogance and the obvious dependence of one part of that
 12 system on the other, there is a substantially higher
 13 duty, we say, to be clear about what's known, what's
 14 understood and what's being communicated.
 15 If I may, I am going to take just a moment to remind
 16 you of some of the aspects of ignorance and arrogance in
 17 the evidence of Lord Clarke. Part of his evidence,
 18 given on 27 July 2021, when being asked about what could
 19 be done, whether a patient should be apprised of risks:
 20 "So it's no good going out there -- I've said --
 21 throughout this tragedy it's just appalling what
 22 actually happened, but what should we have done? Just
 23 gone out and said, 'We think it's important in the
 24 public interest that we tell you that you're going to
 25 die?' And then they say, 'What am I meant to do about

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1 "Answer: Never heard of it. Is that the treatment
 2 that preceded Factor VIII?
 3 "Question: Preceded and continued.
 4 "Answer: Sorry?
 5 "Question: Preceded but also continued to be used
 6 to some extent.
 7 "Answer: Continued to be used today, is it?
 8 Says Lord Clarke.
 9 Again, the combinations of ignorance and arrogance
 10 characterise that relationship.
 11 In respect of Lord Glenarthur, just a couple of
 12 extracts of his evidence, I characterise them, perhaps
 13 slightly more kindly, as ignorance and dependence in
 14 Lord Glenarthur's case.
 15 He was asked about the Galbraith letter and his
 16 reply was:
 17 "I was not aware and I think, at that stage,
 18 I wouldn't necessarily have been expected to. Looking
 19 back on it I think it would have been very useful to
 20 have been aware of it. But, you know, so much of this
 21 stuff was being dealt with at various levels within the
 22 Department by the experts who understood it all in great
 23 detail and, looking at this list of professors and
 24 others who were involved, they were all, you know,
 25 highly qualified in their field. It's only when

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1 difficulties arose or political interests arose or, you,
 2 know a whole series of things that, at that stage,
 3 I would have thought they ought to be brought to
 4 ministers. But one couldn't, as a minister, get
 5 involved in every single detail on these things.
 6 Looking back on it now, I wish I'd seen this."
 7 The Galbraith letter.
 8 Sir, there are -- again, we could have fun for a day
 9 with the extracts of government ministers' evidence, but
 10 those being more serious about it illustrate the
 11 combination of ignorance, arrogance and dependence.
 12 In relation to clinicians we say, over the same time
 13 frame, initially, of course, the time frame of the
 14 development of non-A, non-B, and then growing awareness
 15 of HIV and its consequences.
 16 We recognise in our written submissions,
 17 particularly at paragraph 221, that you have heard
 18 evidence of what we are happy to describe as both good
 19 practice and devastatingly atrocious practice on the
 20 part of clinicians.
 21 We have described what we mean by that. I won't
 22 elaborate on that any further here, but you have -- we
 23 ask the question in our written submissions, and
 24 I'll ask it again orally here: why did clinicians allow
 25 imported large-pool concentrates to be used in light of
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1 briefly and orally now, is the conflict which there
 2 appears to be in the retrospective justification for
 3 what clinicians did or did not do between the clinical
 4 papers published around and about the 1980s. One relied
 5 on by Dr Christine Lee and others is a paper by Mannucci
 6 in 2003, which is, in effect, a -- I was going to say
 7 revisionist history. No, it purports to be a history of
 8 the treatment of haemophilia, what was known, what was
 9 seen and what clinicians were aware of. But what's
 10 striking -- and, sir, I refer you -- I know you have
 11 read it -- paragraph 253 of our note is the -- we say
 12 inexplicable. So you might find an explanation for it.
 13 None that we know of has yet been ventured.
 14 But in Mannucci's 2003 paper, looking back on the
 15 history of how haemophilia clinicians treated their
 16 patients, he talks about a study which he describes as
 17 being of ten haemophiliacs, no case of progression
 18 towards cirrhosis or hepatocellular carcinoma. Yet when
 19 one looks back at the original 1982 report there were
 20 11 patients in that study originally, not ten. The
 21 11th patient had active cirrhosis and died of liver
 22 failure. And it becomes very difficult indeed to see
 23 how those two papers sit well with each other, unless at
 24 least part of the conscious or subconscious purpose of
 25 the 2003 paper is somewhat revisionist of the history.
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1 what the Inquiry has heard and in light of what we
 2 talked about earlier on, about the prevalence of non-A,
 3 non-B and the growing awareness of its risks?
 4 We suggest in our written submissions that the
 5 answer might lie in the unique nature of haemophilia,
 6 the unusual position that a group of self-selecting
 7 experts in that condition formed themselves into what
 8 was, in effect, their club, determining for themselves
 9 the national strategy in their specialist area. And
 10 unlike other aspects of medicine, these weren't patients
 11 who were seen just once and then perhaps not again for
 12 the rest of their lifetime, these were patients who were
 13 destined to spend their lives in regular contact with
 14 these clinicians, engendering a close relationship, but
 15 also making them an ideal cohort for study, as you've
 16 heard and as Mr Cummins has described in relation to the
 17 Lord Mayor Treloar school.
 18 We suggest that that may well have led clinicians to
 19 lose sight of the particular duties they owed to each
 20 individual patient, and the pursuit of science, we
 21 suspect, may have surpassed the care of individual
 22 patients.
 23 We deal with it a little more in writing, but I am
 24 going to leave it there with an eye on the clock.
 25 One thing which is worth flagging up, and I do it
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1 Sir, those -- apparently I'm talking too fast,
 2 I will slow down for the stenographers.
 3 Sir, there is not much --
 4 **SIR BRIAN LANGSTAFF:** I'm not sure everyone will catch the
 5 speed with which you are giving it, but if you take
 6 a little longer that will be fine as long as it is not
 7 too much longer.
 8 **MR SNOWDEN:** Don't worry, we have reached a point where
 9 I think we are very close indeed to stopping. There is
 10 little more, I think, to be said about -- said here and
 11 today beyond what we have put in writing on the subject
 12 of clinicians and the government. Those, we
 13 respectfully suggest, are some of the highlights.
 14 What I was going to do, but, sir, I know you have
 15 already been acutely aware of, is to invite you to go
 16 back and look at Professor Savidge's report in respect
 17 of Susan Hallwood's son, which, as I flagged up at the
 18 beginning of my submissions to you, puts their clinical
 19 treatment, the boys' clinical treatment, in the context
 20 of those dates, which I've outlined for you now,
 21 identifies shocking -- truly shocking -- failures to
 22 comply with what was known, what was being advised and
 23 what should have been done at the various times.
 24 That is the document which I described earlier which
 25 unequivocally, in Professor Savidge's view, describes
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that treatment as negligent and negligent and negligent.

Sir, I will leave that and come towards the end of our submissions now. We have provided for you as much information as we can synthesizing the views as many of our Core Participants as is possible in respect of the recommendations we invite you to make and in respect of compensation.

I'm going to take it slightly out of sequence. One of the recommendations we make in a small chapter of its own is related to inquests and coronial process, coroners.

We note -- it may well be that it was released only yesterday or it may well be that it made its way to me only yesterday, but the Inquiry has now produced a presentation on coroners. Our main points in respect of inquests are these:

That in respect of inquests which took place in the 1980s and the 1990s, there is real doubt, and there is a conflict of evidence -- it may be that different things happened in different areas and so you don't necessarily need to make findings about it, we don't necessarily invite you to -- whether the obscuring of the true cause of death on death certificates and in coroners' verdicts, as they were, in the 1980s and '90s, was at the behest of families seeking to not broadcast

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first of all, the aspects of medical cause of death, where we see there the coroner has identified:

"1a Liver Failure

"1b Cirrhosis

"1c Hepatitis C Infection Acquired from a contaminated blood product ..."

Then the underlying condition, which is II, haemophilia.

In this case the coroner chose to identify and give a narrative version.

Sir, you will see what is said there. The names are redacted but they don't, I think, need to be redacted. I thought they didn't need to be in this case. What it says is:

"Steven ^sp, known as Steve, Dymond had mild haemophilia A. Between 1976 and 1984 he was treated on three occasions with Factor VIII concentrate, a product developed to treat haemophilia. At least one of the Factor VIII treatments he was given was contaminated with hepatitis C. In 1994, he was diagnosed with hepatitis C. As a result of the infection with hepatitis C he suffered a variety of mental and physical symptoms which impacted on his university education, his career, his marriage his ability to have children.

There was little or no support available and the stigma

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publicly the cause of death of the deceased or, as perhaps is the suggestion through Dr Jones in Newcastle, at the request of clinicians, to save -- possibly at the request of clinicians to save the intensity or the draw on resources at having to attend so many coroner's inquests.

Our submission is, now that we are some distance removed in time from the '80s and '90s, that concern falls away, and a majority -- a good number of our Core Participants have expressed to us the desire that death certificates and coroner's conclusions, as they now are, should be full and frank and unstinting in their attribution of cause of death to aspects of haemophilia care or treatment or hepatitis arising from blood transfusions.

With permission of one of our CPs, I'm going to show you, if I may, one final document, CLL0000024.

This is the record of inquest of a very recent inquest, which you will see. It was opened in March 2019 but not concluded until -- that's interesting. I have not got the date. Never mind. Not concluded until the very end of last year.

It is an inquest into Steve Dymond, the husband of Su Gorman.

What I would like to take you to, if I may, is,

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of the virus created isolation, frustration and sadness at the loss of a life imagined. He subsequently developed cirrhosis, a recognised complication of hepatitis C. He was also diagnosed with cancer of the liver and portal hypertension. Both conditions are complications of cirrhosis."

There is then a further description of the medical treatment that was involved in the final days and hours. If we scroll down to the very bottom of the screen as it shows at the moment:

"Stephen Dymond's death is the direct consequence of being given Factor VIII between 1976 and 1984 which was contaminated with hepatitis C."

Again, I sought express permission to show this and Ms Gorman told me that Steve would have been pleased that something more comes of his death and his inquest.

But that is the sort of verdict which is not only helpful but right and what we do in our written submissions is we invite you to be involved, in liaison with the chief coroner, to encourage the chief coroner to draw up some guidance, to allow the chief coroner to recommend that, when your report is produced, coroners can refer to it and to facilitate the production of, where appropriate, narrative verdicts like this, which properly, truly and honestly, and helpfully, record what

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happened.

So that is all we say on coroners for now. In terms of recommendations, coming close to conclusion, if I may, we have expressed our Core Participants' feelings on recommendations and compensation using, again, three words and we invite you to use language like it, if not the same language, in your report. What they seek is closure, reassurance and financial security.

Closure will come from a combination of, we hope, the findings of this Inquiry and the recommendations made. Reassurance is likely to come from the recommendations made in respect of future treatment and care, and that things will change. The financial security is an aspect of the compensation, obviously, but it is the combination of those three things as we express it in our written submissions, which is what our Core Participants seek. It is to restore their dignity, to preserve their health, and to provide the security that was taken away.

One of our Core Participants, in giving his evidence, said this to you:

"This has been my whole life, even though I try not to let it consume me, this has identified me and has become me for as long as I can remember, even though I have tried hard to live independently of it all. It

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an apology.

Now, sir, again, you heard what I said about an apology earlier on. We still don't know quite what's been apologised for. We are none the wiser, at the end of the exchange of written submissions, at least. We may be a little wiser tomorrow, who knows, I hope we will be.

But, we set out in some detail there the strength of feeling amongst our Core Participants about what should be included in an apology. It is not simply saying sorry, there must be some change of perspective. An apology involves change of behaviour. A reflection that something has gone wrong and is to be changed.

So we look for an open apology in the House of Commons by the Prime Minister and published alongside, to evidence the genuineness of that apology, a long-term commitment to remedy and make reparation to all of the victims of this scandal, the government undertaking not to seek the enforcement of any previous compromises or settlements, as Sir Robert Francis has recommended that what's in the past should be left there and people should be allowed to step forwards, free of it. A Government commitment, accompanying that apology, to create and fund a body comprised of a representative cross-section of Core Participants and groups to

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affects almost every facet and decision in life. There are no winners, no happy ending to this morally impoverished situation. What has happened cannot be changed, the damage done to my community is irreversible, there are depths of pain, you can scarcely imagine until you actually get there. It has often taken my physical health and, more recently, it has taken my emotional and mental fortitude. It has left me a shell of a human being at time. I have often felt broken. I'm just tired."

We say sir, we invite you, and I know you will take up the opportunity, to arrive at a combination of recommendations of practical steps, of recommendations in respect of apologies and memorials, recommendations in respect of compensation, to do insofar as is possible the right thing in respect of the individual -- the cohort that he typifies, so far as possible to remedy that situation.

Sir, I'm not going to dwell, in light of the time in any real detail on many of our recommendations. We provided a number, all of which will reflect back to you what our Core Participants have said to us.

You will have observed that at paragraph 799 of our written submissions we identify some as being the more crucial ones to our clients than others. First, is

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consider annually and review the process of identification of infected and affected persons, their treatment, welfare, their care, their eligibility. If you like, a commitment that an apology means doing something seriously different in the future, that steps should be put in place.

We deal at greater length with the apology in writing.

Memorials. You heard Mr Cummins talk about the stained glass window at Treloar's. That isn't right and it isn't enough. So, again, we describe the significance that would be attached to memorials not simply to be a point of reflection or contemplation or remembrance or grieving, but a memorial also will stand as a reminder or a warning to us all of what can happen when things go wrong. So, in a sense, it is not simply to be a looking backwards and grieving moment, it is to be a salutary reminder to take care for the future, something that can be achieved by a memorial in a public place and the significance that goes with the erection of that memorial.

We also invite you to make recommendations in respect of improved patient treatment, consent, record keeping, tax and practical implications, coroners, we have talked about, and then, having reflected on the

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written submissions put in by others, we are very happy to endorse others' recommendation that there be a task force of some sort to ensure that such recommendations as you do make are properly and thoroughly and completely implemented. So those, in brief, are the recommendations we seek. There are others, of course, in writing.

In terms of compensation, may I spend a moment or two on this. I think I still have 10 minutes left. We come back to the themes, if we may, of closure, reassurance and financial security and this is the financial security aspect. What we suggest is that there is a world of difference, as the Inquiry knows and has heard, between the systems which have pertained to date, which have been no more than support, and the language of compensation, which even in its language recognises that something has gone wrong.

We know and, sir, you know that High Court judges regularly recognise in their judgments in claims in tort for catastrophic personal injuries the possibility of turning back the clock or of undoing all of the effects of a tort, negligence or a wrong, and judges, as indeed you when sitting as a judge would have done, recognise that a financial award of damages in a civil court can never truly compensate an individual for their suffering

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instructed by the Government as an independent reviewer. He has, sir, as you know, immense experience of medical legal work, in conducting inquiries himself. He is utterly impartial. We observe today that there is no obvious good reason for, if you recommend it, the Government not to follow a recommendation made by you and by their own independent reviewer.

As I say, in the broadest terms, we agree with the recommendations he makes. We make it clear, as one of our Core Participants pointed out to us that we hadn't in writing, that we include, as he did, naturally clearers within the compensation scheme for an award that is appropriate for the wrong that they have had done to them, recognising that it will inevitably be of a shorter scale and of a lesser magnitude than others.

We recognise that Sir Robert's proposed framework has many points of reference to how courts work in civil claims, to how personal injury damages or fatal accident damages or clinical negligence damages are assessed. We recognised that what he suggests and we endorse is rather like what those of us with long memories will recall how the Criminal Injuries Compensation Board initially operated when it was set up.

We recognise though that the tension, and we know, sir, that you recognise the tension between something

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of a life-changing injury.

But, we suggest that this Inquiry is in the fortunate and better position than the average High Court judge in that it can improve on the remedies and interaction amongst the remedies that would otherwise not be available to a judge.

By giving closure through your conclusions, by giving nonfinancial remedies and compensation, we use not quite religious but close to religious language and suggest you can achieve, you could achieve, this Inquiry should achieve something closer to the concepts of reparation, or restoration, or restitution, not in a legal sense, and perhaps even using the language of the Reverend David Armstrong in the Haemophilia Remembrance Service, redemption.

You will remember, sir, the evocative language used by Professor Sir Jonathan Van-Tam who referred to his hope that people would be able to create a new future. It is all evocative language but with our -- the submission we make is this Inquiry can come as close as possible to achieving that for those who have been we say so badly wronged.

Coming to some of the detail of the compensation arrangements, we in the very broadest of terms, support the framework devised by Sir Robert Francis. He was

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which can be operated still fairly but swiftly, as quickly as possible, as efficiently as possible, as against, at the other end of the spectrum, a long drawn out complicated unsatisfactory adversarial process.

We don't recommend anything at either of that spectrum but we do recommend something on that scale closer to the legal process, for the very reasons that Sir Robert himself recognised, which are that to have the confidence of those who will be receiving compensation through the scheme, they should be reassured and recognised that it reflects what society as a whole considers to be reasonable and that is reflected in the way the courts themselves assess damages.

I see with some trepidation, sir, that you have removed your mask, which suggests a question is coming.

SIR BRIAN LANGSTAFF: Well, it wasn't necessarily coming but I was wondering whether what you are submitting is that the Irish system takes too long or aspects of it do?

MR SNOWDEN: Aspects of the Irish system might take too long. Our concern though, or the concern that has been expressed to us by the majority of our Core Participants, and, sir, you will appreciate that amongst a cohort as large as ours we have a huge range of views on how compensation schemes should operate, to an

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1 extent, I am trying not to impress my own views on top
2 of my clients' views, my Core Participants' views, to
3 express them to you.

4 The question of whether a system takes too long is
5 a matter of two factors, is it not? One is how
6 complicated the system itself is to take any case
7 through it and the other is how many cases come crashing
8 into it all at once, how many drivers arrive at the
9 traffic lights all at the same time?

10 What Sir Robert has tried to do as we read his
11 report and what we encourage you to do, and what you
12 have already done in part through the first stage of
13 interim payments, is to, so far as possible, seek to
14 satisfy as many of the potential claims as might be
15 possible in a quick and expedient way. What we hold
16 back from encouraging you to do is to say the whole
17 system should be so simple that it becomes so removed
18 from the measure of damages that a court would award.
19 The system by which it is awarded could change but
20 different in measure, we say, would be wrong and would
21 feel wrong and wouldn't give the Core Participants who
22 are going through it the same reassurance that
23 Sir Robert intends them to have.

24 **SIR BRIAN LANGSTAFF:** What you are submitting is that it
25 must bear, as you would see it, a visible relationship
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1 slightly with page 242 and a number of observations
2 about the retail prices index and how things ratchet up
3 from the figures which Sir Robert used to derive his
4 figures for the range of his proposed impact awards.

5 Sir, just to dwell for a moment, because I do like
6 the technicalities of these kinds of things -- to dwell
7 on that for a moment. RPI, of course, is released by
8 the Office of National Statistics every month, there's
9 a further release due tomorrow, in fact.

10 Paragraph 874 of our submissions, page 242
11 identified that, at the date at which we wrote it, never
12 mind the *Simmons v Castle* uplift, which is a matter for
13 you to decide, and we've put down in writing what we say
14 about that and the reasons why we say that would be
15 appropriate to achieve parity, comparability with Common
16 Law damages, but never mind that, as at today's
17 calculation, rather than increasing Sir Robert's figures
18 by 19.3 per cent, retail index prices takes us to
19 a 19.9, virtually 20 per cent increase on the figures he
20 has there.

21 So, sir, that you can get a sense of the comparison,
22 the top of the bracket -- and I bear in mind it is only
23 the bracket Sir Robert proposes while he suggests that
24 a panel might be better suited to assess the precise
25 figures -- the top of his bracket comes out as a shade
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1 to the sorts of awards which a court might give --

2 **MR SNOWDEN:** Yes.

3 **SIR BRIAN LANGSTAFF:** -- without itself being as detailed as
4 a court award and, certainly, not taking as long as it
5 might take to get a court award.

6 **MR SNOWDEN:** Precisely so. Sir, that is exactly our
7 submission. It needs to bear appropriate comparison.
8 Sir, I have set out in writing -- again, today is not
9 a law lecture, you know your law better than I do --

10 **SIR BRIAN LANGSTAFF:** Sir Robert's approach to that was, as
11 it were, was a bedrock award plus personalised
12 elements --

13 **MR SNOWDEN:** Yes.

14 **SIR BRIAN LANGSTAFF:** -- and that, you are saying, your
15 clients would support?

16 **MR SNOWDEN:** Yes, we would. We would. He, of course, has
17 identified -- we make a number of technical submissions
18 which, sir, I know you will have read and I have no
19 doubt you will have understood but which are probably
20 not appropriate to be explored in technical detail here
21 today about, for instance, the damages figure as we
22 might call it. The award figure and what correlation
23 that bears to an award of general damages in Common Law,
24 the function and the purpose of an award of general
25 damages in Common Law and, sir, I probably bored you
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1 over £377,000 as a damages award figure.

2 Sir, of course you will know that the most
3 catastrophic cases proceeding through the court of
4 utterly life transforming brain or spinal injury, in the
5 worst possible situation, today attract awards in the
6 region of about £470,000. So somewhere on the scale
7 between a broken finger and the most catastrophic injury
8 one can imagine, we say it is absolutely right to put
9 these figures very much closer to the top end of that
10 scale and that's where Sir Robert's figures would fall
11 on the current evidence.

12 Sir, we make some other submissions as well about
13 the form of the award, which again are technical in
14 their nature, in relation to periodical payments, the
15 possibility for capitalising, as opposed to annualising
16 payments under a scheme like this but, to put it simply,
17 sir, it reflects a principle which you will have been
18 familiar with in practice and as a judge, which is that
19 while the development of periodical payments in Common
20 Law cases for clinical negligence and personal injury is
21 hugely helpful, in that it can provide a long-term and
22 guaranteed stream of income, it doesn't suit everyone.

23 Some people wish to be cut free from their tort
24 fees, some wish to be cut free from the annual
25 accountability, some people do wish to say "I want once
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and for all to have this settled and done and put behind me, turn 180 degrees and march off in another direction, metaphorically". Allowing people the choice of one or the other or a combination of those, we say, reflects an individual's own preferences and reflects their personal autonomy and that must be, we suggest, a clear component of any compensation scheme.

Sir, I'm not sure there is very much more I can assist you with in respect of the compensation scheme itself. Two further points though. One is this, that a number of our clients have made -- we haven't made in writing -- a substantial number have made strong representations that you should recommend further going back and revisiting of equalling up or parity under the various existing support schemes. That is not to deal with compensation at all, or rather not -- not to ignore compensation but, as a quite separate aspect from compensation, to go back and recommend further changes, or levelling up or parity. Once one starts down that route, it is difficult to see where one can stop, save that there is, perhaps, one step down that route which might be recognised, which is that there are clearly, as, sir, you know, categories of people who have been excluded to date: parents of children, children of parents who died.

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falling within Sir Robert's proposed framework, by which interim payments of £100,000 could, we suggested, also and should also have been made to estates and, in that sense, would then benefit some of the groups currently excluded from compensation or support. Parents would be able to supply in respect of the bereavement of the loss of their child, children in respect of a parent.

Sir, that's the first argument that we put before you. We have already put it in writing. I don't seek to expand on it any further unless you ask me to.

The second is a more radical and slightly broader point which is this, if it is going to take some and if, sir, you share enormous discomfort with the attitudes so far adopted by the Government or the lack of progress towards or the lack of information about progress towards a compensation scheme, and if, sir, you share our real concern that, by acting in that way they have evaded the scrutiny of all of the infected and affected of your team of counsel to the Inquiry and indeed of yourself, in respect of any scheme they propose, then an alternative might be this: that in the course of thinking about and considering your recommendations, insofar as it is possible, you focus first on compensation and that perhaps, as well as recommending further interim payments, you make an interim report

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Sir, there may be, we urge you to consider whether there is, scope to recommend that levelling up, retrospectively, would be appropriate in respect of those classes of people. I say that in the broadest of terms and I say it briefly because I don't want to distract to the main submission which relates to compensation.

SIR BRIAN LANGSTAFF: Do any of your clients want to make a point in respect of those who may have suffered hepatitis B infection?

MR SNOWDEN: We make no specific points about that ourselves but are very happy to endorse the points made by others.

The only thing that then remains is to deal with what I alluded to at the beginning of my submissions, which is the potential that, of course, your report is going to take some time to write, and rightly so, but the potential that there may be yet further delay and passage of time after that before any sort of compensation scheme is implemented and before anyone can apply and benefit from it. So we have suggested, and I'm happy to expand on or happy simply to mention and leave two possibilities.

One is that adopting interim submissions on interim payments, which, sir, I know you have and I won't repeat here, we in that document proposed a logical rationale

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which is about a final compensation scheme.

So, insofar as you, sir, and we anticipate you probably are, going to devise and flash out a scheme, whether it is Sir Robert's Francis's or slightly different, that, as early as possible, that is published, so that while your Inquiry still technically remains extant and there is, therefore, the possibility of calling people back before the Inquiry, you can see and can weigh up the response of Government to your proposal in respect of compensation and can, if necessary, apply the scrutiny that we would invite you to apply to any schemes proposed.

We simply leave those both before you as options.

Sir, I'm not sure beyond that if there is anything usefully I can say with respect of compensation. Of course, we remain very happy indeed to answer further questions on it if you have those but, if not, sir, I was going to do only two things in ending.

The first being to restate -- and I won't restate because it is already on the transcript -- but remind all who are listening here that we invited Ms Grey tomorrow to answer six questions, to clarify six issues for us. That invitation remains open. We will be delighted if it is taken up. If it can't be taken up tomorrow, we might, in due course, invite you to find

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some other time in the next three weeks when the invitation could be taken up. But, sir, we are very serious about our concerns that things should be articulated and made clear in a process such as a public Inquiry.

Sir, finally, we are going to end with a video clip. We are going to end with a video clip of a little boy, a little boy called Lee Turton, the son of Colin and Denise who gave evidence before you. I pause because I don't wish it to be invidious that we picked one Core Participant to particularly remind you of. You know, sir, and you have heard and you remember the heart rending evidence of each and every infected person, bereaved spouse, bereaved child, bereaved parent. There are many other examples we could have chosen, Susan Hallwood, the Smiths in Cardiff, John Peach who Mr Cummins mentioned who, for the first time, became involved in anything to do with this Public Inquiry when he gave evidence about his boys who died, having been exposed at Treloar's.

We could also have focused on others who typify aspects of this scandal which have not yet been remedied, for whom no redress whatsoever has been available, like Lauren Palmer who lost both of her parents.

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parents who lost children who have been excluded from support schemes. Their story represents the long-term effects on parents, as you heard them give their evidence, and I won't repeat it now. It reflects that there have to date been no interim payments for those parents.

Lee died at the age of 10. He died 31 years ago, almost to the day. They have waited that long. But for the utterly unacceptable treatment he received, he would have been a man of 41 today.

Sir, we recognise that there is an absolutely essential job of legal analysis to be done, I hope we have said what our Core Participants want. I know that others will focus on different parts of analysis but this is not all about lawyers. This is not at all about lawyers. The Inquiry is not about lawyers. I cannot think of a better way to give him and his family a voice than to end with him not me.

This is what pharmaceutical companies, clinicians and the Government have caused. This family's ongoing torment is as a result of Government delay, denial and failure to take responsibility and this is what all the words we have written and spoken like in real life.

(Video played)

MR SNOWDEN: Thank you.

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But this particular family story, which you will remember, so I do no more than summarise it, illustrates so many aspects of what we have said in our submissions today, Mr Cummins and I. It represents the huge number of children who were infected by this scandal. He, Lee, was one of the estimated 380 children who were given HIV.

He, Lee, typifies the story of children being given concentrates when they should not have been. His initial assessment was that he was no more than a mild haemophiliac, 7 per cent, initially on cryoprecipitate as a baby, his parents were then told it wasn't available and they had to have concentrates from March 1982 when he was ten months old.

He continued to be given concentrates through '83, '84 and '85. He was HIV negative in February '84, positive by March '85. That story resonates with so many others that you have heard and so many other witness statements you will have read. But the family story also illustrates the stigma for the family, press intrusion about his school. Despite asking the GP not to tell the school, the school found out, the family had to move to avoid stigma and abuse.

It also represents the fact that the child's life has not yet been recognised for compensation, the

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SIR BRIAN LANGSTAFF: Thank you very much indeed.

We need a break. We will take it until 3.55 pm.

(3.30 pm)

(A short break)

(3.55 pm)

SIR BRIAN LANGSTAFF: Yes, Mr Bragg.

Closing submissions by ANDREW BRAGG

(A Core Participant)

MR BRAGG: Good afternoon, everyone.

Firstly, Sir Brian, I would just like to say thank you for giving me the opportunity to contribute to this Inquiry. It is very important to me and I hope that I can add to the learning and to the recommendations that come out of it.

Also thank you to the team, who have supported me all the way through this and been very helpful, and I appreciate that.

So what I'm going to do today is just basically talk around my recommendations to the Inquiry. I have made three. In my submission in November they were very short and succinct. What I want to do is just add a bit more flesh around that, to say why I have arrived at those conclusions.

So I'm going to work through a repeat of my background, for those who were here when we were talking

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1 about the Skipton Fund, it will be a refresh on my
2 experience of hep C, a bit about my profession and what
3 I do for a living, and then how my professional
4 expertise has come into play every time I have been
5 interacting with the Health Service, and then how that
6 has shaped the recommendations. And I will run through
7 the recommendations.

8 Starting with hep C, I had a road traffic accident
9 in Norway on 18 August 1986. I rode into a tunnel on
10 a motorbike and it had no lights on it, it turned right
11 and so I went straight into a wall. I was treated in
12 hospital in Bergen. Excellent. They saved my life
13 probably. They definitely saved my leg.

14 I was discharged from Bergen, got flown home, went
15 into the hospital in Liverpool for a couple of days and
16 then I was in outpatient care in Liverpool until January
17 1987.

18 I had two operations there. One to take pins out my
19 feet, my whole foot and ankle together, and then screws
20 out of my shin. I had a nail, metal nail -- about that
21 long -- that went from my knee to my ankle which held my
22 right leg together.

23 In February '87 I started work again in Lancashire,
24 so I moved to Blackburn Infirmary. In October of '87
25 they decided to take this nail out of my leg, and that

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1 Newcastle rang me up and said, "There is a clinical
2 trial, some new drugs for the NHS, are you prepared to
3 go on this trial?" I said yes. So a bit later that
4 year I started interferon ribavirin therapy. That was
5 48 weeks of -- hell is probably the best way of
6 describing it. But at the end of that I cleared.
7 I didn't have hep C anymore.

8 So three negative PCRs and I was discharged.
9 However, I did have an awful lot of ongoing issues as
10 a result of having hep C. So I had liver fibrosis,
11 I had non-alcoholic fatty liver disease. My liver
12 function tests were still typically over three times the
13 normal max, so running about 130. So obviously there
14 was still inflammation going on. My heart rate was
15 between 110 and 120 sometimes and my blood pressure was
16 very concerning for the doctors.

17 So I had been on medication since 2002. The
18 interferon really scrambles your immune system. My
19 expectation was I'd get through the interferon and it
20 would return to normal. It didn't. So I am still very
21 vulnerable to infections. So I get infections every
22 year. And every other year or every third year I get
23 very severe infections. So I have had sepsis three
24 times, been hospitalised with pneumonia. My last one
25 was 2019 where I got what was called ESBL, which is a --

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1 was a major operation, and I definitely am aware that
2 I had a blood transfusion after that, because I remember
3 waking up with antibiotics with blood and a third bag,
4 I didn't know what it was.

5 I was diagnosed with hepatitis C in 1999. I worked
6 for ICI, I had been working with ICI India on a project
7 there and I got ill. When I came home I didn't feel
8 well at all for a long time. ICI had an occupational
9 health team so those doctors really wanted to know what
10 I had had in India. So they kept looking and looking
11 and looking and eventually said, "We can't find anything
12 which might be attributable to what you had in India, so
13 we will widen the scope".

14 The next thing they said was, "You've got a problem
15 with your liver."

16 And a few weeks later they said, "You've got
17 hepatitis C, here's a letter, go and talk to your
18 doctor."

19 So at that point I came under the care of the
20 regional liver unit in Newcastle. They confirmed the
21 diagnosis. They informed me that I would not receive
22 any treatment because it was too expensive. So for the
23 next couple of years I went every quarter to be told
24 that I still had hepatitis and nothing was happening.

25 Eventually, in 2001, Professor Bassendine in

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1 doesn't respond to antibiotics. So I was very ill and
2 the message I got through my GP was that the hospital
3 would not admit me unless I was critical because they
4 would have to create a special isolation area for me.

5 So I did manage to get through it, thankfully, but
6 you do live in reservation about what your next
7 infection is going to do to you.

8 I also developed type 2 diabetes in 2017. That's
9 probably liver-related because when I started taking the
10 medication my liver function results declined. So I'm
11 only two times the max now.

12 So there are a number of things. That means over my
13 time over the last 20-odd years I have had a lot of
14 contact with the Health Service.

15 Now, my professional background is I'm a chemical
16 engineer. I'm also a chartered scientist. So I started
17 work in the chemical industry in 1976. So I've spent
18 all my working life working in the chemical industry,
19 which is all about high hazard chemicals. These are
20 things which could seriously impact both our employees,
21 our neighbours and people who use it. So we are very,
22 very focused on managing safety, on understanding risk
23 and taking those actions to make sure that had we
24 controlled those risks such that we don't impact on
25 people.

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1 And, you know, sort of through my background,
2 because I started as a chemist and then between '82 and
3 '86 I did a chemical engineering degree, I have worked
4 with regulation all my life, understanding regulation,
5 implementing regulations. I've worked in manufacturing,
6 I've worked in research, technology management, business
7 development. And currently, since 2008, I have been
8 looking after sustainability for the company. So my
9 official job title these days is global sustainability
10 and regulation manager.

11 I work for what was ICI and is now part of a big
12 Japanese company.

13 So, in my working life I deal with regulation,
14 I have to understand the implications of regulation and
15 also understand how regulation can be managed within the
16 company: how do we deal with it? How do we make sure we
17 deliver against it?

18 Alongside all these roles I have also been a lead
19 auditor. So I audit our operations globally for safety,
20 for manufacturing effectiveness, for project
21 effectiveness. So understanding organisational systems.
22 So I'm quite experienced in actually visiting somewhere,
23 it might be a couple of days or a week or so, but going
24 in and understanding how well that organisation is
25 functioning.

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1 audited in a very rigorous way and all our failings will
2 be exposed and we will be expected to put it right and
3 make sure it never happens again.

4 We also have external inquiries, like this one. So,
5 for example, when Piper Alpha happened, 185 people died,
6 and the learning for us was really significant from that
7 inquiry, because we weren't getting it right. There
8 were real opportunities to do things in a far more
9 professional way, and so -- not just the oil and gas
10 offshore industry but the chemical industry had a real
11 big stand-back and we really re-visited how we managed
12 the personal safety of everybody our operations impacted
13 on. So inquiries like this can actually be a very
14 significant vehicle to drive change, to drive
15 improvement.

16 If we think of the aviation industry, nobody gets on
17 an aeroplane and expects the crew to wing it
18 essentially. They expect the crew to work together, to
19 use checklists, to make sure that they are doing
20 everything that they need to, that they are highly
21 trained so if something does go wrong they know what to
22 do. We expect that. And yet those practices, those
23 ways of working I don't see very much of in the NHS.

24 So that concerns me.

25 So what have I seen when I look at the NHS? Number

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1 So every time I have been with the NHS I have been
2 a professional observer of organisational systems. So
3 I have been looking at how the medical teams who are
4 treating me are functioning. It is not always a very
5 pretty picture. So there are lots of examples of
6 where -- poor team working, poor communication,
7 unsystematic working, working from memory -- so lots of
8 boxes which, in my business, we would not accept but
9 seems to be fairly routine in the Health Service.

10 The type of things I'm looking for is not really
11 specific to my industry. There are lots of industries
12 where you face complex challenges which potentially put
13 lives at risk. So the chemical industry, oil and gas
14 industry, offshore, nuclear industry, aviation, building
15 complex structures. In all of these, managing risk,
16 managing personal safety, managing the safety of third
17 parties is absolutely the core of what you do. But
18 I see very little of that thinking in the NHS.

19 So, how do we end up so good at this and perhaps NHS
20 not so good? Well, we have external regulatory drivers
21 that keep us honest. So in the UK we have the
22 Health and Safety Executive. So they are responsible
23 for managing safety for all businesses, operations in
24 the UK. So if we have an instance or an accident which
25 results in serious harm or death, we will be externally

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1 one is that it's a firefighting organisation. The
2 typical type of working is they are presented with
3 a problem: you've got a patient, you deal with it, the
4 patient moves on, you forget about it. There is no
5 learning, there is no improvement, you've just got
6 a series of patients that walk past you and you deal
7 with it and then you walk away.

8 Now, that's actually very common in most
9 organisations but it is very uncommon in highly
10 effective organisations. Highly effective organisations
11 don't work in that way. You know, you have very
12 systemised approaches. You understand where the risks
13 are, you put in practice the processes and procedures to
14 do things safely, to do things consistently.

15 You audit. If you have an incident, you investigate
16 it, you report it, you learn from it and you apply those
17 learnings. That's how you get to be good. If you don't
18 do that, you are not good. So I see in the NHS
19 an organisation which is crying out to actually drive
20 towards being a better organisation, a more highly
21 effective organisation, a less dysfunctional
22 organisation as it is the moment, but there doesn't seem
23 to be any ambition to do that.

24 So some opportunities I have noted as a patient,
25 very unsystematic. So people, doctors particularly,

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1 work from memory. So if you think of a pilot, you don't
 2 expect a pilot to remember how to fly an aeroplane and
 3 all the checks you need to do because you learned it at
 4 flight school. 10/15 years on, you need something which
 5 reminds people how to do things. We called it standard
 6 operational procedures. You actually put down in
 7 a one-size page, these are all the key things you need
 8 to get right and these are the things you need to check
 9 before you do something. They are called "checklists".
 10 Checklists are very common. The aviation industry has
 11 them all over the place. I don't see it. I just really
 12 don't see it.

13 You need team working. You need teams to come
 14 together, cross functional teams. The NHS is a classic
 15 where you have got lots of different functions. You
 16 have got lots of different types of doctors. You have
 17 got different types of nurses. You have administrators.
 18 It is a very technical world these days. More and more
 19 complex machinery is required to support treatment. But
 20 it is also an organisation that has a lot of individuals
 21 in it that don't really work together. They gather in
 22 groups but they don't bond as a team and, even more so,
 23 they tend not to communicate very well. I have sat
 24 there and watched big gaps in communications where
 25 people either have done things or not done things and

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1 a surgeon. He was intrigued by checklists. They didn't
 2 use them in his hospital but he was intrigued by it. So
 3 he took the time out to go into is the aviation industry
 4 and construction industry and saw how they used it and
 5 he thought there was some potential.

6 The World Health Organization then approached him
 7 and asked him to be part of a team that looked at what
 8 would the impact of a checklist in surgery across
 9 a range of hospital globally, so it was a project run by
 10 the WHO and he was involved in setting up the checklist
 11 and the process to monitor performance before the
 12 checklist and the performance after.

13 And the experience was from that that the rate of
 14 error, the rate of failure was relatively high. They
 15 were looking at perhaps 30 per cent error rate in the
 16 operations they monitored in the two months before they
 17 started the study. After introducing checklists, they
 18 halved it. Less than 15 per cent, and that was just in
 19 a relatively short period of time.

20 So they were enthused. One of the hospitals in the
 21 UK -- now that was in mid-2000s, 2005 and 2006 and you
 22 won't see that much in hospitals: very successful, lots
 23 of opportunity, no learning, no implementation.

24 So if you get an opportunity read this book, I will
 25 reference for the Inquiry team but it is well worth --

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1 certainly haven't communicated around the rest of the
 2 team, so mistakes have been made. You have to think
 3 about it and work on it.

4 They certainly don't measure and they certainly
 5 don't measure what goes wrong, so there is no overview
 6 of how well they are doing. I don't see any real
 7 systematic approach to learning from mistakes, trying to
 8 pick up on what you could do better next time and then
 9 introduce it in your team and then try and spread that
 10 out across other teams, and we got hospitals all over
 11 the world, they are all going through this, they should
 12 be pretty good at it by now but they actually don't seem
 13 to be.

14 As an overview, my view on the NHS is it is not
 15 a learning organisation. It is a firefighting
 16 organisation that just lives day to day. It needs more
 17 systematic and standardised approaches to reduce that
 18 potential for making errors and mistakes and they need
 19 much better team working and communication, they need to
 20 work at it, they need to recognise the value of team
 21 working.

22 I would recommend that, if you get the opportunity,
 23 if you read this book, it is very enlightening, it is
 24 called The Checklist and it is written by a guy called
 25 Atul Gawande, who is a doctor in America, he is

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1 because it is quite revealing in terms of the thinking
 2 that doctors have about how they manage what they do
 3 professionally and the impact a checklist might have on
 4 actually making things better. So good book. Recommend
 5 it.

6 Quick observations about the NHS. This is more
 7 general, rather than my specific "I have experienced
 8 this". The NHS culture towards openness and reporting
 9 professionally appalls me. The fact that the NHS can
 10 suppress whistleblowing, that they can bully, intimidate
 11 whistleblowing, that they can legally hamstring people
 12 to prevent them from expressing their concerns is
 13 extremely unprofessional, extremely unprofessional. You
 14 need -- we encourage our staff to be open, to report to
 15 us, to tell us, when things are going wrong because they
 16 are the people who see it happening.

17 The culture you create by doing this stops it. Now,
 18 it is not just at local level. It is in the press, so
 19 everybody knows about it, so this is being approved,
 20 effectively, from top down. A bit like the old saying
 21 that the fish rots from the head. For me, we need to
 22 put a stop to this. We need to make sure that anybody
 23 who has a concern in the NHS, they feel they can express
 24 it. If somebody is doing something which is malicious,
 25 then all the disciplinary measures in the world already

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exists to deal with that, so what you are suppressing is people who have concerns about what they are doing in their profession. So we need to make that more open, we need to make sure that organisations cannot close down that type of thing.

The other thing is about responsibility for outcomes. There have been lots and lots of inquiries into things that have gone wrong in the NHS and what do we hear? We always hear there is an apology, "We are very sorry, we promise we will never do it again", and yet there is no learning, there is no implementation and you can guarantee there is every opportunity that they will do it again because they haven't actually addressed the issues that were identified.

So, organisations need to take responsibility. Things do go wrong, it is inevitable, but you have to own it, you have to recognise it and you have to deal with it.

Right now, the NHS is not in a safe space in terms of that aspect of its organisation. It needs responsibility, it needs to accept and deal with when things go wrong.

I have got an example of something which doesn't relate to this Inquiry but something which triggered something in me. There was a lady called Louise

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my observations.

I make one comment, that my first two recommendations are both generic because they relate to a much wider problem in the NHS but they are also specific to this Inquiry because my belief is if my first two recommendations had been implemented early enough on, we would not be here today. This Inquiry would not need to have been constituted because the problem would haven't have existed. So, yes, they are very generic in terms of this is a problem which is NHS wide, but it is also specific to this Inquiry in terms of it relates to why we are here today and why did it go wrong.

Slide number 1. My first recommendation is about creating a statutory responsibility for all employees in the NHS to form a report when serious injury or death has incurred which might have been preventable. So something has gone wrong. There has been an area, there has been a mistake. There is an opportunity to do something. There is an opportunity to not do something and, as a result, an individual has received harm which was avoidable.

The background to this is that some of the things I've talked about, about use of standardisations and checklists, and all that, there is a whole gamut of

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Dempster, who was part of the East Kent Hospital Trust Inquiry. She gave birth in May 2015 and the labour went wrong and she had to have a caesarean. Her son was born large and healthy but she had a massive haemorrhage afterwards and probably if her mother, who was a trained nurse, hadn't have been there, she would have probably died.

The surgeon told her the bleeding was due to the size of her son. For seven years the Hospital Trust maintained that it was her baby that was responsible for her haemorrhage. She gave evidence to the Kirkup Inquiry and in that Inquiry the chairman called her and said he had discovered a document which had not been disclosed to the family and in it it was evident that the hospital knew it was as a result of surgical error and for seven years had lied to her.

So the report found that staff had omitted key details in accounts given to families, effectively covering up the truth. To me, that is a good example of responsibility. Something went wrong, you have to own up to that. You don't cover it up, you own up to it.

As a background, this has guided me to sort of think about what does -- what have I learned, what would I recommend to this Inquiry and so my recommendations have been shaped by that thinking and my experiences and

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things that needs to happen to make the NHS better. I'm just focusing on one aspect, which is about reporting. Right now, there is very little reporting into what happens in the NHS. So, there is no current accurate estimate of how many avoidable injuries of death occur at all within the NHS. No reporting at all. There's a paper from the London School of Tropical Medicine. They estimate that about 10 per cent of patients suffer harm and about 5 per cent of deaths are avoidable.

The fact that there's a couple of papers around, which are roughly all in the same area, which suggests maybe 5 per cent avoidable deaths but the NHS itself has no records at all of how many instances it has and how they are ranked, is a huge gap and omission that needs to be corrected. It does not happen in my industry, it doesn't happen in other industries, so I believe there is a real need to create a mandatory reporting, bottom up. So it is the responsibility of staff to record -- to report when something goes wrong.

I have got an interesting quote from Jeremy Hunt MP, who got talked about a little bit earlier on in the day. This comes from something called the Health Care Safety Investigation Branch, which was formed in 2017. It will shortly become slightly larger in branch but it's going to be charged with investigating things in the NHS. But

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in one of their articles, Jeremy Hunt had attended the seminar that they ran. This is a quote from the article, this is 8 June 2022:

"So Jeremy Hunt described arriving in office in 2012 when the Mid Staffs Inquiry was in progress. He told us at that time he knew very little about patient safety. He recalled being told that 10% of patients are harmed as a result of their care and that is just how it was. He learned that of all deaths 4% are potentially avoidable. That is 150 patients per week dying unnecessarily."

That is the equivalent of an airliner falling out of the sky every fortnight and yet it wasn't even spoken about and we are still in the same position today:

"He described the overwhelming feeling that it was just wrong and he had to do something about it."

So we are talking about 2012 and we are now in 2023 and nothing's really changed yet.

Now, if we think of Boeing as an example, the 737 MAX that -- Boeing lost two aeroplanes. So that's the equivalent of one month's deaths in the NHS which are potentially avoidable. You know, potentially avoidable. It is very difficult to -- without definitive information it is difficult to quantify.

But what's happened to Boeing? Boeing's share price

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actually very ineffective, because most people don't follow it through. If you've got a reason why you can avoid doing something, you avoid it. Statutory requirements, regulatory requirements have to be followed, so people do it. So very much we need a regulatory approach.

It needs to be at local level. Observation of the NHS is there is lots and lots of different regulatory bodies but they are all at very high organisational levels, and whether or not their objectives filter all the way through to the ground level is a really moot point.

If you require reporting of every incident, that reporting inevitably has to be at local level. So at local level you drive transparency. You drive the ability to report without fear of anything going wrong or being victimised. That you investigate it. That the information is openly available.

So you take responsibility that: an error has occurred and we are going to do something about it, because the numbers are out there. That will drive doing something.

It just so happens that there is as regulation in the UK that will do that. It is called The Reporting of Injuries, Diseases and Dangerous Occurrences

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has halved. The sales of 737 MAXes was halted for almost two years. They have had to completely redesign the elements that were non-functional, weren't working well. And that's for a few hundred people, when we are talking about thousands of people in the NHS.

The driver to do something is very, very significant. We are blind to it because it is not measured and reported and it is not reported openly. So my first proposal is very much about driving that reporting and putting that into an open, transparent arena, so we all know about it.

If what happened to us in terms of hepatitis C and HIV had been reported as an error and a mistake and it was in the public domain and there had been investigations to try and -- we wouldn't be here now, they would have dealt with this years ago. But they didn't do that, they didn't publish the numbers, they hid it, they obscured it, they destroyed the data. That's not an open and transparent organisation.

Well, inherently if the organisation is not open and transparent, which would appear the NHS isn't, then you have to create a statutory driver for it to happen, because they are not going to do it on their own volition.

So my experience is that voluntary initiatives are

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Regulations, which was last updated in 2013. It is called RIDDOR.

Anybody in industry is very familiar with RIDDOR. That's what we report against. It is run by the Health and Safety Executive. If we have an injury that falls into the RIDDOR classifications, by law we have to report it.

Now, it just so happens, and this is the bit I didn't understand until I was looking into this, that RIDDOR actually applies to it the health and social care sector as well. So there is an existing piece of legislation which should apply to the Health Service.

During my admittedly limited snapshot survey into doing this I actually found some very effective RIDDOR reporting flowcharts in some hospital trusts -- for employees only. RIDDOR also applies to patients. We are a third party under the care of that organisation. So if we are adversely affected by something that happens in the hospital such that it falls into dangerous occurrence or death, it should be mandatory reporting. It isn't at the moment.

So if we could drive RIDDOR reporting in hospitals in an effective way, then we would start flushing out all these incidents. And it would have stopped us being here today, because this would have been open public

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domain information 30 years ago.

So it is the type of thing that I would see for this Inquiry as a really beneficial outcome. It is part of driving the change that needs to happen in terms of turning into a more responsible, more effective organisation.

You have to care about patients. It would appear to me at the moment that it is an accepted fact of life in the Health Service that patients are harmed or die and that's just the way it is. We have got to change that. We have got to break the cycle. If doctors who have signed the Hippocratic Oath, which is do no harm, can actually accept that they are doing harm and just shrug their shoulders and walk on, you have to break that perception. So regulation is the only way for me.

RIDDOR should actually solve that problem. My proposal 1 should be a relatively simple thing to implement, which is: patient safety is RIDDOR reportable. The key thing is how do you make sure it is rigorously enforced? How do you make sure that at ground roots level it is not ignored? That it is taken seriously?

That's probably the difficult question in all this: how do you make your medical teams comply with RIDDOR such that all those incidents are flushed out?

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safety investigation branch which Jeremy Hunt gave the quote to.

Now, they have carried out -- they reported about 22 -- issued about 22 reports so far between 2017 and 2022. They've looked at probably a hundred. It is important to recognise that they are probably a useful adjunct to actually investigating things, but they will do it on a higher level, a group level, that the real responsibility to investigate is actually at grassroots level, where the incident happened.

So if you have the combination of the Health and Safety Executive collecting and driving for this information, you have this new HSSIB body as an extra internal Health Service expertise to recognise there are systemic problems, group problems or wider problems, which perhaps might be better dealt with as a group, but fundamentally you need to get right down to the ground floor in the organisation, the individual teams in the hospital where things are happening right now, be it the surgical teams or in the intervention teams in the wards. So getting their involvement and engagement will be key.

I'm not proposing how you do that but it is absolutely fundamental to making this work.

Those are my first two recommendations, which is

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Now, in my industry we are way beyond stopping deaths or stopping serious injuries; we are into near miss reporting. These are the things which have gone wrong. Didn't result in any harm or adversity but could have done, had the potential to do. So there is a pyramid of where you start with death and then you go into serious injury, then minor injury and then -- you know, we are driving down into the bottom of the pyramid. We've got to get that culture where we have that responsibility and ways of working into the NHS, so people see it is part of their job to look for errors and report errors and make sure it doesn't happen again.

So if we use RIDDOR -- slide 2 -- my second proposal is about creating a new organisation within government who has a responsibility to collect this information, to investigate incidents and make sure that effective action has been taken.

Well, if we use RIDDOR, the Health and Safety Executive automatically is that organisation, it is already existing. It does it across the UK as a matter of fact anyway. So it is just an extension of existing responsibilities.

But there is this new body being formed later this year called the Health Service's Safety Investigation Body, and it has been formed out of that health care and

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really trying to drive out and trying to stop things going wrong. Avoidable errors, preventable errors. Because when they say "errors", it is actually meaning harm to the likes of you and me.

My final proposal is actually a bit more personal, which is really having an effective, joined up way of monitoring people who have suffered from hepatitis C. So my experience was that I got diagnosed and put on the shelf for a couple of years. I got the treatment. I had three negative PCRs and I was discharged from the regional liver unit. No interest.

My GP didn't pick me up as being anything special, I just came back as a patient. The local hospital didn't pick me up. So I had been in, like, limbo land since 2002, 20 years. Yet, there is a whole series of potentially serious health problems that I am experiencing and might get worse and there is no overview of monitoring me, making sure that I'm on track.

So my proposal would be, if you get diagnosed with hepatitis C, there is some system that captures all individuals and monitors them regularly against best practice for both health monitoring and early identification of potential consequences.

So my experiences is that I have to get to hospital

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1 admission stage before anybody actually reacts and
2 I don't think that is right. It is predictable that
3 I've got a whole series of things that are wrong with
4 me, from having hep C, that will result in complications
5 and will result in me getting ill regularly, and yet
6 I always feel I have to fight my GP even to get
7 antibiotics.

8 Twice, I have self referred myself to hospitals.
9 The first time was in 2015 when I had had sepsis,
10 biliary sepsis, and the consultants in the hospital told
11 me I had cirrhosis. Now, that was a surprise to me.
12 I knew I had fibrosis but I didn't know I had cirrhosis
13 but that was it. Nothing else happened. When
14 I questioned the hospital: not interested. The doctor:
15 not interested. So I got in touch with the regional
16 liver unit and I contacted the head of the unit,
17 described what was going on and asked if they would see
18 me. The answer is, "Well, if you get referred by your
19 GP yeah we are happy to see you". My GP was not at all
20 happy to refer me. Not at all.

21 So I had to lean on them. It turned out that their
22 diagnosis was that I was still at fibrosis stage,
23 I hadn't got to cirrhosis, which was a great relief but
24 I shouldn't have to fight to get that. That should be
25 something that just was a routine consequence of dealing

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1 it would still be below the level which a GP would
2 recognise as having an infection. He recognised that in
3 my case I should have antibiotics on a more routine
4 basis. I got that letter, the GP got that letter,
5 shortly after that, I got this ESBL infection and the
6 same GP who had received the letter came to see me at
7 home and wouldn't prescribe me antibiotics. When
8 I mentioned this letter she said, "That's not for us,
9 that is for the hospital".

10 So it is not joined up. So this is really saying
11 "Can we please have a joined-up health approach to
12 people who have had hepatitis C". Now, I'm talking from
13 personal experience here. I don't know what the
14 experience of everybody else is, so some people might
15 have had a wonderful time but I'm guessing there are
16 quite a few people like me out there. So just having
17 a standardised approach to doing it would actually
18 really help and would certainly make me feel a lot
19 better and less at risk.

20 So these are my three recommendations to the
21 Inquiry. I hope that it fits in with the type of
22 thinking that you have already seen. I believe it would
23 be conclusions that might actually support the wider
24 output from the Inquiry. Of course, if you have any
25 questions, any queries, please ask. I'm more than happy

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1 with my condition.

2 The second time I referred myself was -- every year
3 I get infections. Sometimes they are just debilitating,
4 sometimes they are really serious and I get
5 hospitalised. It really detracts from the quality of
6 life and it can be quite worrying. I wanted to know why
7 I was getting these infections. I could not get
8 a sensible answer out of the GPs. The GP would not
9 refer me to any higher authority. So, again, I got in
10 touch with the consultant in Newcastle, the consultant
11 immunologist, described what was happening and got the
12 same -- "Yeah, of course, we will see you, just get the
13 GP to refer you". The response of the GP was "You can't
14 do that, we are trying to reduce referrals. I will have
15 to refer this to committee".

16 So I don't know what committee. But, eventually,
17 I got there and it turned out that in your base immune
18 system there is basically four proteins and, in my case,
19 two of those proteins are at very, very low levels. One
20 of them called the c-reactive protein is actually
21 what -- if you go to the doctors with an infection, they
22 will take a blood sample. What they are doing is taking
23 a sample to measure the CRP level.

24 What I was told by the immunologist was that my CPR
25 level naturally was so low, even if it went up 100-fold,

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1 to add and embellish on this.

2 So closing, thank you for giving me the opportunity
3 to be here today and I wish everybody here the very best
4 and good luck to us all.

5 **SIR BRIAN LANGSTAFF:** Well, that says it all, I think.
6 Thank you very much.

7 Now, I won't ask you because I normally ask
8 Ms Richards but she is here, so I will ask her: who are
9 we seeing tomorrow?

10 **MS RICHARDS:** So tomorrow, sir, we have closing submissions
11 by Ms Grey on behalf of the Department of Health and
12 Social Care and no doubt we will wait and see whether
13 Mr Snowden's questions receive any form of response.

14 Then we have a closing statement by Barbara Scott
15 who, like Andrew, is an unrepresented Core Participant.

16 **SIR BRIAN LANGSTAFF:** Thank you very much. I think that
17 probably was in part for you but mainly for those who
18 have given us presentations today.

19 **MS RICHARDS:** I think so too.

20 **SIR BRIAN LANGSTAFF:** Until tomorrow at 10.00.

21 (4.42 pm)

22 (The Inquiry adjourned until 10.00 am on Wednesday,
23 18 January 2023)
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