Friday, 20 January 2023

(10.00 am)

Closing statement by MS MONAGHAN KC
on behalf of 4 individual Core Participants

SIR BRIAN LANGSTAFF: Yes, Ms Monaghan.

MS MONAGHAN: Good morning, Sir. Good morning.

Sir, I speak a behalf of four Core Participants, Mr AK, Paul, Robert James -- whom I shall refer to as Robert -- and Mr AH, all of whom gave evidence before you, Sir.

They have asked me first, please, to thank you, sir and the whole of the Inquiry team for the way in which this Inquiry has been conducted. They have asked me to convey in their own words that they have during this Inquiry felt listened to, treated with respect and felt safe in participating.

They have also asked me to say something about the participation and conduct of the Department of Health. The Department of Health and Social Care, of course, are centrally involved in the events being examined in this Inquiry and bear responsibility, we say, for much of what occurred, that is an avoidable catastrophe leading to the deaths of hundreds of people, pain, hurt, life-changing infections of many more, and profound distress and bereavement of yet more.

The Department of Health, as you will recall, were allocated four hours to make closing oral submissions. At some point beforehand, it appears a short time beforehand, they apparently indicated that they needed only an hour. That is, the Department of Health, they, chose to limit their oral submissions -- before a public hearing, at the end of a public inquiry, addressed to those infected and affected in the room and listening remotely, they decided to limit their oral submissions to a mere 35 minutes.

Indeed, Sir, if one takes out your questions, probably more like 30 minutes. My clients consider that derisory, contemptuous and disrespectful. I hope it is clear -- I don't think Ms Grey is here -- but I do hope it is clear that's not a criticism of Ms Grey, that's the Department of Health. But perhaps even worse for my clients is the vacuousness of the purported apology.

You will remember, Sir, and it is perhaps important to remember, that the Department of Health made an opening statement, and when they made their opening statement in the Inquiry hearing room, they were listened to carefully and respectfully by those here, and those included people who had a right to be angry with the Department of Health and, if they had expressed that anger there and then, they could probably have been

forgiven for doing so. But they listened. They listened graciously, courteously and carefully.

As you will recall, Sir, those in the room expressed -- indeed, expressed their warmth at the involvement of the Department of Health, or at least their counsel, for all to see. You may remember that, Sir.

In that opening, four and a half years ago, as you picked up on Wednesday, Ms Grey said on behalf of the Department of Health that her clients accepted things went wrong, things happened that should not have happened, and so she said, on behalf of her clients, unreservedly -- unreservedly -- that they were sorry and that they were sorry that this happened when it should not have happened.

In their closing submissions too, they said that things happened that should not have happened and that they did not depart from their unreserved apology for the fact that that was so.

On Wednesday, Ms Grey referred to the sincerity of her apologies and to do what can be done to provide some real and practical assistance. Sincerity of the apologies. When asked by you, Sir, what wrong the Department had in mind when acknowledging a wrong, Ms Grey was able to say only that the Department didn't

have a position to offer you. There was no meaningful then, Sir, admission of wrongdoing, no meaningful apology, they were empty words and the Department of Health through Ms Grey is unable to explain why they admitted a wrong when they say they didn't know -- are unable to identify what wrong that might be.

It is difficult to think otherwise than it was an endeavour to close things down: "There, we have apologised, that's the end of it". And it was only when you inquired, Sir, following Mr Snowden's raising of the issue, that something apparently had gone wrong and Ms Grey was stumped in answering the question.

My clients consider the Department of Health's conduct deeply and grossly offensive. That might be one thing. But it causes them concern too, Sir, about what the Department might do in response to this Inquiry. I will come back to that at the end but it is an important matter that these are vacuous apologies, empty admissions and a contemptuous response to an important public hearing ending this Inquiry.

Before I come to our substantive submissions, there are two further introductory observations I would like to make. First of all, again, it concerns the Department of Health but a rather different point.

In their submissions, Sir, the Department of Health refers to the passage of time and the impact on memory. I don't need to go to that but, for your note or for the note of anybody who might be interested in reading it, that's at paragraph 1.16 of their submissions. They refer in particular to discussion in the case law on the process of setting, resetting and rewriting and the limitations of memory.

My clients would like to remind the Inquiry, please, Sir, and no doubt you will have this well in mind, that for those affected and infected, their experiences are very much seared into their memory in a way that might not be true of others. But it is certainly true of them, and they have continuity of memory because they live with their experiences every day and the recalling of them is not punctuated by larger lapses in time.

So for that reason, Sir, it is our submission that considerable weight should be afforded their evidence.

Second, Mr Snowden has expressed disappointment with the way in which the pharmaceutical industry has chosen to respond to this Inquiry. As Mr Snowden said, it is understood that the companies that might be expected to engage are following the Inquiry but have chosen not to actively participate.

This has meant that the examination of the pharmaceutical companies, that I am sure everybody would

have wanted to see and hear, has been lost, through no fault of anybody except the pharmaceutical companies. It is them that have decided not to actively engage. And for the avoidance of doubt, Sir -- for the avoidance of doubt -- we do not make any criticism of the Inquiry in that respect.

As to my clients then, by way of brief introduction, Mr AK, Paul, Robert and Mr AH, all of whom, as I have said, the Inquiry heard from, are all infected with HCV and HIV. All of them experienced testing without consent, secrecy, stigma, harsh disclosure, an absence of support from mainstream services, a lack of empathy from treating clinicians and misinformation. Three of my clients, adults at the time of their infections, unlike the fourth, benefited from support from organisations and clinicians supporting gay men and drug users.

I will touch upon their particular experience as I go along but, with that little introduction or that short introduction, I want to say something about what binds them together as a group of Core Participants, because there's nothing obvious about their personal circumstances that would draw them together.

But what binds them together are those matters that we identified in opening, that is the stigma associated

with HIV and hepatitis C, and the impact of that, which I will come to, and a human rights framework. That is human rights norms that my clients invite you, Sir, to have in mind when addressing the issues that you will in due course address and, in particular, those human rights norms include the right to life, dignity, bodily autonomy, health and nondiscrimination. Well-understood human rights norms observed internationally, regionally and increasingly domestically.

As to the overarching themes that I have just summarised, they are best encapsulated by the words of Robert in his witness statement, his second witness statement, that important extract, to which we refer in our closing submissions, is set out in the written submissions but, mindful that this is a Public Inquiry and perhaps few people, relatively, will have had the opportunity to read all the submissions, I would like to read that extract because it identifies the approach that my clients take to this Inquiry.

So can we please have WITN1004002. Thank you.

I would like to look -- this is Robert's second witness statement and he addresses the concerns, the impetus for engaging in this Inquiry and identifying the themes that he and the other Core Participants in my group want addressed and, if I can start by paragraph 3,

it is a long extract but it means I don't have to summarise the points in my submissions. So he says:

"I have come to see the issues raised by this Inquiry as centrally engaging human rights."

That is a point adopted by all Core Participants, as is indeed the whole of this statement:

"I have approached the making of this statement with that in mind. I believe there is a universal right to be treated with dignity, regardless of an individual's situation. I think the state should only restrict or temporarily suspend a person's rights when that person has interfered with or violated the rights of another. I believe the state has failed me and other haemophiliacs in this infected blood scandal. They have failed by first removing the dignity of the groups that became most affected by HIV and viral hepatitis; promoting and reinforcing a stigmatised view of those groups; failing to prevent this stigma from affecting the decision-making of those in positions of knowledge and authority [a matter I will come back to]; failing to acknowledge and implement risk reduction strategies; and ultimately failing to stop a significant number of vulnerable and disabled people in its care from becoming infected with debilitating and frequently fatal infections.

"From the first appearance of AIDS, there were suggestions it was 'a judgment from God' and that people with the syndrome deserved to die from it. This perception came on top of state-legitimatised stigma against gay people, drug users, sex workers and migrants. Immediately, it led to a separation between those with HIV that were infected through blood products and others with the condition. This implicitly divided all people with AIDS as either innocent and worthy of care (haemophiliacs) and others as guilty and worthy of blame (gay men, sex workers, [intravenous] drug users). This division denied those deemed guilty of their human dignity and ultimately demeaned those deemed innocent. Those of us infected through blood or blood products were routinely exceptionalised and separated from the general service provision for people with HIV [again a matter I will come back to]. I feel strongly that this haemophilia exceptionalism affected the initial risk perspective in the early stages of AIDS; the approach to the management of blood products; the provision of clinical to those affected with AIDS, and the availability of community support services."

So stigma and human rights informs my clients' engagement with this Inquiry and will inform the submissions I make orally today, Sir.

That's the statement of Robert, as I have said, but it is a contribution adopted by all of my clients.

Moving then, please, to human rights. I will come to some factual matters in due course but I do want to lay out, if I may, shortly this framework because it is important for my clients.

There are three key human rights instruments, we say, that shed light on the treatment and experiences of those infected and affected: the European Convention on Human Rights, the International Covenant on Economic, Social and Cultural Rights and the UN Convention on the Rights of Persons with Disabilities.

Now, at the time of the events we are concerned with, these instruments did not form part of domestic law but at all times they bound the UK as a matter of international law and importantly too they both establish and reflect ordinary human rights norms now expected to be conformed -- to be complied with, states to act conformably with, by at least liberal, democratic states. So these are human rights norms.

So the fact that they are not incorporated or only incorporated in part, in respect of some of them, doesn't matter to the approach we say you can take to them and, of course, we are not suggesting, for obvious reasons -- or for a number of reasons, in fact, but we

are not suggesting that the Inquiry make a finding of any legal wrong and that, therefore, I hope, establishes our position.

It creates a framework for understanding.

SIR BRIAN LANGSTAFF: You are saying that the principles which I should apply, or I should recognise as applying, are those the state has agreed to internationally and one would be surprised if it were to accept any different principles in dealing with its own citizens.

MS MONAGHAN: Precisely, Sir. That's precisely the point we make and, indeed, the UK has agreed to adopt those human rights norms but it is right to say, as well, that these are broad international covenants, certainly the UN Covenant is one that's 1966 and widely adopted -- a large number of states are signatories to it and have ratified it. But the point is, as you have probably identified, if I may so say, sir, is that these are established human rights norms, they are international norms and if there were any doubt about it, we can be satisfied too that the United Kingdom has decided positively that it will conform to those international norms by binding themselves, as a matter of international law, to comply with them.

So that's our introductory observation.

If I can take you please to the key extracts that we

invite you, Sir, to have regard to. First of all, the context, the background is the Universal Declaration of Human Rights, adopted by the UN General Assembly in 1948.

We have that at RLIT0001983. Thank you.

I don't need to read all of this, of course, and you may well be familiar with it, Sir, but it is one of the foundational documents of the UN, one of the foundational human rights documents. And importantly, in the preamble, the first page of the preamble refers to dignity. A point picked up I think by Mr Snowden more generally in his submissions.

So:

"Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

"Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind ..."

Skipping the next paragraph. The last paragraph in the preamble:

"Whereas the peoples of the [UN] have in the Charter [UN Charter] reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

"Whereas [Members] have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms ..."

That is the preamble. Then we get to the substantive articles. Article 1, again, dignity.

Foundational to all of these instruments is the concept of dignity and equality. And we see it there at Article 1:

"... born free and equal in dignity and rights."

At Article 2, a non-discrimination guarantee, seen again in all the main human rights instruments.

Protecting or requiring that discrimination is prohibited, that equality is secured not just in respect of those classes whose status is enumerated but also other status, which will include those with haemophilia and, importantly too, for the approach my clients are taking, those with hep C and HIV.

Article 3, the right to life.

Article 5: "torture", "inhuman or degrading treatment".

Inhuman or degrading treatment.

Those are all the extracts -- no, in fact I shall take you to one more which is Article 25(1). This is picked up in the next instrument that I'm going to take you to. Article 25(1):

"Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family ..."

Health is a matter picked up in the next instrument I would like to take you to, and that's the covenants.

So the UN Covenant on Economic, Social and Cultural Rights. I have got it in shorthand. And, again, as I have said, that's one of the older conventions, one of the older treaties.

And if I can ask you, please, Lawrence, if you wouldn't mind, to turn that up. That's RLIT -- ah, you're ahead of me. Thank you.

If I can ask you then to, please, look at that and in the first instance -- again, the preamble, simply to observe in the third substantive paragraph -- let's go to the second just to remind ourselves:

"Recognising that these [human] rights derive from the inherit dignity of the human person ..."

And referring in the next paragraph to the Universal Declaration of Human Rights, that which we have just looked at. Then, if I can turn, please -- invite you to

turn to Article 2.

We see there 2.1:

"Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognised in the present Covenant by all appropriate means, including particularly the adoption of legislative measures."

Again, a duty -- a duty -- to progressively realise the rights contained in the Covenant. And 2, again, a non-discrimination guarantee encapsulating or protecting those whose status is not specifically enumerated but whose status can be described as another status, which plainly is the case here.

Then if I can take you please to Article 12. This is a specific provision, a particular provision, targeted provision, addressing health.

So Article 12:

"1. The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

"2. The steps to be taken by the States Parties to

the present Covenant to achieve the full realisation of this right shall include those necessary for ..."

And moving straight to (c):

"The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

"(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness."

So a health guarantee that the UK has promised to progressively realise.

In relation to that health guarantee, there's been a general comment by the Committee on economic, social and cultural rights and, as you will probably recall, Sir, that's the body that reviews monitoring data and state reports, but it also provides general comments which are designed to assist in the interpretation of the treaty provisions.

So they are important documents but they are important too because they are not adding to the Convention's substantive rights. They are simply telling states what they mean and, therefore, what they have already subscribed to.

So if I can take you, please, to the General Comment No. 14. RLIT0001985.

This is General Comment No. 14 (2000). As I have indicated, it is a document to assist with interpretation, not a new set of provisions. Paragraph 1 emphasises the importance of health, as it is the right to health, as it is found in the covenant:

"Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity."

Again, dignity is the key threshold, the key test for compliance.

And at paragraph 3 it acknowledges, we say this is certainly true:

"The right to health is closely related to and dependent upon the realisation of other human rights ... including ... human dignity, life, non-discrimination, equality ..."

As well as, the next line, "access to information".

Then, please, if I can ask you to turn to paragraph 8, the "Normative content of Article 12":

"The right to health is not to be understood as a right to be *healthy*."

Of course.

"The right to health contains both freedoms and entitlements. [They] include the right to control one's health and body ..."

Bodily autonomy as I shall describe it.

"... and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation."

And the last sentence refers again to equality of opportunity.

You will see at paragraph 10, which I needn't read to you, but starting -- in fact it is the last sentence, although it is rather a long one, HIV and AIDS is referred to in terms, noting the particular difficulties and, we would say, stigma and lack of support for that growing number of people, populations, experiencing or contracting HIV and AIDS.

So those are the main human rights -- the general human rights instruments.

SIR BRIAN LANGSTAFF: Do you want to refer me to the last sentence of paragraph 11?

MS MONAGHAN: Yes, thank you, sir. So, consequently, the rights that -- health must be understood as the right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realisation of the highest attainable standards of health.

In fact, it will be as well -- certainly I would invite you to look at the whole of the comment because you will see over the page -- again I won't read it all out, but if you want it take a moment to read it now or later, Sir, it is a matter for you -- but you will see that it identifies the constituent elements or the conditions that must be met, if the obligation in relation to health is to be met.

So availability, accessibility, economic accessibility, information accessibility -- one of the things that did not occur here -- acceptability and quality. But I commend the whole of it to you because it provides, as I have said, a more detailed structure for examining the extent to which the article 12 obligation in the Covenant has been complied with.

So just in relation to that and perhaps summarising where we get to, the general comment is a helpful source for summarising that, but we do say that, looking through the prism of the rights contained in the human rights instruments -- I will come to the Convention of the Rights of Disabled Persons in a moment, but looking at the events that occurred through the prism of those human rights instruments, we say the Inquiry will want to consider the failure, among other things, to meet the pledge to ensure self-sufficiency in blood products; in relation to HIV and hep C; core obligations would include facilitating or providing early public health information particular to people with haemophilia receiving blood products; information about the risks associated with Factor VIII and the risks associated with non-A, non-B hepatitis, hep C, in the 1970s and 1980s; the risks associated with commercial US products; the creation of an authoritative and centralised channel for disseminating public health information; and steps in place to mitigate imminent virological risks, self-sufficiency, alternative treatment, proper licensing, blood security and, importantly, as I will come back to it, appropriate services and dignity.

The last instrument I should like to refer you to, Sir, is the Convention on the Rights of Persons with Disabilities. That's RLIT0001986. I rather suspect you might have read these, Sir, but I shall, if you don't mind, I do want to touch upon them because we are --

SIR BRIAN LANGSTAFF: I have but, as you say, you are here in a public sphere saying what your clients would want the public to hear.

MS MONAGHAN: Thank you. Sir, if I can ask you, please, to look firstly at the "Preamble", simply to observe again that this is a convention inspired by the UN's foundational documents, the Charter, we see that referred to at paragraph (a), and at paragraph (b) The Universal Declaration that I took you to a moment ago and then, if we look, please, at Article 1, the purpose of the Convention is identified. That is:

"... to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons" --

SIR BRIAN LANGSTAFF: There we are. You were just ahead of the screen.

MS MONAGHAN: I'm sorry. I'm not quite used to this, Sir, and you told me about hurrying or somebody did, so I'm terribly sorry. Are we there now?

SIR BRIAN LANGSTAFF: We are. If you want to check ever it is on the screen to your right, the big screen.

MS MONAGHAN: I think it is here but I was concentrating on my notes and not the screen, but there you are. Apologies.

SIR BRIAN LANGSTAFF: You may want to start Article 1 again.

MS MONAGHAN: Thank you. So Article 1 identifies the "Purpose", and:

"The purpose of the ... Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

Persons with disabilities are described inclusively and they include persons with long-term physical

impairments, which:

"... in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

So I know you will know, Sir, this embraces a social model of disability. So it is concerned less about the focus on a person's impairment and more about the way society, the state, services here respond to those people with impairments.

Of course, our clients are disabled for a number of reasons: haemophilia, HIV, and hepatitis C.

Article 2, if I can take you please to the third paragraph "Discrimination". Again, prohibits or requires states to prohibit or guarantee -- prohibit discrimination and guarantee non-discrimination, noting too that discrimination means:

"... any distinction, conclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms", in all the spheres identified there.

Then if I can ask you, please, to look at Article 3. Article 3, the "General principles" are identified and emphasising again dignity, "Respect for inherent

dignity", and also now and, importantly as with general comment number 14, "individual autonomy, including the freedom to make one's own choices and independence of persons", and non-discrimination, participation, respect for difference, equality of opportunity, accessibility, equality between men and women and respect for evolving capacities of children.

So discrimination, bodily autonomy, individual autonomy and non-discrimination.

Then at Article 4, reflecting the language used in the Covenant and seen in other international instruments, Article 4:

"States Parties undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination ..."

For that purpose, States Parties are required to adopt appropriate measures, designed to secure that. (c):

"To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

"(d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in

conformity with the Convention ..."

So a prohibition in engaging in acts and practices inconsistent with the convention and to take appropriate measures to eliminate discrimination:

"(f) To undertake or promote research and development of universally designed goods [and] services ...

"(g) To undertake or promote research ..."

"(h) To provide accessible information ..."

Something that has a question of information has emerged many times and I will touch upon it in one moment:

"to promote the training of professionals and staff working with persons with disabilities ..."

In the development -- 3, so paragraph -- so subparagraph 3. Thank you Lawrence:

"In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations."

What we know here is that there was no sharing of information, no targeted appropriate services, and no participation in decision-making. But I will come back to that in a moment. Over the page, in my page it is, Article 5, again, a non-discrimination guarantee, needn't take you to that.

Article 8 "Awareness raising":

"States Parties undertake to adopt immediate, effective and appropriate measures:

"(a) To raise awareness throughout society ... regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities ..."

Highly relevant to what my clients say and what in due course I will say about the impact of stigma.

Then, relatedly at (b):

"To combat stereotypes, prejudices ..."

Then 2:

"Measures to this end include:

"(a) Initiating and maintaining effective public awareness campaigns ...

"(i) To nurture receptiveness to the rights of persons with disabilities;

"(ii) To promote positive perceptions and greater social awareness towards persons with disabilities ..."

Just finally, although I can -- finally on this

section, still the same Convention but this part, if we look please at Article 15, part of the civil and political rights part of the Convention, Article 15, we have there the prohibition on torture or, for our purposes, inhuman or degrading treatment:

"In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation."

Highly important. And of course it was important post-war for very obvious reasons, and so we see that issue flagged many times, in the various documents.

Then at Article 25, that's the last section I need to take you to:

"Article 25

"Health

"State Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."

And appropriate measures must be taken:

"... to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation."

To that end, (a), State Parties shall:

"Provide persons with disabilities with the same

range, quality and standard of free or affordable health care ..."

Then (b):

"Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and [as will become more important to my clients] older persons."

Then, (d):

"Require health professionals to provide care of the same quality to persons with disabilities as to others ..."

Free and so on. And:

"... informed consent by [among other things] raising awareness of the human rights, dignity or autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for private and public health care ..."

So very significant human rights measures, very significant human rights obligations, a focus on autonomy, dignity, non-discrimination and positive obligations on the state to ensure that there is a true -- a true -- and realisable right to enjoy

health, dignity, equality in services, appropriate services, and non-discrimination.

The very last document I will take you to, and I know you will be extremely familiar with this, but I will take it just briefly if I may, again.

And that's -- that one! Thank you.

This is the last document as well.

Sir, we have here the European Convention on Human Rights. I know I needn't ask you to study it but just to flag again -- internal number page 5, please, Lawrence -- the preamble.

Again, the first substantive paragraph referring again to the declaration -- the Universal Declaration of Human Rights. So, again, inspired by those fundamental human rights values that we see immediately post-war. Then at page 6, if we can, we see at Article 1 what the state promises to do:

"The High Contracting Parties shall secure to everyone within their jurisdiction the rights and freedoms defined in ... this Convention."

The material parts.

Article 2, the right to life. I will come back to that.

Article 3, prohibition on inhuman or degrading treatment.

Then if I can go to internal number -- page 11, please. This is article 8, Sir:

"Right to respect for private and family life.

"1. Everyone has the right to respect for his private and family life ..."

You will know, Sir, that the concept of private life engages personality, both physical and intellectual or mental, emotional and so on -- it is concerned with personality as well as physical privacy. So, important guarantees.

Then, at Article 14, again, a prohibition on discrimination.

As we have said in our written submissions, and I know will be familiar to you Sir, Article 2, although appearing as a negative obligation, imposes two particular obligations: the negative obligation, prohibiting a state from depriving a person of life; and a positive duty to ensure that the right to life is protected.

But beyond that there are particular obligations imposed in the case of particular individuals or classes of individuals where there is a known risk to life. So there is a duty arising under Article 2 -- you will remember the Osman line of cases -- a positive obligation under Article 2 to take protective measures,

preventative measures in the case of an individual or class of individuals, where there is a risk to life.

There is also a procedural obligation -- and this is for historical purposes only now -- but there is a procedural obligation, as you know, to undertake a prompt and effective investigation. And I probably needn't say more about that because I think the observations that could be made about that are obvious and have been made by many others.

Similar positive obligations arise under Article 3, prohibition on inhuman degrading treatment, as those that arise under Article 2. That is where there is a risk that there will be -- or that substantive right will be violated. So there is a risk of inhuman or degrading treatment. And importantly, as I have said about Article 8, it protects one's personality, one's interests as they touch upon oneself. They also, therefore, touch upon bodily integrity, autonomy and dignity.

And Article 14, as you have seen, is the non-discrimination guarantee.

So there is a succession of human rights instruments, starting immediately post-war, emphasising the need for respect for human dignity in the case of all people, and then specific aspects: life, prohibition

on degrading treatment, health, and so on.

Those are, as I have indicated, important matters for my clients.

With that context, then, I should like to make some observations on the facts, some submissions on the facts.

Firstly, as to knowledge of risk and the response to it, mindful, as I have already indicated, about the positive obligations inherent in the conventions, the duty on the state to do something where risk is identified, the timing of the emergence of risk or the emergence of knowledge of risk is important, obviously, because it tells us how things developed. But it is important for my clients too, and no doubt many, many, many others of the Core Participants, because it helps them understand not only whether the transmission of infected blood could have been prevented at particular times, but whether, in the case of HIV, it could have been eliminated at the very outset, and whether or not, therefore, they may not have contracted hep C or at least HIV themselves.

So timing is important for my clients and, no doubt, everybody else participating in this Inquiry, for their personal reasons as well as the broader public interest.

We had the benefit and I had the benefit of hearing

Mr Snowden speak on Tuesday, I think it was, about the emergence of evidence concerning risk, a viral transmission associated with blood and blood products. We adopt what Mr Snowden says. Along with our written submissions, we don't -- that is, Mr Snowden's submissions and our written submissions in general comprise the submissions that we would wish to make today.

And so that those listening understand the position we are adopting, it is no benefit to the Inquiry to repeat submissions that have already been made by others where there's no disagreement and where we have set them out in the written submissions. So they are extremely important matters but it isn't necessary for me, Sir, to repeat them before you and before those in the hearing room, remotely or physically.

Having said that, there are a couple of matters I would like to draw your attention to in relation to chronology, but keeping repetition, I hope, to the very bare minimum.

What is clear, we say, is that the risk of transmission of viral infection, hepatitis in particular, through the transmission of blood and blood products, was known a very, very long time before the events with which this Inquiry is primarily concerned, post-transfusion hepatitis, as it was then described, was known of by the 1940s and the relationship between pool size and transmission -- increased risk of transmission relative to pool size -- was known of well before factor concentrates came to be used in the United Kingdom. As we heard too, by the early 1970s at the latest, evidence had begun to emerge indicating the existence of another hepatitis causing agent, non-A, non-B and with the development of tests for hepatitis A and B it became clear that non-A, non-B, hep C, evidenced -- let me just start that sentence again. I have expressed that very badly.

What was known were the development of tests for hepatitis A and hepatitis B and the discovery therefore of non-A, non-B hepatitis, what came to be known in consequence is that unknown viruses could be transmitted through blood and blood products.

So by the time we are in the '70s, known viral infections can be transmitted; known pool size is relevant; known that unknown viruses could be transmitted and, soon afterwards, in the case of non-A, non-B, hep C, it was particularly understood that pool size was significant for determining the extent of risk.

SIR BRIAN LANGSTAFF: Are you submitting to me that non-A, non-B was an unknown virus? The reason I ask is this:

it may be thought that much of the material which starts in the 1940s, if not before, identifies that there is something which causes after transfusion the effect of hepatitis and it is identified in the 1940s, if not before, that that is most probably the virus. In one sense, it is unknown because no one isolates the virus, no one can test for it, no one can see it under the electron-microscope, or whatever microscope was used in those days.

But there was no doubt that blood had or could have a virus in it or viruses in it, which would cause effects amongst which, importantly for this Inquiry, was the consequence of hepatitis.

MS MONAGHAN: Yes.

SIR BRIAN LANGSTAFF: But non-A, non-B might be thought, unless there is evidence that it is an actual late comer, which evidence isn't apparent, I think, in the document, but I will listen to any submissions to the contrary, was always there, it was always part of the viruses that were causing hepatitis. So it was not unknown in that sense, what was unknown about it was that it was -- that part of the virus cohort, the virus army that was attacking liver hadn't yet been identified.

MS MONAGHAN: Yes.

SIR BRIAN LANGSTAFF: So that is what you are submitting to me, is it?

MS MONAGHAN: That's what I'm submitting. So when I talk about an "unknown virus", I'm talking about a virus that hadn't been identified, and the significance for us of drawing attention to that is it was plain, therefore, by then that viruses generally were able to move through blood, blood products and the fact that one couldn't identify it didn't mean that there was an absence of risk. What was known therefore ought to have informed decisions later on, both in respect of hepatitis C but also HIV.

SIR BRIAN LANGSTAFF: In simple terms, you are submitting you don't need to know how something is caused if you know that it is caused by doing something?

MS MONAGHAN: Yes.

SIR BRIAN LANGSTAFF: So A simple example, you press a button over there and a light comes on over there, you press a light switch, you know that if you do that, that happens. You hope, as long as the bulb is working. But you do not know how, you don't have to understand electronic theory or electricity or anything, or incandescence in order to work that out: you know it happens.

MS MONAGHAN: Yes.

SIR BRIAN LANGSTAFF: On a simple level, is disease, do you submit, like that, that if you know you do this that may happen?

MS MONAGHAN: Yes, precisely, and the fact that one can't identify the virus at a particular time doesn't mean that one can't identify the risk factors associated with the transmission of viruses: large pools, commercial blood products, and so on. So it is emphasising the importance, we say, of understanding that HIV didn't come out of the blue, in the sense that, of course it was a different virus, of course it hadn't been identified, but the fact that there was a virus that hadn't been identified wasn't something that ought necessarily have taken everybody by surprise. Viruses were known of. They were transmissible by blood products, the risk factors -- large pools, commercial products -- were known about and had been known about since the 1970s.

So it is really identifying that there is no sudden discovery. HIV is the discovery, what causes viruses to be transmitted and the risk factors associated with that was something that was known about from the 1940s onwards, increasingly.

Of course the other feature I talked about, size of the pool, but of course paid donors was the other matter. Commercial products was known to be a risk factor in the 1970s, so these risk factors ought to have been well in the minds of those dealing with people who needed the transmission of blood products like people with haemophilia.

Given that what was known -- given that it was known that large pool plasma, large pool blood products, commercial products were known to increase risk of transmission -- in the case of hepatitis -- the extent of the risk associated with Factor VIII ought to have been apparent very early on, particularly commercially produced Factor VIII, but what we see is that those risks were consistently underplayed, consistently minimised by clinicians, pharmaceutical companies and others involved in the administering and supply of blood products.

There are a number of reasons for that, we say. First of all, there was a general but considerable resistance to anything that might suggest that the distribution of what was seen as a new wonder drug which -- should be disrupted. Clinicians using Factor VIII expected gratitude from patients and perhaps generosity from pharmaceutical companies which in turn, made vast profits from the production of Factor VIII at times when they knew the risk.

So risk must have been obvious by the late 1970s. The risks associated with Factor VIII, however, were downplayed for a number of reasons, including an investment among clinicians in what was seen to be a wonder drug and what they could do for their patients and, of course, as we have already heard several times, perhaps informed in part by clinicians' relationships -- some clinicians' relationships -- with the pharmaceutical companies. So a downgrading of risk.

We see that reflected early on. I don't need to take you to the documents. Some of them you may have seen but I hope I have managed to not repeat. But we see early on correspondence, for example -- we remember this from counsel to the Inquiry's presentation -- but Dr Jones, director at the Newcastle Haemophilia Centre and a key player in the UKHCDO -- wrote to colleagues in 1974 confidentially -- you may recall that, Sir -- that the link between commercial concentrate and hepatitis had been proved and that it carried the risk of jaundice but that it was generally agreed that the advantage and indeed the necessity of concentrate outweighed the risk of hepatitis.

At around the same time, you may recall, Sir, he was writing to colleagues describing the risk of hepatitis contamination as "very worrying". So there were

frictions between what was said at various times and to whom but what was certainly the case was that, in assessing risk and whether it was worth taking, there was no discussion or involvement of patients.

The position, we say, didn't change, that is minimising risk when the indicators of what came to be known as HIV/AIDS began to emerge in the very early 1980s, in all probability for the same reason, additional to stigma that I will come to.

Again, as with hepatitis C, I won't track the emergence of the evidence because Mr Snowden has done that for you on Wednesday *(sic)*. But, again, I should like to pluck out a couple of points in particular.

First of all, the minute in which Mr Gunson's report is referred to, the early minutes, July 1982. You will recall there is a Department of Health -- or DHSS as it was -- minute. He was described as consultant adviser, and he was also Chief Medical Officer, as I understand it. When he gave evidence, you will remember, in the --

SIR BRIAN LANGSTAFF: I don't think he was Chief Medical Officer. He was the adviser to the Chief Medical Officer.

MS MONAGHAN: I beg your pardon. I had seen two things and that's why I was -- adviser to, thank you. Adviser to the Chief Medical Officer.

SIR BRIAN LANGSTAFF: I think the Chief Medical Officer at the time was Sir Henry Yellowlees.

MS MONAGHAN: Thank you.

Just then to re-wind. You will recall the Department of Health minute, I think, in which his observations were recorded. He was consultant adviser, as you have just reminded me, to the CMO. When giving evidence in the HIV Litigation, you may recall he said he first suspected -- and there was a presentation given to us about this -- the link between haemophiliacs and AIDS during 1982, when there were incidences of haemophiliacs who contracted immune deficiency.

We saw thereafter, in July 1982, the minute I just referred to, when it was reported that he said there was likely to be considerable publicity over the following weeks concerning the safety of American Factor VIII.

So very early on, again, noting concerns about the safety of American Factor VIII given the emerging new virus, HIV.

Notwithstanding that, notwithstanding the fact that that would indicate that he was following closely what was happening in the US, we see that he was minimising, in due course, the extent of the risk.

So while he says in his memo, or while it is recorded as him saying in the memo, that the voluntary unpaid donor system adopted by the UK was safer than the US system, no action was taken in relation to that. We come to see what happened about that.

But what we say, Sir, is that immediately upon him acknowledging and recognising that, the risks associated with Factor VIII and the emerging virus, HIV, immediately that warning sign ought to have been met with action: unequivocal warnings to patients and their carers, and a pause in the use of Factor VIII at least.

As I already indicated, it didn't come out of the blue. The risk of transmission of viruses was known and the risk factors associated with it, size of the plasma pools, paid donors, were well known. Nothing was done at all.

Evidence continued to emerge -- we will come back to what Mr Gunson says, having identified it at that early stage -- of evidence continues to emerge, as you heard from Mr Snowden -- the San Francisco baby case, the 20 year old man in Cardiff -- but still nothing was done promptly. And instead we hear from Professor Bloom, giving reassurance to The Haemophilia Society that it had not been proven that AIDS was transmitted through blood products and so there was no need for the haemophiliac community to be unduly concerned.

So risk was known of, it was a risk potentially of

a fatal illness. The risk factors associated with the transmission of viruses were long since known but no action was taken at all. Not only was no action taken at all but Professor Bloom, a key player in the UKHCDO, was telling the haemophiliac community that there was nothing to be worried about.

Clear warnings then ought to have been acted upon but weren't. We saw then the frightening memo written by Dr Galbraith on 9 May, or dated 9 May 1983, in which it is observed that the mortality rate of AIDS exceeds 60 per cent one year after diagnosis and is expected to reach 70 per cent. Still nothing happened.

And as I say, rather than sticking to his guns, so to speak -- that is not a good pun -- we see Dr Gunson rowing back on the concerns that he apparently had in summer 1982.

So, in July 1983 Dr Gunson, having already flagged the risks, concluded, together with Professor Bloom and Dr Galbraith, that a return to cryoprecipitate wasn't recommended since the perceived level of risk at present does not justify serious consideration of this solution.

So, again, a playing down of risk, a reduction apparently in the concern expressed by Dr Gunson earlier on and matters continued in that vein. So in October 1983, as we heard, at a UKHCDO meeting, Professor Bloom,

the dominant voice, as I have said, an important voice, said there was no need for patients to stop using commercial products because at present there was no proof that commercial concentrates were the cause of AIDS. Of course, as you know, Sir, proof is not what is required, a risk assessment is what is required and a risk assessment is required not just as a matter of good clinical practice and the precautionary principle, but also having regard to the obligations under the human rights instruments that I have just identified for you.

Proof is not required. Risk is the focus and a proper assessment of risk, bearing in mind that the impact of that risk being realised is death or in all likelihood death.

But no steps were taken. Much was left as we heard repeatedly to the judgement of individual doctors.

I can see it is 11.15. I'm going to pick that point out, it is a slightly fresh point, so I wonder if this would be a convenient moment to break.

SIR BRIAN LANGSTAFF: Let's pick it up then at 11.45 am.

(11.16 am)

(A short break)

(11.45 am)

MS MONAGHAN: Thank you, sir.

SIR BRIAN LANGSTAFF: Yes.

MS MONAGHAN: I was about to say -- I started by observing a moment ago or before the break that no steps were taken centrally to address risk and instead much was left to the judgement of individual doctors.

Sir, we heard from Dr Winter as you may recall, that the absence of centralised guidance meant that there were major variations in treatment and care and so he said, Sir:

"You would be utterly bemused by the different ways in which ten patients could be treated by ten different doctors. I mean, it was astonishing and something that will surely come out of this Inquiry is the great variability of care."

So an absence of urgent action when risk became apparent and, even then, as matters proceeded, no central or authoritative guidance, but instead letting haemophilia clinicians get on with the job in the way that they saw fit.

So no central standard setting.

We have observed throughout our written submissions -- my clients have observed, their shock at the response to risk that we have seen but, importantly, before I come to my next point, in our submission, it is important to observe that this was not a situation where there were rogue doctors. One or other doctors making problematic decisions in a particular case. This decentralised *ad hoc* variable decision-making, without central standards and the diminishing of risk, was something that was endemic. It fed through the whole of the practice of haemophilia clinicians and so, inevitably, there were differences in approach and problems emerging from that.

In addition to the doctors and the difficulties that we see emerging because of the absence of central standards, there is a case -- of course, the question of the pharmaceutical companies that I have already raised.

My clients, in their opening, observed that, for them, they were concerned whether there were incentives from pharmaceutical companies for doctors or Haemophilia Centres to offload what were cheap and, in the event, infected products, despite risks.

My clients' concerns have become more concrete having heard the evidence, in particular, for example and by way of illustration only, the meeting at Heathrow Airport and the evidence of Professor Tuddenham, when he spoke of lavish entertainment, showered on doctors by pharma in the expectation that they might gain influence and the funding of research that might be affected -- the outcome of which might be affected by conscious or

unconscious bias.

So we have the clinicians, no standard setting, minimising of risk; we have the pharmaceutical companies, again, minimising risk as they inevitably would, given the huge profits to be made; and if not improper relationships, certainly relationships that give rise to concerns about corruption that I will come to in one moment.

So loading off dangerous products in a context where there are no central standard-setting. Indeed as you heard, Sir, the pharmaceutical industry only took action in relation to Factor VIII when compelled to do so and when they appreciated that not taking action might cost them more in revenue than taking action.

You will recall, Sir, that when compulsory screening was introduced, it was resisted, in the first instance, and when introduced in the mid-1980s, you will remember Armour, for example, insisting that there was no risk inherent in Factor VIII, albeit at the same time voluntarily withdrawing unscreened products.

So, as I have indicated right through, doctors with the pharmaceutical industry minimising the risks involved, no overarching standard setting or regulation.

At the third cohort or institution, of course, were blood services. They could have properly been expected

to have played a leading role in apprehending and responding to risks but instead, we were told -- you were told, Sir, in the presentation from counsel to the Inquiry, that the blood transfusion services were a fragmented and disorganised shambles.

So, again, no central standard setting, no guidance, no unified national regulatory systems. So Sir, bringing that all altogether for the moment, having regard to the framework that I invited you to consider, the absence of risk, the response of the clinicians, the pharmaceutical industry and blood services is such that those important rights guaranteed in the instruments I took you to were wholly undermined and violated.

The right to life, the right to bodily autonomy, the right to health, the right to dignity, and the right to non-discrimination. All engaged and if any regard had been taken to those rights and obligations, and there plainly wasn't any regard, urgent steps would have been taken and they were not.

That's risk, Sir. I'm going to move now to patients. I don't think, Sir, that the Inquiry has heard from many if any infected or affected persons who was said that they were treated entirely properly by clinicians and services responsible for their care or the care of their loved ones.

Certainly from the perspective of my clients, based on their own experience and the evidence they have seen and heard, there was a universal or almost universal ignoring of the rights of patients to information and to give or refuse consent to treatment. Patients and their parents or carers were not warned about the risks associated with Factor VIII, including of the enhanced risks associated with particular products, commercial products, for example. Instead, patients were largely marginalised from their own care.

As we have said in our written submissions, the approach of clinicians was epitomised by paternalism, "doctor knows best", and this idea, this notion of clinical freedom: doctors' freedom to make their own choices as to treatment, without regard to the wishes of patients or the interests of patients.

Misinformation was widespread. This included, as I have already alluded to, the minimising of the extent of the risk posed by Factor VIII and the right to information about their health status in the case of patients, including my clients, was not respected. Again, all matters addressed by the human rights instruments that I identified and took you to this morning, Sir.

So products were chosen and administered without proper consent. We heard about what that means from the medical ethics expert group. That means agency, autonomy and liberty. Again, core interests reflected in the human rights instruments that I took you to. Risk assessments were made without the involvement of patients, no systems were in place to empower patients in the making of treatment choices.

The response to the identification of risk arising from the link between HCV, HIV and Factor VIII, and the experiences of those infected and affected by HCV and HIV, were both affected by stigma. Clinicians and policymakers were resistant to the notion that innocent people with haemophilia could be affected. While people with haemophilia who were infected, like my clients, faced stigma and marginalisation.

As Robert said in evidence, the association with homosexual men, sex workers and drug users made it very much a disease nobody wanted to be near. High levels of paranoia, bombardment of tabloid stories, presented as the worst disease associated with bad people, and the characterising, as he has said, of people with haemophilia as "innocent victims" did nothing and, if I may say so respectfully, does nothing to remove stigma. It merely reflects the stigma attaching to HIV and HCV and dumps blame on marginalised communities.

As we have said, that stigma was institutionalised. Bigotry was widespread. You will remember the words of the Chief Constable of Manchester: "People with HIV swirling in a cesspit of their own making".

So inadequate engagement with patients, no information, no consent, and affected by stigma.

The fact that there were these distinctions between the "good" patients, people with haemophilia, and the "bad" patients, sex workers, drug users, homosexual men, meant that there was a division of services, as you heard from Robert. So the whole approach of the patient being in charge of their treatment was lost. Notwithstanding that had they been directed to specialist HIV services, they would have experienced very different care. But the bifurcation of those who had contracted HIV and HCV meant that my clients, along with many others, did not secure the specialist services that international human rights instruments insist they are entitled to access, because of stigma and prejudice.

My clients make the point, as they have already, that everybody is deserving of respect, care and empathy, wherever, whenever and however they were infected. And importantly, had that approach been adopted during the AIDS crisis, the likelihood is that people with haemophilia would have received better care.

So the reduction of stigma, the taking away of stigma, respect for the dignity of all people who contracted HIV in all likelihood would have helped everybody, including those who had contracted it through blood transmission but who were deprived of access to specialist services because of the stigma associated with that cohort. The "dirty" cohort.

We also saw evidence, considerable evidence, of haemophilia clinicians objectifying patients and treating them with a lack of empathy. You will recall Professor Ludlam writing to Dr Craske in 1980, accepting an invitation to serve on the Hepatitis Working Party of the UKHCDO, in which he stated that he was very conscious of the "almost unique group of haemophiliacs we have in Edinburgh because they have never received commercial concentrate, and therefore, as you are aware, they are useful material" for a variety of studies. Useful material.

Sir, the dehumanising of haemophilia patients, the objectification of them, is utterly stark.

We see that too in the observations of Dr Rizza and his reference to chimpanzees and the need to find a human cohort to administer and test concentrates on. Again, a dehumanising and an objectification of real life people.

Also evidence including, as occurred in my clients' case, of samples being taken from patients and then stored and tested, sometimes for research purposes without consent. Evidence of a failure to secure ethical approval for research, for which such research would have been required. Research was undertaken, anticipating that injury might be caused, see Rizza.

Tests were taken, HIV and HCV tests were taken from patients without consent. And where positive, there was often delay in communicating results, creating risk for loved ones and others.

So systemic practices right across the board depriving patients of their bodily autonomy and those aspects -- those rights embraced by the right to health caught by the human rights instruments that we went to this morning.

As to each of my clients, they experienced many of the experiences I have just identified. I will say something briefly about them because they are obviously important. I won't have time to recite everything but I will make a few observations. Mr AK was infected with hepatitis B as a child. He was later notified in 1990 that a blood sample had been taken in August 1980, ten years before: no consent. Tests taken, sample kept, not notified until many years later.

He was given no warnings or advice about risks associated with Factor VIII nor was there any discussion with his clinicians about the choice of factor product that might be available and he, to the best of his recollection, has never in the whole of his adult life been given a choice of blood clotting treatment.

He tested negative for HIV on 3 August 1982. His positive result was on 18 December 1984. So he was infected at some point during that period after, we say, the link between Factor VIII, hepatitis C and HIV was known.

He did not ask whether he wanted his blood tested for HIV and he did not know about it until he was told after the event at a hospital appointment.

SIR BRIAN LANGSTAFF: He couldn't have known about the August '82 event, could he, because by then there was no test, that was obviously a retrospective test.

MS MONAGHAN: Sorry, I'm not sure I'm understanding that, Sir.

SIR BRIAN LANGSTAFF: Yes. There wasn't a test for the presence of HIV until the HIV virus had been identified and isolated. That was done at least definitively in 1984, in April it was announced in the US. It was very shortly after that that there was a test for the presence of the antibodies to HIV, this is my

understanding -- and it was that test which was then applied to a number of serological samples which had been taken from patients.

If there was a test done on blood which is dated August '82, it was obviously one of the samples that had been taken, it was sitting there waiting to be tested for whatever it might be tested for at some stage in the future. That was the point I was making.

MS MONAGHAN: I see.

SIR BRIAN LANGSTAFF: It supports your argument that he didn't know that his blood was going to be tested.

MS MONAGHAN: Yes, I understand the distinction. Yes, I'm sorry. Yes. So the blood had been retained, so they were able to test it presumably having identified the date on which it was taken -- and I have got lots of nodding from the members of the public, thank you. They are giving me a lesson on testing. Thank you.

You can come up here if you like!

So, yes. So the sample must have been retained and, as you have said, Sir, tested later on, once testing had become available. So he was able to deduce that he contracted HIV during the period of 1982 and 1984, 1984 being the date of the positive test.

SIR BRIAN LANGSTAFF: What I understood from your client's evidence was that he didn't know that a sample had been

taken for the purpose of testing at some referred time in the future for something.

MS MONAGHAN: No, no, as you have said, there was no consent given to testing at all. No consent given to the retention of samples. These were all done without the not only or consent of indeed all of my client group. This was a feature of the treatment afforded people with haemophilia and the transmission of viruses.

As you have just alluded to and I was about to say, he wasn't asked whether he wanted to be tested and he didn't know he had been tested until after the event. He was told in a way which was unempathetic, asked if he wanted to know his status, said yes. "I'm afraid you are positive", was the answer. No explanation about what the diagnosis meant. No counselling or information to help him manage and understand the infection and, as he described it -- you may have his statement there, I don't know if he described it to me or in his statement -- but the experience was a lonely one, as he describes it.

He had very little support at the outset from outside the Haemophilia Centres and he makes the observations, as you may have picked up, Sir, that the two positive experiences he had in the NHS mainstream services came -- the two positive experiences arose from

contact with people outside the mainstream Haemophilia Centres, so a counsellor and a young doctor on secondment: the only positive experiences he had.

Otherwise, like my other two adult clients at material times, the support he obtained was outside mainstream services: Body Positive, Terrence Higgins Trusts, Mainliners, and they ought to be given credit those early organisations, early NGOs operating in a hostile environment and putting out a hand to support those who had contracted HIV, whatever their circumstances.

The advantage of that, as you have already heard, is that they were specialists. They knew how to access support services and they were able to assist him.

As to Paul then. Paul, again he received no advice or information about the risks of Factor VIII, nor were his parents.

By November 1976, he had been given US commercial Factor VIII. By 1977, he had developed acute hepatitis B as a result of infection and he and his family were told they had been "unlucky".

He was told of his infection with HIV in June 1985 at a short appointment to briefly discuss one or two results, he was told. He was not prepared for that appointment, given any support and nor was he given support afterwards. He was told that he would probably only have a couple of years before developing symptoms and a few years to live, and he was told to keep his diagnosis secret because of stigma.

As he says, the stigma in the mid-1980s through to the mid-1990s was one of vile hatred and fear. The impact on him, like Mr AK, was devastating.

But, again, he assumed he had been unlucky because he had read the 1 in 1,000 story, the Haemofact leaflet, authored by Dr Lee and Dr Kernoff and it was just bad luck.

Eventually Paul was referred to an HIV clinic, that is outside haemophilia support services, where as he said, his experience of health services improved significantly. He met gay men, drug users, much of the advice he received came from organisations like Terrence Higgins, Body Positive, Mainliners and similar organisations, and importantly he was able to provide support to them too because of his knowledge.

He was told he had HCV in 1992 but not to worry about it because the HIV would kill him first. As to Robert, again, neither he nor his parents were told that there was an increased risk of infection associated with Factor VIII. He was not aware at any point of being asked or his parents being asked whether he wished to

revert to cryoprecipitate. He was diagnosed with HIV in 1985, when he was 18 years old. And again, as with the others, he was not informed in advance that he was being tested for HIV.

He was told of his HIV diagnosis when he called to make an appointment to see a haemophilia doctor. And if he hadn't done so he anticipates he would not have been informed until some time after that.

Just before I come to Mr AH, the youngest of my client group, I emphasise, as my clients have, and I have emphasised more than once but it is important to do so, that organisations like Terrence Higgins, Body Positive and Mainliners were concerned with ensuring that their human rights, their fundamental rights and their dignity rights were protected. And there was a complete distinction between organisations like that, and specialist HIV services supporting gay men and drug users, a complete distinction between the care and specialist services and Haemophilia Centres; HIV clinicians were collaborative, warm. A complete contrast to the patriation, distant attitude of those clinicians in HIV centres.

The last of my clients then is Mr AH. He was 7 when his parents were informed that he was HIV positive and his parents were not warned of risk at any time. When

they were told of Mr AH's infection they were told they should prepare for his death.

He was in fact told inadvertently -- well, negligently -- aged 12 by a supervisor at the hospital of his diagnosis, causing him considerable distress.

Mr AH was a child, as I have said, and while in his early teens, so still a child, he developed AIDS, causing physical illness but also considerable mental distress. And as with others, his family experienced the negative consequences of the stigma attached to AIDS, that is while he was still a boy.

So their experiences were typical, unique to each of them, each experience is unique, but they were typical to the extent that no consent was sought, no information was provided, testing and treatment occurred without the provision of information, without empathy and support, and without access, save when they sort it out themselves, to specialist services.

I'm now going to move to my next topic, Sir. I suppose I ought to say, although I think it is obvious, if I were to round up the observations I have just made about my clients, I would say, again, that those experiences fit comfortably within a human rights model, and one could test whether the response of the state through NHS services met the standards set by

those human rights instruments by looking at the provisions in them.

So my next topic is care and support. Leaving aside for the moment the direct contact with Haemophilia Centres, the lack of empathy, the lack of support, counselling and so on; care and support generally provided to patients following infection was wholly inadequate and largely depended upon the awful financial system schemes about which we have heard.

Establishment of those schemes were largely motivated by the need on the part of government to acknowledge public sympathy but at the same time to avoid hints of admission of legal liability.

Even with the inadequacies in those schemes there was evidence of resentment amongst some operating in this area, resentment that even those schemes had been established.

Sir, you will remember Professor Lee describing herself as irritated by the establishment of a funding scheme because it suggested liability, she said. And as she put it, "The idea that we would give somebody some treatment that they knew would cause harm is frankly ridiculous and it is actually quite hurtful for those people, those many people who cared for patients."

It is our submission, Sir, that there can be no doubt now that that is precisely what happened. Products were administered that were known to cause harm and her assertion that it is frankly ridiculous to suggest otherwise simply reveals her own lack of empathy in relation to these matters. She is irritated by the prospect of support for these patients.

That absence of empathy and indeed self awareness can be spotted elsewhere. You heard, Sir, of a Daily Mail test from Mr Stevens, trustee of the Macfarlane Trust, in deciding how to calculate how the sums to be paid, asking himself "How would it look to the readers of the Daily Mail?"

Barely credible. Significant problems with the financial schemes, as you heard in great detail, and I only touch upon a couple of points. First of all, the institutional arrangements meant that they lacked independence. It seems that trustees hadn't appreciated what their obligations were in charity law but, in any event, the arrangements lacked independence from government.

The Macfarlane Trust, for example, seemed to think that they were simply administering a fund for the Department of Health. In addition the way in which these organisations, these funds, carried out their functions in relation to intended beneficiaries, was

often arbitrary, hostile and demeaning. Decisions were often made without any principled basis for determining outcome.

Again, as you heard from Mr Stevens, of the Macfarlane Trust, he told you:

"I was simply, as it were, on my own, a free agent doing, giving, making such decisions, giving such judgement as seen to be right, really, as an individual."

Utterly arbitrary, utterly unprincipled. We also heard that potential beneficiaries were kept at a distance. We heard about the postbox, so as to avoid having to make contact directly with patients or proposed beneficiaries. Applications were routinely required to be processed through local Haemophilia Centres resulting in an element of postcode lottery and, importantly, in the experience of my clients, was that awards were made often following demeaning -- demeaning -- means testing, about which there was widespread resentment.

The trustees of the Macfarlane Trust in particular were derisory, disrespectful to intended beneficiaries. You will recall the reference to the "great unwashed" in correspondence between Mr Clarke and Mr Stevens, along with other examples explored in evidence of grossly

offensive and contemptuous remarks.

It is almost impossible to believe.

Certainly, and this is apparent just from the short observations I have made, the trusts managed their funds and managed applications without generosity, without compassion, without empathy and in the absence of a culture of kindness.

My client, Paul, described in his witness statement, but I could find other examples, that seeking assistance from the Macfarlane Trust was tantamount to a begging bowl.

He had to justify any application and all funding was linked to rules and restrictions that didn't fit his lifestyle. He experienced financial hardship, and you heard from Robert too that he avoided, unless absolutely impossible to do otherwise, applying for one-off grants because he disliked the system so intensely.

So, again, no support, demeaning, absence of dignity, absence of access to proper care and services, all embraced by those human rights instruments and no evidence of compliance and, indeed, utter disrespect and an absence of concern and respect for the dignity of all of these human beings.

Sir, my last subject is accountability, and I just have a few observations to make about this, so I will,

I'm happy to say, finish within my allocated time.

So, accountability. Relevant, of course, more generally for the Inquiry but also relevant for the purposes of the instruments I have taken you to. They are all addressed to states: where does accountability lie? And I want to just say something about that.

Almost all of the key actors involved in the matters that have been explored, were employees or agents of the state. So that's easy. The state bears responsibility for their acts.

Those acts were largely the acts of the Department of Health, but also other NHS bodies and clinicians. But as to private actors, the pharmaceutical companies in particular, we say the state also bears responsibility for their acts in providing and supplying, without warning and appropriate protections, Factor VIII, because they had not put in place -- that is the state had not put in place -- proper apparatus or institutional arrangements regulating the activities of pharmaceutical companies, so ensuring the safety of commercially produced Factor VIII.

So far as the instruments that I took you to earlier this morning, Sir, responsibility in those circumstances would fall within the state, because it is their obligation, first of all, to protect against risk wherever that risk comes from, as long as it is known, and the state obligations under the specialist conventions, like the UN convention on the rights of disabled persons, address in particular a need to ensure safe access to health services, as indeed does the covenant.

So the convention, plus the UN instruments, make clear that there is an obligation on the state to ensure safe access to appropriate services, and the state can't escape that responsibility by delegating any obligations to private companies. Instead, it is their duty to put in place proper institutional arrangements. And they didn't.

So the Department of Health, which bore institutional responsibility for the safe delivery of health care, did not, for example, set standards referred to earlier. No specific clinical advice was imparted in the early years to Haemophilia Centre doctors. No broad assessment of risk to be fed down but instead, as I've indicated, doctors were left to sort it out themselves. Advice was on an *ad hoc* basis, often downplayed risk, and was often wrong.

You will recall the evidence of Dr Walford that she relied on the UKHCDO to do the job of working out risk and dealing with it. And when she did step in, it was

to underplay risk and impose a threshold for risk, which was wrong and outwith the requirements of human rights law, but outwith ordinary clinical standards.

So she said that she insisted upon firm microbiological or virological evidence, rather than epidemiological -- that was the second word I practised this morning -- after cryoprecipitate -- no, now I can't remember that one either -- epidemiological association. So she was not concerned, she said, with simple association but rather firm microbiological or virological evidence. So a playing down of risk, no setting of standards and no clinical guidance imparted centrally.

We also heard about the foot dragging approach to self-sufficiency. Again, inexcusable state failures. There was a lack of genuine interest for self-sufficiency as we heard. So funding and capacity was not made available.

The importance of that cannot be overstated. I just pluck out one piece of evidence. That's the evidence of Professor Tuddenham, who said that the:

"... provision of home produced concentrate would have reduced the number of HIV infected patients so that we would have had half or less antibody positive cases that we have now, had Factor VIII sufficiency been

reached in 1977."

So the importance of self-sufficiency cannot be overstated and, as I have already said in relation to regulatory oversight, accountability issues, we heard that the blood security or the blood services were a shambles.

Finally in relation to accountability, no proper or robust regulatory or licensing arrangements were in place. So pharmaceutical companies were able to operate without proper restraint. Since, as we have heard, the industry is worth billions, there was inevitably going to be very little incentive for the industry to regulate themselves safely: why would they? That ought to have been secured through a robust regulatory regime. Instead, the licensing regime was weak and the relationship between doctors and pharmaceutical companies, as I have said more than once and you have already heard from others, unhealthily close and even corrupt.

As to licensing, you heard from Professor Sir Michael Rawlins, a member of the Committee on Safety of Medicines, advising licensing authorities, on that committee from 1979 onwards. He said he had no recollection of any discussion after he joined of either the source of blood donations for factor concentrates,

an example from prisoners or high risk areas or any discussion about pool sizes and their significance.

So no discussions in that body that ought to have been advising on licensing requirements and regimes.

He said that there was a power -- he could see no reason why there wouldn't be a power -- to attach conditions to a licence, wide-ranging conditions to a licence. So, for example, requiring manufacturers to provide information about pool size, only use pool sizes of a certain magnitude or restrict the sources of blood donations. Those could have been imposed, he said, but they didn't consider it. Instead assumptions appear to have been made throughout.

As I have said and I will finish on this in the hope that I don't completely bore you death about it, but it is again important. I referred you to the expression "covert bribery". That was something about which we heard from again from Sir Michael. Evidence of practices, as I have said, excessive hospitality, sponsoring doctors to go overseas but, in addition, perhaps shockingly, treating clinicians appearing before his committee to advocate on commercial companies.

So that's everything, Sir, except not letting Government, and ministers in particular, get away with it. So this is my last point. Stigma and ministers.

Much like social contagion, stigma can be eliminated, Sir, by challenging it, by putting positive public messages out there, respecting and celebrating those communities affected. But the state did nothing during the '80s and '90s to address stigma. Stigma obstructed the identification of risk, safe treatment responses, impacted on the care of patients, and was utterly undermining of the dignity of my clients and the communities affected more widely.

This was primarily a government issue and government ministers should not be let off the hook for not addressing it. And this is not a party political issue, it is a governance issue.

But just by way of example, the only example I can find -- there may well be others -- Lord Fowler told the Inquiry that at critical times there was a complete lack of engagement in relation to the AIDS crisis on the part of the Prime Minister, Margaret Thatcher. She was also, he said, difficult to work with, and personalities can matter in addressing social issues.

But the reasons she gave for disengaging or not engaging are evidently in part because of her own homophobia and the stigmatising that she engaged with in relation to those infected with HIV.

So as Lord Fowler told you, her own concern on this

was actually a rather odd concern -- pausing there, not odd, just typical of homophobic and stigmatising response, but in any event. Her own concern on this was that if young people read the warnings they would be introduced to things that they had never heard about, which might well have been the case, but the implication was if they heard about it, if they'd be introduced to them, they would race away and do them, they would race away and become homosexual.

So prejudice, stigma and ignorance runs through the whole of this history, we say, and it is important to observe, and you may feel able to observe Sir, it's of course it is a matter for you, that that stigma hasn't evaporated. That stigma is still there. My clients still experience it and there is still secrecy and cover up among some parts of the community because of the knowledge of the impact of stigma.

So stigma and human rights, I end with, and those are my submissions unless there's anything in particular I can help you with. I'm a little early but I hope I won't be criticised for that.

SIR BRIAN LANGSTAFF: No, not at all. Thank you very much indeed. You have given us an interesting and slightly different perspective, as you set out to do. So thank you.

MS MONAGHAN: Thank you, sir. Thank you.

SIR BRIAN LANGSTAFF: Ms Richards.

MS RICHARDS: Sir, if we take a break now until 2.00 and then we have the Vice Chair of the UK Thalassaemia Society at 2.00.

SIR BRIAN LANGSTAFF: Yes. So 2.00, the Thalassaemia Society.

(12.36 pm)

(The short adjournment)

(2.00 pm)

Closing statement by MS MAHARAJ

On behalf of the UK Thalassaemia Society

SIR BRIAN LANGSTAFF: Yes, Ms Maharaj.

MS MAHARAJ: Hello. Can I begin?

So good afternoon everyone. I my name is Roanna Maharaj and I'm the Vice Chair of the United Kingdom Thalassaemia Society. Before I get into what I'm going to address you today in our closing statement, I'm going to tell you -- remind you about the UKTS.

So we are the only UK-wide charity for supporting people with thalassaemia and officially registered in the 1970s but active for much, much longer. The Society is very small, created by parents to support one another because their children were dying quite young in life, and now we have grown to a -- still small but we have

grown to an establishment that advocates for better treatment, patient rights, structured treatment regimes and to try to help increase quality of life but also life expectancy of our members.

Thalassaemia is an inherited blood condition that lowers, alters or stops the production of haemoglobin. There are several types of thalassaemia, depending on the severity of the condition. The most severe form is thalassaemia major or transfusion-dependent thalassaemia. In transfusion-dependent thalassaemia individuals aren't able to produce adult haemoglobin required to live. As a result of this, individuals living with the condition can become profoundly anaemic and require regular blood transfusions, ranging from every two weeks to four weeks, from infancy, to survive.

There is no comparable treatment apart from the curable option, which is bone marrow transplantation that's not available to over 90 per cent of our patients.

Individuals with the condition also receive extensive iron chelation medication. I can tell you, being a patient myself, how difficult it is to undergo this treatment, and without it you develop organ failures and you prematurely die if you don't treat it well.

Infection is also something that contributes to the shortened life expectancy and premature death and, if that wasn't enough, talking about what we are here to talk about, patients who receive contaminated blood products also have to contest with the increased risk of needing hepatic liver transplantation or they develop liver cancers.

Throughout the hearing we were aware of the small numbers of our community testifying and, despite the best efforts of our team, who also reached out to health professionals who our patients trusted, we also touched base with other organisations who were representing their patients to try to gain their insight of how they were able to talk to their patients, we really did find it -- we struggled to be able to encourage our members to do so.

One of the things that people spoke about was to re-live the trauma of their diagnosis and rigorous and horrific treatments with interferon and repeated cycles over and over, it was just too much for them to bear.

With that being said, in most of our communities in which thalassaemia is prevalent there is still an enormous amount of social stigma associated with living with a blood condition and within some communities the idea of someone living with thalassaemia

was inaccurately categorised as someone being a burden or less than and, you know, this one gets me the most, they are not "marriage material".

So many of our families felt the only way to protect their loved ones was by not disclosing thalassaemia, so that they were not stigmatised further. Now, the feelings attributed to the psychosocial burden of thalassaemia were then further reinforced by the stigma associated with acquiring hepatitis C and, despite affected individuals acquiring this through their life-saving blood transfusions, that they didn't have any choice, they were worried about the negative attitudes that the general population would have and the idea of when you think about hepatitis C of being -- and how it is acquired, they didn't want to be stigmatised further.

I say this because, even disclosing it to us, they felt like they would be judged and that there were whatever negative connotations that would apply to that and they were afraid that -- I say "us" as a Society. We are quite a new team but in case somebody spoke about it, and we do have this in our thalassaemia community, with even people in the NHS disclosing people's sexuality to the community members, there is a real fright.

Now, the combined range of factors, including illness related uncertainty, due to the hepatitis C diagnosis, prognostic unpredictability, the feeling of shame, stigma and discrimination, as well as the previously unknown fear of transmission to loved ones, all cause that kind of extra additional stigmatisation and add to the burden of their entire health situation.

Another factor that we heard about quite often from some of our patients who did want to testify is that they felt by doing so they were letting down the healthcare professionals who treated them and took care of them for their life span, and they were enormously grateful to their healthcare professionals because without them they saw that they would not have lived, and in thalassaemia, and I know in other conditions, we have some amazing healthcare professionals who -- they do everything in their power to ensure that we have a better chance at life and to live.

But I think that was one of the biggest things for them, that they felt they were being disloyal and perhaps that they would be judged or perhaps that they would be treated differently as a result of this.

But going through this, and we listened to some of the hearings throughout, and trying to decipher about what people -- so what, you know, like, some of the

institutions were saying. In our opinion we thought what happened in the tragedy was inexcusable, it was reckless, it was heartbreaking and one of the real tragedies of our lifetime.

And as a community we found it extremely difficult to listen to some of the testimonies and explanations given by several individuals, you know, medical professionals, government and the health agencies. And a lot of the time some of these individuals stated that this event was an unfortunate tragedy and they were sorry. And I don't think it really offers any respect to our community. For one, it doesn't ease the torturous battles our members faced or that they currently face, nor does it bring back the loved ones that were stolen from our community.

And, you know, being a patient, despite your level of education, despite your experience, when you become unwell or you are sick, you have this sense of vulnerability, and I think your family members also have that. And during that time you look at the ones who are more experienced, you look at your caregivers, you look at the government, the health departments, and you think that they are going to support you, they are going to protect you and provide the best, safe treatment. And in this case that didn't happen. And I think, in trying to cope with the realities in front of you, you tell yourself and you reassure yourself that these agencies that are required to observe and regulate, foresee, plan and evaluate their services along are doing what they are paid to do or doing what they promise -- or supposed to do. But in this case they didn't. They dropped the ball. And due to their reckless behaviour, now our communities are left to pay.

And we still speak to parents of -- like, who lost their children. And you see that tragedy, you see their children's experiences through their eyes, and they are still not the same. They still can't talk about it. They still segregate themselves from the community. They still stay away. And I think that trauma, of not just what the parents have faced but for the people that are still living with this, saying "Sorry" and that "This is unfortunate", will never help them.

We have submitted a list of recommendations as part of our written statement but I'm going to kind of -- recount some of them, I'm not going to say all.

One of our recommendations that I still think, that not just our patients but the community should have access to the medical records. In lots of instances with thalassaemia, because liver iron overload gets -- you know, you can end up with liver fibrosis and

cirrhosis and need a transplantation, it is very easy for hepatitis C diagnosis to be pushed under the table and focus on iron overload. And that is what I think really happened in our community in some way.

When people perhaps -- they died, what was probably -- so we did do some investigations in it and what was recorded in some of that is that they died as a result of thalassaemia. They died as a result of iron overload. But we don't really know the truth of whether they died because having this infection exacerbated their outcome.

So I think there is still a bit in the story that we feel we don't know, and we did try our best to access these documents and even went to the national statistics, and it was sort of spinning a top in mud: we didn't get anywhere.

There's lots of innovative therapies, and because people have been affected by and have been infected with hepatitis, they are not eligible for certain trials because of their previous conditions acquired.

Now, I don't think that's fair, because this is not something that they did to themselves. This is not a lifestyle choice. This is what was given to them as an unfortunate gift. So I do think -- the equality side of what our patients are being offered should be

considered.

Guaranteed and timely access to liver specialists, pain specialists, rheumatologist, dieticians, nutritionists, physical therapists, these are all issues that are affecting our community, but due to the services they are not able to seek these treatment options in a timely manner or at all. Most of them can't pay for it privately and they rely on the NHS.

We also thought that we wanted a guarantee that all healthcare professionals, including medical doctors, nursing teams, et cetera, receive mandatory training and suitably incorporated into medical nursing and other allied healthcare curriculums on thalassaemia, the findings of the Inquiry, the risks associated with blood transfusions, the importance of consent, ethical training, communication skills, patient informed decision-making and patient choice. For us, that's extremely important.

We would also ask for public funding for the UKTS and other organisations to help us support our patients. This is something that they have to live with and we have to ensure it never happens to anybody else again.

A fair compensation package. I don't think -- I don't know what will ever be fair but at least these individuals living comfortably, being able to access

services, is the least that can be given to them. Also I think that a recommendation should be given to the NHS Blood and Transplant, I think more people -- and donors for example -- I feel sometimes they don't understand the risks that they bring to the recipient. It is great to donate blood. I'm alive because of the blood I have received throughout my life. But I think when people donate blood they don't understand really that, while you are giving this great gift, we can't deal with any more health conditions because it is really difficult to deal with the one that we were born with.

So I think there needs to be more emphasis on the communication to the general public, to donors, about how important it is to protect the recipients and to take that responsibility in filling out and answering correctly, honestly on the questionnaires, disclosing information. I do think there needs to be more emphasis on that and I don't think that the communication that I have been seeing is sufficient, and it is a worry to me every time I have a transfusion: am I going to be protected?

In conclusion, in the course of the hearings, it has become apparent that many mistakes were made and many witnesses have acknowledged that they or the organisation they represented failed in one way or the another.

As an organisation, as our organisation, I think for us what was reinforced is that our voice, support, advocacy and our need to call out the injustice in whatever situation we are faced, is even more important. I think being a patient organisation you are always wondering whether you are going to step on somebody's toes, whether you are going to be reprimanded for saying things and I think there is a real fright for us to be able to come out sometimes and say "I think this is wrong" or "Can we ask for a second opinion?" I think this Inquiry has encouraged us to begin doing that to a more significant degree.

At this point, UKTS would like to express our profound gratitude to the Chair and to everyone involved in the Inquiry, who tirelessly supported the hearings, our members and to ensure that they were conducted as effectively as possible, and I think this is the biggest thing that we feel, is that we would like to pay our own respects to the survivors and to the bereaved.

We have been inspired, we have been impressed with the dignity of our members who did come forward and, despite the distressing nature, they try their best to continue living and to support the society to help encourage our members and it is an admirable what they

did in the face of this tragedy.

That's it from me. Thank you.

SIR BRIAN LANGSTAFF: Well, thank you very much.

As you know, I have been keen from the start of the Inquiry that as many people who had thalassaemia, who were prepared to talk about it, should come forward. It has been a worry to me, as I think, again, you know, that we haven't had more, because it seems obvious that there are many who have had a lot of transfusions who would almost -- well, not inevitably, because that is the wrong word -- but who would probably have suffered and who aren't prepared to talk about it for the reasons which you have so eloquently just explained. It is a pity that we haven't heard from them but they have not been forgotten. And I want you to take that back to your members.

You have made a powerful case I think -- given that they find it difficult for social reasons, for reasons of experience, for reasons that they feel they may be letting their clinicians down and so on -- a powerful case for there being a form of advocacy for them which they can access, and I want to think more about that. It may be that the NHSBT, whose representative sits at the back of the room as I say this, will give some consideration possibly to what can be done for those

with thalassaemia in terms of giving them a voice beyond that which they already have. Because I want to consider that further.

But thank you.

MS MAHARAJ: Thank you.

MS RICHARDS: Sir, might I just echo those thanks because within the Inquiry we had been very conscious that there is likely to have been very many people with thalassaemia infected, because of the frequent nature of the transfusions they have received, than we have had individual witness statements, and Ms Maharaj's statement helps us understand why it is, for very understandable reasons, we have not been able to hear from more affected individuals. So it is very valuable from the Inquiry's perspective.

SIR BRIAN LANGSTAFF: It may also follow that some of them have not accessed such schemes as are available to get what limited support there is and anything that may follow later from that. And anything that can be said to encourage them to do that, if they want to, it is a matter for them entirely and their rights not to do it have to be respected, but they shouldn't miss the opportunity from not being aware of it.

MS RICHARDS: Yes. That concludes the submissions for this week and, perhaps timely in light of the submissions that you have just heard, our next set of submissions will be by Mr Cory-Wright on Tuesday on behalf of NHS Blood and Transplant.

SIR BRIAN LANGSTAFF: So next Tuesday, 10.00.

(2.23 pm)

(The Inquiry adjourned until 10.00 am on Tuesday, 24 January 2023)

INDEX