

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.

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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

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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

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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

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

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

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

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

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

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

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

20 So can we please have WITN1004002. Thank you.

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

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

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

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

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

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

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

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

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

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

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

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

4 It creates a framework for understanding.

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

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

24 So that's our introductory observation.

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

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

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

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

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

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

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1 invite you, Sir, to have regard to. First of all, the  
2 context, the background is the Universal Declaration of  
3 Human Rights, adopted by the UN General Assembly in  
4 1948.

5 We have that at RLIT0001983. Thank you.

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

13 So:

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

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

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

23 "Whereas the peoples of the [UN] have in the Charter  
24 [UN Charter] reaffirmed their faith in fundamental human  
25 rights, in the dignity and worth of the human person and

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1 in the equal rights of men and women and have determined  
2 to promote social progress and better standards of life  
3 in larger freedom,

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

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

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

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

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

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

22 Article 3, the right to life.

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

25 Inhuman or degrading treatment.

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1 turn to Article 2.

2 We see there 2.1:

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

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

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

20 So Article 12:

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

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

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

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

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

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

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

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

21 "Recognising that these [human] rights derive from  
22 the inherent dignity of the human person ..."

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

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

3 And moving straight to (c):

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

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

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

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

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

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

25 This is General Comment No. 14 (2000). As I have

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1 indicated, it is a document to assist  
 2 with interpretation, not a new set of provisions.  
 3 Paragraph 1 emphasises the importance of health, as it  
 4 is the right to health, as it is found in the covenant:  
 5 "Health is a fundamental human right indispensable  
 6 for the exercise of other human rights. Every human  
 7 being is entitled to the enjoyment of the highest  
 8 attainable standard of health conducive to living a life  
 9 in dignity."  
 10 Again, dignity is the key threshold, the key test  
 11 for compliance.  
 12 And at paragraph 3 it acknowledges, we say this is  
 13 certainly true:  
 14 "The right to health is closely related to and  
 15 dependent upon the realisation of other human rights ...  
 16 including ... human dignity, life, non-discrimination,  
 17 equality ..."  
 18 As well as, the next line, "access to information".  
 19 Then, please, if I can ask you to turn to  
 20 paragraph 8, the "Normative content of Article 12":  
 21 "The right to health is not to be understood as  
 22 a right to be *healthy*."  
 23 Of course.  
 24 "The right to health contains both freedoms and  
 25 entitlements. [They] include the right to control one's

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1 you will see over the page -- again I won't read it all  
 2 out, but if you want it take a moment to read it now or  
 3 later, Sir, it is a matter for you -- but you will see  
 4 that it identifies the constituent elements or the  
 5 conditions that must be met, if the obligation in  
 6 relation to health is to be met.  
 7 So availability, accessibility, economic  
 8 accessibility, information accessibility -- one of the  
 9 things that did not occur here -- acceptability and  
 10 quality. But I commend the whole of it to you because  
 11 it provides, as I have said, a more detailed structure  
 12 for examining the extent to which the article 12  
 13 obligation in the Covenant has been complied with.  
 14 So just in relation to that and perhaps summarising  
 15 where we get to, the general comment is a helpful source  
 16 for summarising that, but we do say that, looking  
 17 through the prism of the rights contained in the human  
 18 rights instruments -- I will come to the Convention of  
 19 the Rights of Disabled Persons in a moment, but looking  
 20 at the events that occurred through the prism of those  
 21 human rights instruments, we say the Inquiry will want  
 22 to consider the failure, among other things, to meet the  
 23 pledge to ensure self-sufficiency in blood products; in  
 24 relation to HIV and hep C; core obligations would  
 25 include facilitating or providing early public health

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1 health and body ..."  
 2 Bodily autonomy as I shall describe it.  
 3 "... and the right to be free from interference,  
 4 such as the right to be free from torture,  
 5 non-consensual medical treatment and experimentation."  
 6 And the last sentence refers again to equality of  
 7 opportunity.  
 8 You will see at paragraph 10, which I needn't read  
 9 to you, but starting -- in fact it is the last sentence,  
 10 although it is rather a long one, HIV and AIDS is  
 11 referred to in terms, noting the particular difficulties  
 12 and, we would say, stigma and lack of support for that  
 13 growing number of people, populations, experiencing or  
 14 contracting HIV and AIDS.  
 15 So those are the main human rights -- the general  
 16 human rights instruments.  
 17 **SIR BRIAN LANGSTAFF:** Do you want to refer me to the last  
 18 sentence of paragraph 11?  
 19 **MS MONAGHAN:** Yes, thank you, sir. So, consequently, the  
 20 rights that -- health must be understood as the right to  
 21 the enjoyment of a variety of facilities, goods,  
 22 services and conditions necessary for the realisation of  
 23 the highest attainable standards of health.  
 24 In fact, it will be as well -- certainly I would  
 25 invite you to look at the whole of the comment because

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1 information particular to people with haemophilia  
 2 receiving blood products; information about the risks  
 3 associated with Factor VIII and the risks associated  
 4 with non-A, non-B hepatitis, hep C, in the 1970s and  
 5 1980s; the risks associated with commercial US products;  
 6 the creation of an authoritative and centralised channel  
 7 for disseminating public health information; and steps  
 8 in place to mitigate imminent virological risks,  
 9 self-sufficiency, alternative treatment, proper  
 10 licensing, blood security and, importantly, as I will  
 11 come back to it, appropriate services and dignity.  
 12 The last instrument I should like to refer you to,  
 13 Sir, is the Convention on the Rights of Persons with  
 14 Disabilities. That's RLIT0001986. I rather suspect you  
 15 might have read these, Sir, but I shall, if you don't  
 16 mind, I do want to touch upon them because we are --  
 17 **SIR BRIAN LANGSTAFF:** I have but, as you say, you are here  
 18 in a public sphere saying what your clients would want  
 19 the public to hear.  
 20 **MS MONAGHAN:** Thank you. Sir, if I can ask you, please, to  
 21 look firstly at the "Preamble", simply to observe again  
 22 that this is a convention inspired by the UN's  
 23 foundational documents, the Charter, we see that  
 24 referred to at paragraph (a), and at paragraph (b) The  
 25 Universal Declaration that I took you to a moment ago

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1 and then, if we look, please, at Article 1, the purpose  
 2 of the Convention is identified. That is:  
 3 "... to promote, protect and ensure the full and  
 4 equal enjoyment of all human rights and fundamental  
 5 freedoms by all persons" --  
 6 **SIR BRIAN LANGSTAFF:** There we are. You were just ahead of  
 7 the screen.  
 8 **MS MONAGHAN:** I'm sorry. I'm not quite used to this, Sir,  
 9 and you told me about hurrying or somebody did, so I'm  
 10 terribly sorry. Are we there now?  
 11 **SIR BRIAN LANGSTAFF:** We are. If you want to check ever it  
 12 is on the screen to your right, the big screen.  
 13 **MS MONAGHAN:** I think it is here but I was concentrating on  
 14 my notes and not the screen, but there you are.  
 15 Apologies.  
 16 **SIR BRIAN LANGSTAFF:** You may want to start Article 1 again.  
 17 **MS MONAGHAN:** Thank you. So Article 1 identifies the  
 18 "Purpose", and:  
 19 "The purpose of the ... Convention is to promote,  
 20 protect and ensure the full and equal enjoyment of all  
 21 human rights and fundamental freedoms by all persons  
 22 with disabilities, and to promote respect for their  
 23 inherent dignity."  
 24 Persons with disabilities are described inclusively  
 25 and they include persons with long-term physical  
 21

1 dignity", and also now and, importantly as with general  
 2 comment number 14, "individual autonomy, including the  
 3 freedom to make one's own choices and independence of  
 4 persons", and non-discrimination, participation, respect  
 5 for difference, equality of opportunity, accessibility,  
 6 equality between men and women and respect for evolving  
 7 capacities of children.  
 8 So discrimination, bodily autonomy, individual  
 9 autonomy and non-discrimination.  
 10 Then at Article 4, reflecting the language used in  
 11 the Covenant and seen in other international  
 12 instruments, Article 4:  
 13 "States Parties undertake to ensure and promote the  
 14 full realisation of all human rights and fundamental  
 15 freedoms for all persons with disabilities without  
 16 discrimination ..."  
 17 For that purpose, States Parties are required to  
 18 adopt appropriate measures, designed to secure that.  
 19 (c):  
 20 "To take into account the protection and promotion  
 21 of the human rights of persons with disabilities in all  
 22 policies and programmes;  
 23 "(d) To refrain from engaging in any act or practice  
 24 that is inconsistent with the present Convention and to  
 25 ensure that public authorities and institutions act in  
 23

1 impairments, which:  
 2 "... in interaction with various barriers may hinder  
 3 their full and effective participation in society on  
 4 an equal basis with others."  
 5 So I know you will know, Sir, this embraces a social  
 6 model of disability. So it is concerned less about the  
 7 focus on a person's impairment and more about the way  
 8 society, the state, services here respond to those  
 9 people with impairments.  
 10 Of course, our clients are disabled for a number of  
 11 reasons: haemophilia, HIV, and hepatitis C.  
 12 Article 2, if I can take you please to the third  
 13 paragraph "Discrimination". Again, prohibits or  
 14 requires states to prohibit or guarantee -- prohibit  
 15 discrimination and guarantee non-discrimination, noting  
 16 too that discrimination means:  
 17 "... any distinction, conclusion or restriction on  
 18 the basis of disability which has the purpose or effect  
 19 of impairing or nullifying the recognition, enjoyment or  
 20 exercise, on an equal basis with others, of all human  
 21 rights and fundamental freedoms", in all the spheres  
 22 identified there.  
 23 Then if I can ask you, please, to look at Article 3.  
 24 Article 3, the "General principles" are identified and  
 25 emphasising again dignity, "Respect for inherent  
 22

1 conformity with the Convention ..."  
 2 So a prohibition in engaging in acts and practices  
 3 inconsistent with the convention and to take appropriate  
 4 measures to eliminate discrimination:  
 5 "(f) To undertake or promote research and  
 6 development of universally designed goods [and]  
 7 services ...  
 8 "(g) To undertake or promote research ..."  
 9 "(h) To provide accessible information ..."  
 10 Something that has a question of information has  
 11 emerged many times and I will touch upon it in one  
 12 moment:  
 13 "to promote the training of professionals and staff  
 14 working with persons with disabilities ..."  
 15 In the development -- 3, so paragraph -- so  
 16 subparagraph 3. Thank you Lawrence:  
 17 "In the development and implementation of  
 18 legislation and policies to implement the present  
 19 Convention, and in other decision-making processes  
 20 concerning issues relating to persons with disabilities,  
 21 States Parties shall closely consult with and actively  
 22 involve persons with disabilities, including children  
 23 with disabilities, through their representative  
 24 organisations."  
 25 What we know here is that there was no sharing of  
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1 information, no targeted appropriate services, and no  
2 participation in decision-making. But I will come back  
3 to that in a moment. Over the page, in my page it is,  
4 Article 5, again, a non-discrimination guarantee,  
5 needn't take you to that.

6 Article 8 "Awareness raising":

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

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

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

15 Then, relatedly at (b):

16 "To combat stereotypes, prejudices ..."

17 Then 2:

18 "Measures to this end include:

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

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

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

25 Just finally, although I can -- finally on this

25

1 range, quality and standard of free or affordable health  
2 care ..."  
3 Then (b):  
4 "Provide those health services needed by persons  
5 with disabilities specifically because of their  
6 disabilities, including early identification and  
7 intervention as appropriate, and services designed to  
8 minimise and prevent further disabilities, including  
9 among children and [as will become more important to my  
10 clients] older persons."

11 Then, (d):

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

15 Free and so on. And:

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

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

27

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

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

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

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

14 "Article 25

15 "Health

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

20 And appropriate measures must be taken:

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

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

25 "Provide persons with disabilities with the same

26

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

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

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

7 This is the last document as well.

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

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

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

21 The material parts.

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

24 Article 3, prohibition on inhuman or degrading  
25 treatment.

28



1 Then if I can go to internal number -- page 11,  
 2 please. This is article 8, Sir:  
 3 "Right to respect for private and family life.  
 4 "1. Everyone has the right to respect for his  
 5 private and family life ..."  
 6 You will know, Sir, that the concept of private life  
 7 engages personality, both physical and intellectual or  
 8 mental, emotional and so on -- it is concerned with  
 9 personality as well as physical privacy. So, important  
 10 guarantees.  
 11 Then, at Article 14, again, a prohibition on  
 12 discrimination.  
 13 As we have said in our written submissions, and  
 14 I know will be familiar to you Sir, Article 2, although  
 15 appearing as a negative obligation, imposes two  
 16 particular obligations: the negative obligation,  
 17 prohibiting a state from depriving a person of life; and  
 18 a positive duty to ensure that the right to life is  
 19 protected.  
 20 But beyond that there are particular obligations  
 21 imposed in the case of particular individuals or classes  
 22 of individuals where there is a known risk to life. So  
 23 there is a duty arising under Article 2 -- you will  
 24 remember the Osman line of cases -- a positive  
 25 obligation under Article 2 to take protective measures,

29

1 on degrading treatment, health, and so on.  
 2 Those are, as I have indicated, important matters  
 3 for my clients.  
 4 With that context, then, I should like to make some  
 5 observations on the facts, some submissions on the  
 6 facts.  
 7 Firstly, as to knowledge of risk and the response to  
 8 it, mindful, as I have already indicated, about the  
 9 positive obligations inherent in the conventions, the  
 10 duty on the state to do something where risk is  
 11 identified, the timing of the emergence of risk or the  
 12 emergence of knowledge of risk is important, obviously,  
 13 because it tells us how things developed. But it is  
 14 important for my clients too, and no doubt many, many,  
 15 many others of the Core Participants, because it helps  
 16 them understand not only whether the transmission of  
 17 infected blood could have been prevented at particular  
 18 times, but whether, in the case of HIV, it could have  
 19 been eliminated at the very outset, and whether or not,  
 20 therefore, they may not have contracted hep C or at  
 21 least HIV themselves.  
 22 So timing is important for my clients and, no doubt,  
 23 everybody else participating in this Inquiry, for their  
 24 personal reasons as well as the broader public interest.  
 25 We had the benefit and I had the benefit of hearing

31

1 preventative measures in the case of an individual or  
 2 class of individuals, where there is a risk to life.  
 3 There is also a procedural obligation -- and this is  
 4 for historical purposes only now -- but there is  
 5 a procedural obligation, as you know, to undertake  
 6 a prompt and effective investigation. And I probably  
 7 needn't say more about that because I think the  
 8 observations that could be made about that are obvious  
 9 and have been made by many others.  
 10 Similar positive obligations arise under Article 3,  
 11 prohibition on inhuman degrading treatment, as those  
 12 that arise under Article 2. That is where there is  
 13 a risk that there will be -- or that substantive right  
 14 will be violated. So there is a risk of inhuman or  
 15 degrading treatment. And importantly, as I have said  
 16 about Article 8, it protects one's personality, one's  
 17 interests as they touch upon oneself. They also,  
 18 therefore, touch upon bodily integrity, autonomy and  
 19 dignity.  
 20 And Article 14, as you have seen, is the  
 21 non-discrimination guarantee.  
 22 So there is a succession of human rights  
 23 instruments, starting immediately post-war, emphasising  
 24 the need for respect for human dignity in the case of  
 25 all people, and then specific aspects: life, prohibition

30

1 Mr Snowden speak on Tuesday, I think it was, about the  
 2 emergence of evidence concerning risk, a viral  
 3 transmission associated with blood and blood products.  
 4 We adopt what Mr Snowden says. Along with our written  
 5 submissions, we don't -- that is, Mr Snowden's  
 6 submissions and our written submissions in general  
 7 comprise the submissions that we would wish to make  
 8 today.  
 9 And so that those listening understand the position  
 10 we are adopting, it is no benefit to the Inquiry to  
 11 repeat submissions that have already been made by others  
 12 where there's no disagreement and where we have set them  
 13 out in the written submissions. So they are extremely  
 14 important matters but it isn't necessary for me, Sir, to  
 15 repeat them before you and before those in the hearing  
 16 room, remotely or physically.  
 17 Having said that, there are a couple of matters  
 18 I would like to draw your attention to in relation to  
 19 chronology, but keeping repetition, I hope, to the very  
 20 bare minimum.  
 21 What is clear, we say, is that the risk of  
 22 transmission of viral infection, hepatitis in  
 23 particular, through the transmission of blood and blood  
 24 products, was known a very, very long time before the  
 25 events with which this Inquiry is primarily concerned,

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1 post-transfusion hepatitis, as it was then described,  
 2 was known of by the 1940s and the relationship between  
 3 pool size and transmission -- increased risk of  
 4 transmission relative to pool size -- was known of well  
 5 before factor concentrates came to be used in the United  
 6 Kingdom. As we heard too, by the early 1970s at the  
 7 latest, evidence had begun to emerge indicating the  
 8 existence of another hepatitis causing agent, non-A,  
 9 non-B and with the development of tests for hepatitis A  
 10 and B it became clear that non-A, non-B, hep C,  
 11 evidenced -- let me just start that sentence again.  
 12 I have expressed that very badly.

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

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

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

33

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

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

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

16 **MS MONAGHAN:** Yes.

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

25 **MS MONAGHAN:** Yes.

35

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

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

14 **MS MONAGHAN:** Yes.

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

25 **MS MONAGHAN:** Yes.

34

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

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

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

24 Of course the other feature I talked about, size of  
 25 the pool, but of course paid donors was the other

36

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.

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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.

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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

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**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

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1 unpaid donor system adopted by the UK was safer than the  
2 US system, no action was taken in relation to that. We  
3 come to see what happened about that.

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

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

15 Evidence continued to emerge -- we will come back to  
16 what Mr Gunson says, having identified it at that early  
17 stage -- of evidence continues to emerge, as you heard  
18 from Mr Snowden -- the San Francisco baby case, the  
19 20 year old man in Cardiff -- but still nothing was done  
20 promptly. And instead we hear from Professor Bloom,  
21 giving reassurance to The Haemophilia Society that it  
22 had not been proven that AIDS was transmitted through  
23 blood products and so there was no need for the  
24 haemophiliac community to be unduly concerned.

25 So risk was known of, it was a risk potentially of  
41

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

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

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

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

21 **SIR BRIAN LANGSTAFF:** Let's pick it up then at 11.45 am.  
22 (11.16 am)

23 (A short break)

24 (11.45 am)

25 **MS MONAGHAN:** Thank you, sir.

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

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

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

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

22 So, again, a playing down of risk, a reduction  
23 apparently in the concern expressed by Dr Gunson earlier  
24 on and matters continued in that vein. So in October  
25 1983, as we heard, at a UKHCDO meeting, Professor Bloom,  
42

1 **SIR BRIAN LANGSTAFF:** Yes.

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

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

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

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

20 So no central standard setting.

21 We have observed throughout our written  
22 submissions -- my clients have observed, their shock at  
23 the response to risk that we have seen but, importantly,  
24 before I come to my next point, in our submission, it is  
25 important to observe that this was not a situation where

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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

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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 together 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.

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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

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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

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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.

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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.

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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.

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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.

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

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

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

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

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

20 **SIR BRIAN LANGSTAFF:** Yes. There wasn't a test for the  
21 presence of HIV until the HIV virus had been identified  
22 and isolated. That was done at least definitively in  
23 1984, in April it was announced in the US. It was very  
24 shortly after that that there was a test for the  
25 presence of the antibodies to HIV, this is my

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

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

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

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

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

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

9 **MS MONAGHAN:** I see.

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

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

18 You can come up here if you like!

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

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

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

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

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

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

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

22 He was told of his infection with HIV in June 1985  
23 at a short appointment to briefly discuss one or two  
24 results, he was told. He was not prepared for that  
25 appointment, given any support and nor was he given

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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

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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

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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

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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

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1 doubt now that that is precisely what happened.  
 2 Products were administered that were known to cause harm  
 3 and her assertion that it is frankly ridiculous to  
 4 suggest otherwise simply reveals her own lack of empathy  
 5 in relation to these matters. She is irritated by the  
 6 prospect of support for these patients.

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

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

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

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1 offensive and contemptuous remarks.

2 It is almost impossible to believe.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

22 So far as the instruments that I took you to earlier  
 23 this morning, Sir, responsibility in those circumstances  
 24 would fall within the state, because it is their  
 25 obligation, first of all, to protect against risk

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1 wherever that risk comes from, as long as it is known,  
2 and the state obligations under the specialist  
3 conventions, like the UN convention on the rights of  
4 disabled persons, address in particular a need to ensure  
5 safe access to health services, as indeed does the  
6 covenant.

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

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

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

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1 reached in 1977."

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

25 So as Lord Fowler told you, her own concern on this  
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1 was actually a rather odd concern -- pausing there, not  
2 odd, just typical of homophobic and stigmatising  
3 response, but in any event. Her own concern on this was  
4 that if young people read the warnings they would be  
5 introduced to things that they had never heard about,  
6 which might well have been the case, but the implication  
7 was if they heard about it, if they'd be introduced to  
8 them, they would race away and do them, they would race  
9 away and become homosexual.

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

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

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

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1 **MS MONAGHAN:** Thank you, sir. Thank you.

2 **SIR BRIAN LANGSTAFF:** Ms Richards.

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

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

8 **(12.36 pm)**

9 **(The short adjournment)**

10 **(2.00 pm)**

11 **Closing statement by MS MAHARAJ**

12 **On behalf of the UK Thalassaemia Society**

13 **SIR BRIAN LANGSTAFF:** Yes, Ms Maharaj.

14 **MS MAHARAJ:** Hello. Can I begin?

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

16 And, you know, being a patient, despite your level  
17 of education, despite your experience, when you become  
18 unwell or you are sick, you have this sense of  
19 vulnerability, and I think your family members also have  
20 that. And during that time you look at the ones who are  
21 more experienced, you look at your caregivers, you look  
22 at the government, the health departments, and you think  
23 that they are going to support you, they are going to  
24 protect you and provide the best, safe treatment. And  
25 in this case that didn't happen. And I think, in trying

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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

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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

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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

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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

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

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

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

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

4 But thank you.

5 **MS MAHARAJ:** Thank you.

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

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

24 **MS RICHARDS:** Yes. That concludes the submissions for this  
 25 week and, perhaps timely in light of the submissions

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1 did in the face of this tragedy.

2 That's it from me. Thank you.

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

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

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

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1 that you have just heard, our next set of submissions  
 2 will be by Mr Cory-Wright on Tuesday on behalf of NHS  
 3 Blood and Transplant.

4 **SIR BRIAN LANGSTAFF:** So next Tuesday, 10.00.

5 (2.23 pm)

6 (The Inquiry adjourned until 10.00 am on Tuesday,  
 7 24 January 2023)

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<p><b>wherever</b> [2] 50/22 65/1</p> <p><b>whether</b> [12] 31/16 31/18 31/19 39/3 45/14 53/12 55/10 57/25 59/24 78/9 81/7 81/8</p> <p><b>which</b> [48] 1/12 5/19 7/1 7/13 11/6 12/19 13/19 14/2 14/24 15/16 16/6 16/16 18/8 19/12 22/1 22/18 32/25 34/1 34/3 34/11 34/12 34/17 37/21 37/23 39/14 40/5 42/9 44/11 45/25 51/13 52/5 54/1 54/2 54/4 54/15 55/12 60/9 61/23 62/19 65/14 66/1 68/17 70/6 72/17 73/22 82/13 82/21 83/2</p>	<p><b>while</b> [6] 40/24 40/24 49/13 59/6 59/11 80/8</p> <p><b>who</b> [30] 2/23 5/3 37/3 40/12 47/22 49/14 50/15 51/2 51/4 51/5 56/10 60/24 66/21 73/4 73/10 73/11 73/12 75/9 75/11 75/16 76/20 77/9 81/16 81/22 82/5 82/5 82/9 82/9 82/11 82/12</p> <p><b>whole</b> [8] 1/12 8/6 18/25 19/10 45/5 50/11 53/5 70/11</p> <p><b>wholly</b> [2] 47/13 60/7</p> <p><b>whom</b> [4] 1/8 1/9 6/8 39/2</p> <p><b>whose</b> [4] 13/18 15/14 15/15 82/23</p> <p><b>why</b> [5] 4/4 39/24 67/13 68/6 83/12</p> <p><b>wide</b> [2] 68/7 71/20</p> <p><b>wide-ranging</b> [1] 68/7</p> <p><b>widely</b> 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52/20 70/21</p> <p><b>wonder</b> [3] 37/20 38/5 43/19</p> <p><b>wondering</b> [1] 81/7</p> <p><b>word</b> [2] 66/6 82/11</p> <p><b>words</b> [4] 1/14 4/3 7/11 50/2</p> <p><b>work</b> [2] 35/23 69/19</p> <p><b>workers</b> [4] 9/5 9/11 49/17 50/9</p> <p><b>working</b> [4] 24/14 35/20 51/12 65/24</p> <p><b>world</b> [1] 12/17</p> <p><b>worried</b> [2] 42/6 74/12</p> <p><b>worry</b> [3] 57/20 80/19 82/7</p> <p><b>worrying</b> [1] 38/25</p> <p><b>worse</b> [1] 2/16</p> <p><b>worst</b> [1] 49/20</p> <p><b>worth</b> [3] 12/25 39/3 67/11</p> <p><b>worthy</b> [2] 9/9 9/10</p> <p><b>would</b> [50] 4/22 5/8 5/25 6/23 7/17 7/21 11/8 14/9 16/6 18/12 18/24 19/24 20/18 32/7 32/18 34/11 40/21 43/20 44/10 46/5 47/18 50/14 50/25 51/3 52/6 57/1 57/21 58/7 59/22 60/21 60/22 61/11 64/24 66/22 66/24 67/13 70/4 70/8 70/8 74/13 74/18 74/19 75/14 75/21 75/22 79/19 81/14 81/19 82/10 82/11</p> <p><b>wouldn't</b> [2] 14/15 68/6</p> <p><b>Wright</b> [1] 84/2</p> <p><b>writing</b> [2] 38/24 51/11</p> <p><b>written</b> [9] 7/14 29/13 32/4 32/6 32/13 42/8 44/21 48/11 77/19</p> <p><b>wrong</b> [11] 3/11 3/23 3/24 4/5 4/6 4/11 11/2 65/22 66/2 81/11 82/11</p> <p><b>wrongdoing</b> [1] 4/2</p> <p><b>wrote</b> [1] 38/16</p> <p><b>Y</b></p> <p><b>year</b> [2] 41/19 42/11</p> <p><b>years</b> [7] 3/8 52/24 52/25 57/2 57/3 58/2</p>

<div><div>Y</div><div><div>years... [1] 65/18</div><div>Yellowlees [1] 40/2</div><div>yes [17] 1/5 18/19</div><div>34/14 34/25 35/16</div><div>35/25 36/4 44/1 53/20</div><div>54/12 54/12 54/13</div><div>54/19 55/13 71/6</div><div>71/13 83/24</div><div>yet [2] 1/25 34/23</div><div>you [196]</div><div>you're [1] 14/16</div><div>young [3] 56/2 70/4</div><div>71/24</div><div>youngest [1] 58/9</div><div>your [13] 2/11 5/2</div><div>20/18 21/12 32/18</div><div>39/23 54/10 54/24</div><div>76/16 76/17 76/19</div><div>76/21 82/16</div><div>yourself [2] 77/2 77/2</div></div></div> <td></td> <td></td> <td></td> <td></td>				
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