Thursday, 26 January 2023 (10.00 am) SIR BRIAN LANGSTAFF: Yes, Mr Johnston. Closing statement by MR JOHNSTON KC On behalf of the Scottish Government MR JOHNSTON: Thank you, sir. Good morning, sir. Good morning, everybody. I introduce myself, I'm a member of the legal team which represents the Scottish Government, one of the Core Participants in this Inquiry. My role here is solely to represent the Government. We have, it's true, provided assistance to some of the witnesses, civil servants who currently work in the Scottish Government, as well as former ministers and former civil servants in the Scottish Government, in preparing their statements for the Inquiry, but I'm not here to represent them. I should say while on this subject that the Scottish Government has also provided many documents to the Inquiry and arranged for numerous witness statements to be given and it remains ready and willing to assist the Inquiry in completing its work. I'm going to be quite brief in these submissions.

I'm going to be quite brief in these submissions. What I'd like to do before I come to add some points to the written submissions is to begin with an apology.

has been infected or affected.

In her statement, the First Minister also said that we must do everything in our power to ensure that such terrible events never ever happen again, and that is why this Inquiry is so important.

The evidence given to the Inquiry by those who were infected or affected has been delayed and it has been harrowing. We can now understand those difficulties and hardships at least a bit better.

Giving evidence about, and reliving, these traumatic events cannot have been easy, and we acknowledge the courage of the witnesses who have given evidence to the Inquiry and assisted it in coming to understand how their lives and the lives of people close to them have been affected by their infection.

Making this renewed apology is really the most important thing I can do in these closing submissions. Nonetheless, I will turn to a few further points. First of all, a few points to set out the scope of the submissions I am making. I note that in our written submissions we've given a brief account of some issues which confronted Scottish administrations in the past. Many of those arose prior to devolution. Now, as the Inquiry is aware, prior to devolution, there was a fair degree of operational independence in NHS bodies in

I do so because the Scottish Government is acutely aware of the suffering of those who were infected with HIV or with hepatitis as a result of NHS treatment with blood or blood products. It profoundly regrets that anybody should have suffered in that way.

Now, the evidence given to the Inquiry has made the extent of that suffering clear and it's also shown how people, infected or affected, have been let down by many people over many years.

The Scottish Government also deeply regrets that it's taken so long for Government to listen properly to the concerns of those people and to take action, and we recognise that the long delay has added to the hardship and to the distress.

In March 2015, following the publication of the report of the Penrose Inquiry, the First Minister made a statement to the Scottish Parliament and in it she apologised on behalf of the Scottish Government and on behalf of the NHS in Scotland to everyone who has had to deal with the devastating impact of infected blood or blood products. She mentioned that she could not begin to understand the difficulties and many hardships which individuals and their families had had to contend with.

And on behalf of the Scottish Government I make this apology again and it's a sincere apology to everyone who

Scotland but the NHS was actually responsible to the Secretary of State for Scotland, who was a minister in the United Kingdom Government.

That has changed since devolution, and it's now responsible to the Scottish Government.

For the period prior to devolution, therefore, prior to 1999, the submissions which have already been made on behalf of the Department of Health and Social Care are also relevant to issues which arose in that period in Scotland.

So far as our written submissions are concerned, we attempt to marshal the main elements of evidence which bear on what was done by Scottish administrations in the past both before and after devolution. But it's only a summary and this Inquiry has a much fuller picture of the relevant events than is available to the Scottish Government, and weighing the evidence, reaching conclusions about it, are of course for the Inquiry alone.

This morning I'm not going to go over the historical, as it were, material which we've set out in our closing submissions. In what I say today, just as in our written submissions, we are not seeking to advance any case or any line of argument. We're not seeking to justify or excuse what was done by ministers

(1) Pages 1 - 4

or civil servants in previous administrations and, on the other hand, we're not seeking either to criticise particular individuals for what they did at the time. All of those things are, we think, for the Inquiry to do in its report and, indeed, if criticism is warranted, then, no doubt with appropriate caution, the Inquiry will criticise those whom it feels ought to be criticised.

Today what I'd like to do is address only two topics. The first is to make some comments additional to our written submissions about the compensation framework proposed by Sir Robert Francis and second is to comment briefly on some recommendations made by other Core Participants. Those are, in particular, the ones made by Thompsons Solicitors since those ones are directed specifically at the situation in Scotland.

So turning, then, to the compensation framework. It's important to say this at the outset: the Scottish Government supports the payment of compensation and the setting up of an appropriate scheme to deliver it. We strongly support also the key principle which underpins the Francis framework, namely that there is a decisive moral argument for making payment to those infected and affected, without the need to establish legal liability. Indeed, that is the basis on which the Scottish Infected

concerned, there are a lot of matters of detail to consider, but those are not a matter for today. But a critical issue on which it may be helpful to give the Scottish Government's perspective is this: at the most general level, it's the issue whether the scheme should be uniform across the United Kingdom or ought, on the other hand, to take account of local conditions in the various nations of the United Kingdom. I have just four general observations to make about the scheme which the Inquiry may possibly wish to consider.

This is the first: we accept -- and indeed, this was Sir Robert Francis's view -- we accept the desirability in principle of establishing a United Kingdom-wide compensation scheme. The notion underlying that is that the infected and affected community in each part of the United Kingdom should be treated in the same way, and we think that's a key aspect of fairness.

Having said that, however, the Scottish Government remains committed to the benefits of retaining the SIBSS scheme, which I've already mentioned, to retaining it as a separate Scottish seem for continuing support payments.

Now, that's consistent with the general position of parity of approach throughout the United Kingdom, but it would give flexibility to retain a separate Scottish Blood Support Scheme, or SIBSS, already operates.

We also acknowledge this is a unique situation, not least because the victims have had to wait so long for proper support. Our understanding is that most of those infected and affected would rather claim under a compensation scheme than go to court, and that underlines the importance of devising a scheme which is comprehensive, complete and works well for those who will make claims on it.

It's Cabinet Office which is taking the lead in considering how best to implement the proposed compensation scheme, no doubt in light of recommendations which this Inquiry will go on to make. The Scottish Government, and indeed the other devolved administrations, expect to be involved in detailed discussions about the structure of the scheme and we are looking forward to taking part in those. Our hope is that agreement on how to proceed will be reached on a four nations basis. In our submission, that would be appropriate.

For the same reason, we also think it would be appropriate that the scheme should be funded by the United Kingdom Government, because those who were infected were infected before devolution took place.

So far as reaching the agreement about the scheme is

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approach where the members of SIBSS would prefer that.

I could give one example. The current system under SIBSS is that beneficiaries in the group of hepatitis C stage 1 sufferers are able to make self-assessments in which they place themselves in one of three categories based on how affected they are by the virus. That has wide support within the community in Scotland, as I understand it, and that's the sort of thing where the Scotlish dimension is, we think, of value, and to have differences, to some extent, differences of approach, is of course entirely within the spirit of devolution.

Coming to my second point, establishing a United Kingdom-wide scheme inevitably gives rise to a question how the scheme should deal with situations where the law across of the four United Kingdom nations is not the same. The Scottish Government is aware that the Inquiry has obtained evidence considering the extent to which heads of damages in personal injuries litigation are the same in Scotland as in England and Wales.

Broadly speaking, since the principle which underlies awards of damages is the same in each of these jurisdictions, that the claimant, to the extent that money can do this, should be put in the same position as if he or she had not suffered the injury, given that underlying principle, there's a significant

correspondence between the heads of damages which are recognised. But in our written submissions we've drawn attention to what might be called four structural issues which nonetheless could have the effect that the same case would attract a different award on either side of the border, Scotland on the one hand, England and Wales on the other.

Those four points -- I don't propose to go into the detail again, it's in the submission -- are: firstly, different discount rates; secondly, the fact that Scots law does not recognise the concept of aggravated damages; thirdly, different rates of interest awarded on damages; and fourthly, the treatment of damages in fatal claims where the governing legislation is different on either side of the border.

This is not the place to discuss these issues in detail, so the only point I am making here is that while some variation across the United Kingdom nations may be entirely appropriate, significant differences in the levels of award does not seem justifiable. These four structural issues are capable of having a significant impact on the level of awards, and therefore leading to unequal treatment, and it's therefore important that they be considered and resolved before a scheme is put in place.

the scheme as long as it was possible to identify the elements which the settlement covered. He mentions that in his report, for example, in paragraph 2.57 and 9.6. The Scottish Government agrees with Sir Robert Francis on this point, because it reflects the general principle of restitution, which I've already mentioned.

Now, those are the only points I'd like to draw attention to in relation to the compensation scheme, and of course they're all matters for the Inquiry to consider and on which it will reach its own view.

SIR BRIAN LANGSTAFF: May I just ask you one question about the way in which previous payments should be taken into account. You're expressing an understandable principle that those in like situation should be treated alike --

15 MR JOHNSTON: Yes.

SIR BRIAN LANGSTAFF: -- or at least equally. The schemes may be one thing, but there are various other payments which may have been made as a result of the circumstances, both of an infected individual and those whom the infected individual relies upon for his or her -- normally his, in the circumstances we've been looking at -- care and attention. That may involve social security payments. If those social security payments hadn't been paid then the individual would have had to borrow, at considerable expense, et cetera

So that was the second point.

The third point also flows from the potential for unequal treatment, and it's a point we again make in the written submissions, which is about the extent to which account ought to be taken of payments made under previous schemes. I should make it clear that this is not a point about penny pinching; nobody is arguing against payment of substantial compensation to those infected and affected. Nor are we suggesting that every past payment should be deducted. The only point we make, as a matter of fairness, is that equal treatment of those affected or infected should mean that the scheme treats individuals in the same or similar circumstances in the same way. In short, they should all be compensated fairly.

We think that points towards looking at the whole picture over the years, rather than starting completely afresh when the new scheme commences.

The fourth point I make is this: it relates to one of Thompson's recommendations, which is that awards which were made to settle litigation should not be taken into account under the new compensation framework. Now, that's a departure from Sir Robert Francis's recommendations which were that such sums should be deducted on a like-for-like basis from awards made under

1 et cetera, and it would be incomprehensible and
2 inconceivable that there shouldn't have been such
3 payments. Are they to be taken into account?
4 MR JOHNSTON: Payments made under a social security scheme?
5 SIR BRIAN LANGSTAFF: Because arising out of exactly the

SIR BRIAN LANGSTAFF: Because arising out of exactly the same situation, which would not have been paid had the individual been fit and working, and his carer being able to go to work and earn rather than having to devote their time to care.

MR JOHNSTON: Yes, I see that, sir. Well, clearly the way
 that you've explained the situation, sir, one can only
 see that to take account of those on the facts that
 you've suggested would result in hardship and
 unfairness, and there's no suggestion that that should
 be the outcome of any scheme that's put in place. So --

SIR BRIAN LANGSTAFF: So then taking it a stage further,
might it be said that to a considerable extent, if not
the entire extent, the payments made under the support
schemes were made because of the very particular
hardships and the very particular expenses the people
suffering incurred at the time, such that their need for
those was depressingly similar to the circumstances
which might give rise to social security payments of

which might give rise to social security paymentsa more limited nature?

24 a more limited nature?

MR JOHNSTON: Yes, I can see on particular facts that that

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1 might well be said, sir, yes. I think what it comes 2 down to essentially is that one can distinguish between 3 support on the one hand and compensation on the other, 4 and when one draws that distinction it may be easier to 5 see which payments, if any, ought to be taken into 6 account and which ought not. Because, essentially, as I say, we're not arguing against the payment of 8 substantial compensation. We're not arguing that people should be in a position where they are suddenly faced 10 with having to repay support payments. Clearly not. 11 The concern is only that, if one has certain individuals 12 who have received very substantial payments, then one 13 has to be able to understand why, on Sir Robert 14 Francis's proposed framework, other people will be 15 treated in a different way. Really, the point goes no 16 further than that. 17 SIR BRIAN LANGSTAFF: So, in essence, you're drawing 18 a distinction between payments which are made in support 19 and payments which go beyond support and into 20 compensation? 21 MR JOHNSTON: Yes, in essence, that's it.

compensation, your submission is in some way that should be taken into account?

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SIR BRIAN LANGSTAFF: And to the extent that a payment, if

it can be identified -- the extent the payment goes into

recommendation, which is that the duty of candour within the NHS should be extended. There should be improvements in whistleblowing and the NHS complaints system should be reformed.

There has, however, been a lot of recent activity in this area and I could mention, I think, just two things. The first is that in Scotland the Duty of Candour Procedure Scotland Regulations of 2018 came into force on 1 April of that year, 2018, and that's explained in Caroline Lamb's statement to the Inquiry. I'll just give the reference for the notes. It's WITN7458001. Now, those regulations apply where an unintended or unexpected incident has occurred during the provision of healthcare and it's resulted in death or harm.

The working of those regulations was reviewed after a year in 2019 and, in her witness statement, Caroline Lamb notes that the review made a series of recommendations and suggestions which have been considered and implemented by the NHS boards. Indeed, there is further comment on this in the submissions made on behalf of the NHS boards in Scotland, to the effect that patients are now more involved in decisions about their own care and the principles of realistic medicine and shared decision making are widely adopted across NHS Scotland.

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MR JOHNSTON: Yes, the submission is -- I don't wish to labour the point -- the submission is simply that when one has regard to the broader picture and treating everyone equally and fairly, that it would be appropriate that that should at least be something that could be considered in appropriate circumstances. SIR BRIAN LANGSTAFF: Yes, thank you very much.

MR JOHNSTON: I'd like to move on to my second topic for this morning, which is some brief comment on some of the recommendations made by other Core Participants and it's not an exhaustive response to any of their recommendations and, of course, some of their recommendations are primarily for other bodies to consider and address.

So these comments relate only to those which particularly affect the Scottish Government, so far as there is anything we would like to add to the written submissions and, for the most part, the points that I'm going to mention now are not covered or are not covered in any detail in the written submissions.

So the first heading I have is issues concerning Government and the NHS, and the first topic under that heading is candour and transparency, which I can divide up into two parts. The first is about medical treatment and, here, what I'm looking at is Thompsons'

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So that's the first point.

The second is that there have also been recent improvements to support whistleblowing, and the National Whistleblowing Standards came into force in April 2021. Those are all followed by all NHS boards, all of which have an independently appointed non-executive director for whistleblowing.

So, in short, the provisions for ensuring candour and openness have been bolstered considerably in recent years. Nonetheless, the Scottish Government will consider closely any recommendations for further improvement which the Inquiry wishes to make.

Turning from there to the same issue within Government recently, Inquiry counsel raised with senior civil servants whether there should be a statutory duty of candour, and that was discussed in the evidence session on 14 November 2022. Some Core Participants think there should be. Lesley Fraser gave evidence about this in relation to the Scottish Government, and her counterparts in the other UK nations did so too.

All four witnesses explained that civil servants are already subject to the Civil Service Code. Lesley Fraser also explains in her statement -- the reference is WITN7351001 -- she explains the other safeguards and initiatives that are in place in order to maximise the

So our view, in light of this evidence, is that there is already a well-developed system which secures openness and candour in decision making and policy development, and the up-to-date details are in the witness statements. Our submission is that what's important is that this system should work as effectively as possible, rather than there being a need for further legislation to make the duty a statutory one.

quality and reliability of advice and decision making.

But once again, of course, we will consider any recommendations which the Inquiry makes.

The only other topic under this heading of Government is the question of Government records. Of course there's no dispute about the importance of ensuring that Government records of significance are saved and retained, and now that records are stored electronically, issues experienced in the past with paper files going missing should not arise. The position in Scotland with regard to Government records is similar to that in England although the legislation is different. Very briefly, for the Inquiry's information, I'll just note that Scottish public bodies are subject to the Public Records (Scotland) Act 2011. And under that Act, Scottish public authorities, which include the Scottish Government and the Scottish

Scottish Government, through SIBSS, has provided beneficiaries with advice, mostly via the SIBSS newsletter, on how to access insurance.

Secondly, it's clearly important to note the context that insurance and mortgage markets operate on a UK-wide basis, so it's likely that any action, if recommended by the Inquiry, would need to be taken at a United Kingdom level

In one of the statements given on behalf of the Scottish Government, Sam Baker (the statement reference is WITN0713018) recommended that the four United Kingdom Governments should liaise with UK Finance to help increase lenders' understanding of the infected blood support schemes, and to provide reassurance that payments from those schemes will continue in the long term. That's a recommendation which Thompsons endorse.

Bringing the position up to date, our understanding is that there certainly were significant problems in the past for infected blood victims in accessing life or travel insurance or mortgages. Based on discussions with the insurance industry and representatives of the Association of British Insurers, the Scottish Government's understanding is that, for many people, the situation has improved. It's certainly true that those who have issues such as cirrhosis or liver cancer will

Parliament, are obliged to operate records management plans. Those set out the arrangements for managing the records they hold or which contractors who carry out any of their functions hold, or indeed records which they create or those contractors create.

Now, each of those records management plans has to be agreed by the keeper of the records of Scotland, who has the power to review whether authorities are complying with their plans, and if not, to issue action notices to them. Those notices are publicised and they will be mentioned in the keeper's annual report. So that's the current statutory regime.

Our submission is that this statutory framework is adequate, it is comprehensive, and it's subject to independent scrutiny. And that being so, we do not think there is a need, as Thompsons suggest, for Government papers to be held by an independent agency.

The second broad topic within the recommendations to which I'm now going to turn is the issue of non-financial support. We've set out some submissions about this in the written submissions starting at paragraph 155, and there are just a few points which I would like to add. The first is about insurance and other financial products. And it's simply to note a few points about this. The first is to note that the

face increased insurance premiums, but broadly, our understanding is that the position has improved as the industry has come to recognise the proper way in which to take account, if at all, of these viruses.

Those are just a few additional points to add to what is said in our written submission, and I note of course that we will, if the Inquiry wishes to make recommendations about this, consider them.

Three more topics under this heading. The first is psychological support services, which we already mention starting at paragraph 157 of the written submission.

And it's simply to note that the Scottish Government remains committed to providing psychological support services to the infected blood community, and as long as there is a demand for it, it will continue to support it, whether that is done by funding it directly or working with National Services Division and with boards to ensure that the service is provided. So the Government commitment is, in short, there.

Next, physiotherapy. This is a point which we did not mention in our written submissions, and so it's worth noting that we support Thompsons' proposals for a physiotherapy service for patients with bleeding disorders. And we note that the NHS boards have made a similar recommendation. Obviously it will be up to

them to consider how best to deliver it in relation to Scotland.

Then finally under this heading, there's the issue of palliative care which we already touched on in our written submissions starting at paragraph 160. But I'd like to make it clear that the Government is committed to ensuring the delivery of palliative care services for all patients, including those with advanced liver failure, according to what they need and wherever they may be, and that commitment extends to their families and carers too.

Thompsons' recommendation is that there should be a short life working group established on this issue.

As we've noted in our written submissions, however, there are already advisory and steering groups already in place, and so we would need to consider if a new group is needed or whether any Inquiry recommendations might be best considered by the existing groups.

We note from the NHS board submissions that they state that those with advanced liver disease and associated conditions are best cared for within the existing palliative care services. And they point out that giving local palliative care teams either within the community or in hospitals, giving them easy and reliable access to expert advice from relevant

statement I've mentioned explains, the then Chief Medical Officer wrote to remind medical professionals about the risks of hepatitis C for those who had had transfusions before September 1991. And a public information notice was issued across Scotland and, as the statement explains, posters and leaflets were displayed widely in places such as GP practices, pharmacies, dentists, libraries, and so forth, to urge those who had had a transfusion to seek a test for hepatitis C.

The numbers of people in Scotland likely to have been infected via transfusion but still undiagnosed is likely to be extremely small based on the working group's calculations. So far as the future is concerned we therefore think it is doubtful that more public appeals would be needed or would be effective, but we will, of course, consider anything the Inquiry recommends, including looking at whether further engagement is needed with particular groups of health professionals such as GPs.

The second topic under this heading is the Patient Safety Commissioner, as to which we already made some submissions in the written submission at paragraph 187. So what I say here is by way of bringing those slightly up to date. The Scottish Parliament is currently

specialists in relation to the particular and specialised needs of individual patients, would ensure that all of these teams, these palliative care teams, can follow best advice.

That, however, is precisely the sort of point which the new Strategy Steering Group for Palliative and End of Life Care, which we mention in our written submission at paragraph 162, will wish to consider in developing its overall strategy for provision of palliative care.

I'm coming now to the third and last group of recommendations, which I can loosely describe as relating to future steps.

So the first of these is about locating people with hepatitis C who have never been diagnosed. The Scottish Government carried out significant work on this issue in response to the Penrose Inquiry recommendation that a hepatitis C test should be offered to anybody who had received a blood transfusion before September 1991 but who had not yet been tested. The details are set out in another witness statement by Sam Baker, the reference to which is WITN0713020.

In short, a short life working group was established to implement the Penrose recommendation. It included representatives of the infected and affected community who supported the group's proposal. And as the witness

considering the Patient Safety Commissioner for Scotland Bill and it is at stage 1 of the three-stage Parliamentary process.

The lead committee on the Bill is the Health, Social Care and Sport Committee. It issued a call for evidence which closed on 14 December 2022 and, in response, it received 54 submissions, including one from Haemophilia Scotland.

The next step is for the committee to hear evidence and to produce its stage 1 report. Once that is done, the Bill will go before Parliament as a whole to consider its general principle.

So that's the current state of play on the Bill. The Bill as introduced allows the Commissioner to make recommendations for systemic improvement in the safety of healthcare and under the Bill, as introduced, the Commissioner would be able to consider issues relating to blood or plasma-derived medicines, and that accords with the proposal made by Thompsons in their own recommendations.

The final point I wish to make is that Thompsons recommend that a task force should be established, and that it be established to implement any recommendations which this Inquiry makes. The Scottish Government is happy to consider doing that in relation to Scotland and

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it's equally happy to participate in any United
Kingdom-wide task force. Thompsons make a further
proposal that the work of the task force should be
scrutinised by the Scottish Parliament, namely by the
Committee I've just mentioned, the Health, Social Care
and Sport Committee.
So I should make it clear that the Scottish

So I should make it clear that the Scottish Government's position is that it would clearly be happy to keep that Committee updated on the work of the task force. Obviously, the extent to which the Committee wished to scrutinise it would be for the Committee itself to decide.

In short, there is willingness on the part of the Government to participate here, but we will need to see the Inquiry's recommendations before deciding how best and how most effectively they should be taken forward.

Sir, that's all I wish to add to our written submissions, and all I want to do in concluding is to reiterate the apology with which I began, and to say that the Scottish Government looks forward to the Inquiry's report, its findings and its recommendations, on which it will reflect with great care.

SIR BRIAN LANGSTAFF: Thank you very much.

There's one very small matter of detail in relation to the facts, which I wonder if you can help me with,

and it goes back to ... just give me a moment.(Pause)

Yes, it goes back to paragraph 25 of your submissions and this is in respect to the use of commercial product in Scotland for those who were treating people with haemophilia. If I just read it out to you:

"Government in Scotland had indicated to haemophilia clinicians even before the AIDS crisis emerged that commercial products should be avoided if possible."

Then you say they relied heavily on advice from experts.

There is no reference which you give for that statement. If you know it, tell me off the top.

Otherwise, I'd be grateful for clarification in due course as to what the factual basis for that is. I'm not immediately -- it doesn't immediately come to my mind. Plainly, it must be there somewhere. I'd be grateful for your identifying it, or those who instruct you being able to identify it and pass on that information because it might be quite useful for me to know when it was that the Government in Scotland indicated that and in what terms.

MR JOHNSTON: Yes, certainly. Unsurprisingly, I'm not in a position to produce the document right now but, yes,

we will certainly do that.
 SIR BRIAN LANGSTAFF: The

SIR BRIAN LANGSTAFF: That said, that point of detail -- I'm sorry for the time in relocating that -- can I thank you for your submissions. It will not have escaped the attention, particularly of those who are resident in Scotland, of the number of significant commitments which the Scotlish Government has made to them through you, here, in public today. So thank you very much.

9 MR JOHNSTON: Thank you, sir.

MS RICHARDS: Sir, if we can take a longer than normal break
 and then resume at the scheduled time of 12.00 for the
 closing statement by Nicola Leahey.

SIR BRIAN LANGSTAFF: Yes, indeed. So we will take a break until 12.00 and then we will hear from Nicola Leahey.

15 (10.48 am)

(A short break)

17 (11.58 am)

18 SIR BRIAN LANGSTAFF: Yes.

19 Closing Statement by NICOLA LEAHEY
20 MS LEAHEY: Afternoon, everyone, both here and watching
21 remotely.

My name is Nicola Leahey, and I thank you for giving me this opportunity to present my closing statement, which I've entitled *Blood Is the River of Life*.

Some might say that we're nearing the end, but for

us it will never end. This trajectory has changed our
 lives, shortened lives, lost lives, lost our futures,
 tainted our spirits, made us mistrust and lose
 confidence in ourselves and others.

I was infected with hepatitis C following blood transfusions in 1975 and/or 1980. I was only diagnosed in 2009, and received the horrific treatment of ribavirin and interferon in 2010 and consequently suffered the life changing effects.

I felt that my body had been absolutely violated, that I'd been physically and mentally abused, stripped of my dignity, my self-esteem diminished. I mourned my lost opportunities. I felt betrayed. I lost faith.

But I discovered you lot in 2018. It was so wonderful to meet others in the same situation -- sad, but wonderful -- who understand the worry and uncertainty, the fear of the unknown, the stigma, the guilt of surviving when others lose the battle. We are united. Thrown together through no fault of our own by one common theme: contaminated blood.

I have read, researched and listened. I have learnt a lot about the illnesses, about fellow victims, about people, those in authority, about organisations and about myself. Just prior to my diagnosis, I'd taken early retirement because I'd lost confidence in myself,

because of the lethargy, the brain fog and generally losing myself. The power of this community and the support networks have been a life saver.

Now, with the greatest respect, I have come to realise that the vast number of personnel involved in this Inquiry, and beyond, have had the security of wages and salaries because of our plight.

Many of our community have been denied that privilege of education, careers, furthering careers, and the security that goes with it. We have not had that security of a life free from anxiety, pain, suffering. Instead, we've had the uncertainty and fear of the future and eventual death.

Yet, all we ask is to be treated with empathy, respect and dignity. We shouldn't be made to feel like beggars receiving handouts, tossed to us whenever or however the powers that be make that decision. Our predicament, through no fault of our own, has now lasted for many decades, unnecessary suffering and numerous deaths, consequential medical and psychological trauma, medical and administrative failures, failed promises and knock-backs.

No wonder our faith and confidence in the very constitution of our country has been shattered.

The Inquiry has produced a mass of statistics but,

all health information to be accessed wherever we are nationally. Yet we still have big gaps of patient information being available and shared. Surely in this day and age of technology we should be capable of having a national and, indeed, an international system.

Number 2: the establishment of a patient passport for all hepatitis C and B patients, HIV patients and all recognised association conditions. These are already in existence for cancer, diabetes, cognitive problems and other conditions. This would alleviate the stress endured by the constant worry of what is now happening to our bodies. We have been ignored in the past, which has increased the time between diagnosis and treatment, and, therefore, contributed in many cases to early loss of life.

Number 3: the establishment and support for Freedom to Speak Up initiatives, within all departments, both governmental and NHS. The Inquiry has highlighted the lack of acceptance and encouragement for personnel to feel able to and confident to voice their concerns.

Number 4: the establishment of clearly defined policies that should be implemented, adhered to and audited. During my career in the NHS, cut short by the effects of hepatitis C, the difference between policies and guidelines was distinctly laid out. A guideline is

as I well know because statistics was part of my job, data is meaningless without the facts behind the figures. The facts are here: the people, the lives, the deaths, the suffering, the injustices. We have long awaited recognition and action and we now need to have our confidence in fairness and morality restored.

This Inquiry has highlighted so many areas in need of change and improvement. Some are to such an extent so obvious, and that's what makes it so infuriating.

I truly believe that the evidence heard has proved that this has been a multi-system failure that has categorically been allowed to fester and grow, much to our detriment. In my evidence in Leeds, in June 2019, I spoke about lessons learnt. So please, let's learn from what has been termed the worst tragedy in NHS history.

Lawrence.

My recommendations fall into three categories and relate to communication, education, support and finance. I'll start with the recommendations that I'd like to see in relation to communication.

The establishment of improved communication between all health care providers. I am aware that at least 20 years ago, a national electronic system was planned which would connect all institutions and departments for 30

a "should". A policy is a "must". I have observed, during the Inquiry hearings, that the lack of clear policies has given people in positions of responsibility the opportunity to individually interpret and perhaps disregard important decisions relating to the quick and timely identification of treatment of diseases and their effects

Number 5: the production of a flowchart, simple flowchart, describing the process for seeking advice, support and application for medical and financial assistance once diagnosed with hepatitis contracted from infected blood. This would signpost the infected patients to where to seek medical records and evidence, and how to join the support groups. Also, importantly it would assist the medical professionals in identifying patients and the process for the treatment and the support available from the relevant schemes.

Victims' evidence has demonstrated how the lack of clinicians knowledge and awareness has caused needless stumbling blocks resulting in delays and frustration.

My second set of recommendations that I'd like to see are in relation to education: the establishment of continuing education and awareness, especially for the medical profession and supporting professionals.

It is essential to recognise the importance of

treating patients as individuals, recognising and accepting that the patient is more than likely the expert of their own body, their feelings, et cetera, whilst the medical professionals are the experts in caring for that body.

If I may, I suggest educating all healthcare professionals in the skills of communicating with patients in an individual way that can be understood.

That can go down now, Lawrence, thanks.

Teaching and observing the way that professionals inform patients of sensitive and bad news. How many times have we had this bad news given to us in inappropriate places?

Teaching the art of encouraging patients to ask questions and giving them the opportunity to be part of that pathway of care.

Teaching and practising the principles of the duty of candour, along with the importance of openness and transparency in all healthcare settings. This has so much been an obvious omission in a lot of the evidence that we have heard.

Now, education and new research is a component for continual professional development. One of the examples of importance of research findings that we've heard was research findings were not being widely distributed and

exists.

People should be entitled to the same level of care wherever they reside. We need to have reassurance and confidence in the very same healthcare system that has failed us. There needs to be a better understanding of the importance of the patient's ongoing welfare; the patient requires that continual reassurance that everything is okay.

There are many patients like myself which, who following treatment have been declared free from hepatitis C and then discharged with no more regular follow-ups. But how do we know that our liver is not further deteriorating or that we have developed liver cancer, if we don't have regular ultrasounds or FibroScans? I have regular blood tests to allay my fears but not all victims have understanding GPs, and I would definitely like to see it as a normal occurrence for us to have regular, once-over check-ups, similar to a Well Woman/Well Man check-up. Surely we're owed that?

Number 2: the commitment to a secure future funding to organisations such as the Hepatitis C Trust, to provide the essential, ongoing support for victims.

Their support, advice and just being at the end of a phone has been so beneficial to so many. Also, I must say that the Hepatitis C Trust Zoom meetings are so much

shared with the right people, and it was the lack of awareness in the best practice to reduce the number of unnecessary -- unnecessary -- blood transfusions.

Teaching the importance of recordkeeping, documenting why a document was required and informing the patient of the reason for that decision.

Raising awareness of the importance of recording all decisions, and that it is just as important to document why something was not done as well as documenting what was done. And that is so important, documenting why they didn't do something.

Teaching and a raising awareness in the taking and documenting of consent.

Teaching the importance of the correct comprehensive recording of information on death certificates.

Something else that we keep hearing about.

Teaching and raising the awareness of recording and auditing and learning from such things as adverse events, serious incidents and near-miss incidents.

That's education.

Now, my final set of recommendations that I'd like to see are in support of support and finance: the establishment of a universally agreed policy approach to the ongoing medical and psychological support for all victims, thus ending the postcode lottery that now

appreciated.

Number 3: the establishment soon of a funded initiative to get the whole nation tested for hepatitis C. We've heard about the look-back exercises in some parts of the country. Why not everywhere? Why not now? Again, it demonstrates the importance of documentation in patients' records, as well as the importance of accurate and complete communication between secondary and primary health clinicians.

Number 4: the establishment of an arm's length body to manage the process of assessing and paying the compensation agreed. This was recommended in Sir Robert Francis's report, but nothing has been heard of it.

I feel it is imperative that this body be professionally led, trained in the history and the life-changing impact of the tragedy and understands the necessity to act swiftly to reach a satisfactory conclusion with empathy and respect.

Number 5: to establish further interim payments for all the infected and affected people, especially if the final settlements are to be in the distant future, a future that so many might not have.

Number 6: the establishment of a robust, administrative system to honour and guarantee for life in legislation, the continuation of the regular

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1	financial support, thus providing reassurance and	1	appreciated your compassionate, respectful, dignified
2	security.	2	manner now it's funny, actually, that, what you've
3	Number 7: importantly, the recognition and inclusion	3	just done, because we watch, we wait, for you to peel
4	of all those infected and affected by contaminated	4	back your mask and then ask your cleverly composed
5	blood, the self-clearers, the bereaved parents, the	5	questions. Even though you don't always get answers.
6	bereaved children, and those infected after the deemed	6	I thank all the Inquiry team and support staff.
7	cut-off dates.	7	I have personally appreciated Catherine's regular Zoom
8	Thanks, Lawrence.	8	catch-up meetings, so valuable to keep in touch with
9	Now, questions to be considered.	9	people, to hear people, to let people feel relaxed that
10	What next?	10	they can talk.
11	Are we yet again going to be fed empty gestures and	11	I thank Jenni and the legal teams. I fully
12	left waiting for responses and action, therefore	12	appreciate how it must have been challenging and
13	prolonging our anxieties? A Government minister said,	13	harrowing hearing the tragic accounts of the infected
14	"Time is of the essence". So that should be honoured by	14	and affected.
15	a timetable of updates detailing the progress of the	15	But most importantly, I must say, I thank all my
16	implementation plans.	16	friends and my family for the support that I've
17	Another question: would it be possible to see the	17	received.
18	final report before the press and the public?	18	Now, I've stood here with a beating heart, somewhat
19	How can we keep in touch? The camaraderie that has	19	rapid, but I'd like to honour and remember those of this
20	been developed has been so instrumental in the survival	20	community that unfortunately, through no fault of their
21	of many of us.	21	own, do not have beating hearts anymore.
22	Now, I'll finish by saying something positive. I've	22	Thank you.
23	made some wonderful lifelong friends, for which I'm	23	SIR BRIAN LANGSTAFF: One of the submissions which was made
24	eternally grateful.	24	to me earlier this week, and indeed on paper, is
25	I thank you, Sir Brian. Like so many others, I have	25	that I should see things in context, because actions and
	37		38
1	words can mean different things in different contexts.		INDEX
2	You've given us a perfect example of that. You've asked		
3	for people to be respected, yet you call them "you lot".		Closing statement by MR JOHNSTON KC 1
4	But from you, it's affectionate.		
5	MS LEAHEY: Yes.		Closing Statement by NICOLA LEAHEY
6	SIR BRIAN LANGSTAFF: Thank you very much.		· ·
7	MS RICHARDS: Sir, just to say what we have coming tomorrow.		
8	We will have Mr Aldworth and Mr Robinson on behalf of		
9	the Belfast Health and Social Care Trust and the		
10	Northern Ireland Blood Transfusion Service and we expect		
11	to conclude by lunchtime.		
12	SIR BRIAN LANGSTAFF: So tomorrow 10.00, Northern Ireland.		
13	(12.20 pm)		
14	(The hearing adjourned until 10.00 am the following day)		
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