Tuesday, 25th February 2020

(10.34 am)

SIR BRIAN LANGSTAFF: Before I begin, can I just pick up on what happened yesterday when we heard from the intermediaries. At the end of proceedings, a couple of people approached counsel to the inquiry, and asked if they could take advantage of the intermediary process. They wondered if it had been too late. Well, it isn't too late. We offer to anyone who wants it, whether they're in this room now or whether they are listening remotely, the services of the intermediaries. All they have to do is contact the Inquiry and ask to be put in touch with the intermediaries, and then the intermediaries will in due course produce a supplementary report covering anyone who wants to take advantage of their services. You've seen what -- how it's presented, and how they deal with it, and who they are, and it will be the same people who will be presenting the supplementary report.

As for today, can I welcome Professor Christie to the panel. We have to swear you in, so let that be done, please.

PROFESSOR DEBORAH CHRISTIE (affirmed)

PROFESSOR MYFANWY MORGAN (continued)

DR NICKY THOMAS (continued)

DAME LESLEY FALLOWFIELD (continued)

MS SIAN EDWARDS (continued)

PROFESSOR JOHN WEINMAN (continued)

Examined by MS RICHARDS

MS RICHARDS: I'm going to pick up where we left off yesterday looking at the psychological and emotional impacts on family members, spouses, partners, children, parents, etc.

Some of the emotional responses that a partner or other family member may experience will be the same or very similar to those which would be experienced by the person who is themselves ill; is that fair?

PROFESSOR WEINMAN: Yes. I don't know whether -- Deborah, is that a good opportunity for you to talk a bit about experience of illness in families?

PROFESSOR CHRISTIE: Yes, I think that when an illness comes into a family, it's not just the individual that's affected. The young person, the adult, whoever it is that's given the diagnosis lives in a system, a complicated and

complex system, and everybody in that family is equally affected by varying degrees of emotional response, be it sadness or guilt or distress, but it's not one person that carries that load alone.

MS RICHARDS: In particular, some of the shared emotional responses may be fear, uncertainty. You've alluded to distress, so the distress of watching a loved one in pain, whether it's physical or mental pain. We've heard in particular from witnesses who had family members, often partners, receiving interferon treatment, interferon, ribavirin, of the effect of that on personality, and personality change, and coping with the personality change, for example, of one's partner may be an additional emotional psychological burden for a family.

PROFESSOR CHRISTIE: Yes, absolutely, and the -- it's that contrast. It's knowing what that person used to be like and then realising that they're different and feeling angry about it or distressed by it. But equally by the fact that it's not that individual's fault, that it's something external that's happened to cause this, and whether it's possible for people to be

able to blame the illness, if you like, rather than blame the person. So that can be very, very difficult, because you're faced with somebody who is perhaps short-tempered or grumpy or distant or withdrawn, and what you want to do is you want to be with them, and take care of them, and they might -- be rejecting you or pushing you away. And so then you get an additional layer of difficulty, if you like, that adds to the difficult situation.

DR THOMAS: If I could add to that and say that I think the lack of information around how the interferon base medicines are going to impact on a individual is also another factor. So I think the partners, the supporting people were having to discover as they go along that this change in personality and character is attributable to the medicine and not just to a difficult personality. And I think that's been coming through quite strongly through some of the transcripts, that they're having to find this out as they go along because they weren't given that information upfront, although very limited information about this was presented.

PROFESSOR WEINMAN: Actually to say a little bit more about this, because I think the way you've phrased the question was this sort of shared response, people responding in a similar way, and we certainly heard that, that some families, you know, had this very solid response. They pulled together, they coped.

But we also did read, and I know from other work I've done, where there were really important discrepancies between family members. And if you remember what I was talking about at the beginning of yesterday, I talked about the way people make sense of illness, and certainly there's quite a lot of work around that, looking at what we call dyads, say a parent and a child, or partners or whatever, where one has a particular way of thinking about the illness and coping with the illness and it's not matched in the other person, and that -- where you get those rifts it can be really distressing, where maybe the person who is affected rather than infected perhaps in some way blames the other for not coping in a certain way, and some of those rifts that you can see, because of the different ways of processing and thinking about the illness, can be very powerful and actually

very hurtful because you don't get that power of the support within the family and that cohesion which, you know, we've seen some work so well, but it also can break down, pretty -- and we certainly read and heard a number of witnesses talk about that they just couldn't take it anymore, you know, they felt the other person somehow wasn't involved, might have been within a couple and so on. So we need to remember that. It's not always a good group response in that way from a family perspective.

MS RICHARDS: One of the additional burdens potentially for family members will be additional caring responsibilities, either directly for the person who is infected or having to take on additional caring responsibilities, for example for children, because their partner is not able to do that. What kind of toll can that take in practical, emotional, and psychological terms, both on individuals and on families as a whole?

PROFESSOR CHRISTIE: Well, it can have a significant impact, psychologically. So it can have an impact on your identity. So if you imagine you having -- if you've got a job that you love and

you enjoy, and you have to give that job up to look after somebody that you love and want to care for, there's still that dilemma of having to give that job up and what that means for who you identify as. Because a lot of us see ourselves as the job. The job that we do is how we describe ourselves when we introduce ourselves to people. And that can get lost.

There can be enormous financial implications obviously if somebody has to stop working. We see this a lot in families where there's chronic illness where one of the -- somebody in the family has to give up a job, so there's a financial impact.

And socially, if -- again, if you think about most of the -- most people who have jobs have relationships within their workplace, they have friends that they go for a drink with afterwards or they have the -- you know, the Christmas party, and that might seem really minor, but actually is a big thing, because you've lost that whole social circle and your life becomes condensed and focused on -- just into that very small sort of family unit.

So there's a -- and there can be resentment

as well. There's all these complicated feelings that need to be thought about and processed and understood and spoken about. And as Professor Weinman said, you very often find it difficult to talk about it because you want to protect somebody. You don't want them to know that you're resentful. You don't want them to know that you're sad that you've given up your job or angry or you don't want people to know that you haven't got money to do things. So there's also that sort of closing down on communication, which has an impact on family relationships.

MS RICHARDS: We talked yesterday about the process of adjustment for the person who is unwell, and the impact upon the concept of self-identity for the person who is unwell. But what you're describing is those same two processes or ideas impacting as well upon family members.

PROFESSOR CHRISTIE: Absolutely. Because when we -- as we grow, throughout our lives we go through various developmental phases and -- becoming a parent, becoming a partnership, becoming a grandparent, all those different developmental phases comes with certain expectations, our own expectations from our families, from society, from films, from everything that we read about what it means to be a good grandparent or to be a good mother or a good wife or husband.

And that identity then gets disrupted by the introduction of an illness and particularly by an illness that is potentially life-limiting. It kind of just cuts you off at the knees and throws -- can throw you under the bus.

If you've got a good support system, then you can be amazingly resilient and you can pull together, as John said, and many, many people do that. Many people do that in an amazing way, an inspiring way, but equally, it's very, very difficult.

MS RICHARDS: There are two pieces of literature I just want to refer you to there, materials you've referenced in the report, which provide confirmation of what you're saying.

Henry, could we have EXPG0000022, please. It should come up on the screen in front of you.

It's a paper called -- by Golics and others 2013, and it's called:

"The impact of patients' chronic diseases on family quality of life: an experience from 26 specialities."

We can see from the abstract, methods, it talks about semi-structured interviews being carried out with 133 members of mostly chronically ill patients from 26 medical specialities, family members invited to discuss all areas of their lives that have been affected by having an unwell relative.

Then if you look just over halfway down that page, please, Henry, at "Conclusion", you can see it says:

"This large scale multi-speciality study has demonstrated the significant yet similar impact that illness can have on the quality of life of patients' family members. Family quality of life is a previously neglected area of healthcare which needs to be addressed in order to provide appropriate support for the patient and family unit."

Then there are just a couple of references within the paper I wanted to show you, and then ask you to comment on. On the same page under the heading "Background" we can see it said there:

"The quality of life of family members as well as patients, can be hugely reduced in terms of physical effects, psychological distress and social problems."

Then the last sentence of that paragraph:

"Previous work has shown that family members of patients can be more emotionally affected by illness than patients themselves."

Then if we turn, please, Henry, to -- it should be the fourth page. It's headed page 790 in the article itself. That's the one.

Towards the bottom of that page, please or the bottom half of that page. Thank you.

So we see there under the heading "Emotional impact" it records:

"92% of the family members interviewed were affected emotionally by the patient's illness, mentioning worry (35%), frustration (27%), anger (15%), and guilt (14%). Worry was reported when the family members were thinking about the future or the patient's death. Less common psychological effects included feeling upset, annoyed, helpless, stressed and lonely."

Then it's reference to support, some people finding it difficult to find someone to talk to, and this resulting in them blocking up their feelings, finding it very difficult to cope, with many describing breaking down in tears when alone.

Then if we just go -- the study then looks at number of different impacts: daily activities, family relationships, the family members own health, work and financial impacts. But we'll pick it up, please -- it should be page 8, Henry -- in the discussion towards the end of the article.

We can see there:

"The impact of a patient's illness on families is widespread and profound. Family members are affected in multiple ways across all medical specialities. This study has identified the major ways in which family lives can be affected by disease and the commonality of issues across all diseases."

Then if we can go down the left-hand column on that page to the second paragraph, thank you. If you could highlight the paragraph beginning "Family members", thank you.

"Family members of patients from all specialities felt a great emotional impact, the most widely previously reported topic. They often felt they had to hide their feelings from the patient in order to provide support - for many this was very difficult. This emotional impact has a major influence on many areas of their lives, eg on health and sleep. Family members of patients can be more emotionally affected than the patients themselves, particularly in the area of oncology. This may be because attention is mainly focused on the patient and much consideration given to the patient's needs. In contrast, the family member and their concerns are usually ignored or not understood."

Then if we look at the right-hand column on that page, this is the last reference, second paragraph down, please, Henry, thank you, beginning "The impact on family finances":

"The impact on family finances and employment were major issues. Family members described the financial impact of having to reduce or give up work as a result of the patient's illness, often compounded by the patient also giving up work. Looking after an unwell patient is expensive."

Then the next paragraph, please, Henry, the

first three lines of that:

"Family members described their own existing medical conditions worsening, several developed depression. This study identifies family members as a hidden patient group, with an apparent 'ripple effect' of illness; one patient being unwell has the potential to create several more 'patients' in the family. This can then magnify problems with finances and family relationships in a vicious cycle. This hidden burden has a potentially huge financial impact on the healthcare system that could potentially be reduced by appropriate family support."

Any observations or comments about those findings?

PROFESSOR WEINMAN: I think they fit exactly, really, with what we're saying. And this is, you know, part of the very strong evidence that we've drawn on. There's a huge literature on the stress of caregiving, generally, whether it's with, you know, a very sick child or an elderly parent. And that literature shows really strongly that, you know, you not only see psychological changes, you see physical changes, changes in immune function. There are even

studies looking at how quickly -- you know, if people have wounds, if they are caregivers, those wounds are slower to heal because the immune system is compromised because of that really long chronic stress that's not going away. It's pretty uncontrollable in that way, it's something that's always going to be there.

So I think, you know, these sorts of findings really underline how -- you know, how much of a burden it can be. But again, as we said yesterday, for some people, it's a powerful and important thing to do, and the roles they take on, as caregivers become really important to them, become part of that new self, that new identity. So although it's pretty bleak, pretty negative, there is that other side that we shouldn't forget.

MS EDWARDS: Yes. Just to say, of course, that this study was done in 26 specialities, and none of those specialities are ones where people hide their diagnosis, and I think that makes an additional, very profound difference, because this is a distressing report, and it shows how awful it can be for people, physically and emotionally. But these people generally will be

people who can share the stories and what they're going through with their friends and their neighbours and healthcare workers, and I think when you take that part away, it has an even greater impact on the conclusions that this report has made.

MS RICHARDS: And that's picked up in the second piece of literature I wanted to just ask you to look at, which is a World Health Organisation analysis of the impact of HIV on families.

Henry, that's EXPG0000039, please.

This is a 2005 paper by the World Health Organisation entitled "What is the impact of HIV on families?" Again, referenced in your report.

If we could go, please, Henry, to page 4. Under the heading "Findings", if we could just highlight the first paragraph, please. It picks up on one of the very points that Ms Edwards has made:

"Human Immunodeficiency Virus has a large psychological, physical and social impact on infected individuals and their families. Stigmatisation worsens this impact. It hinders the prevention and treatment of HIV and hampers social support and HIV disclosure."

It is that latter point I think you were emphasising then.

If we could go on, please, Henry, to -- it's the page numbered 8 at the bottom of the page. Yes, it should be page 8.

So if you look under the heading "HIV and families", the second paragraph beginning "In the first 15 years of the AIDS epidemic", could you highlight that, please, Henry. This records that:

"In the first 15 years of the AIDS epidemic, families had to deal with the death and the loss of family members. Since the introduction of HAART in 1996, however, their widespread use has reduced the number of AIDS related deaths in Australia, Europe and United States. Now families must deal with the HIV infection as a chronic disease to be managed for the lifetime of infected members."

Now. If we just go on, please, to the page 10, Henry. There's a passage "Psychosocial issues" which covers much of what we said yesterday, but if we then look at "Families" at the bottom of the page, please, Henry, at the heading "Families", it talks about:

"The social stigma that surrounds HIV may have adverse repercussions not only for the individual, but also for their family.

"HIV has an impact on partners and on the dyadic relationship. Care giving is associated with stress and AIDS-related stigma."

If we go over the page, please, to page 11, we see in the second paragraph, please, Henry, beginning with "Children", you see a discussion there of the emotional distress that:

"... children may experience due to the HIV infection of a parent."

Then if we go on, please, to page 12, Henry, under the heading, "The impact of disclosure on the family", halfway down the page. We pick it up in the second paragraph:

"A review of the evidence in the early 1990s showed that when people disclosed their HIV status, family members experienced a range of emotions, including feelings of helplessness, fear of the loved one dying, concern about care and fear of becoming infected. A recent qualitative study, with mainly European participants, showed that even in the post-HAART era disclosure of an HIV infection may have an

emotional impact on the family members; they may be surprised and saddened by the disclosure. The potential for terminal illness -- as well as the impact of medical treatments and constant adjustment of hopes and fears -- can affect both the individuals infected with HIV and their families."

I think that's all we probably need to look at from that paper, but again, perhaps invite you, Ms Edwards, to comment upon what we see set out there.

MS EDWARDS: Well, maybe one of the others whose social context --

PROFESSOR MORGAN: I think --

MS EDWARDS: -- the report.

PROFESSOR MORGAN: It brings out very clearly that the impact extends beyond the individual to the family, and in terms of stigma the family is often also stigmatised. They have an associative stigma by their close association. So they share very much in the whole stigmatisation process, as well as in these other social impacts. Originally the emphasis was very much on the, just the patient, but I think that a lot of the recent work is very

much emphasising the family unit, and the importance of taking that through in terms of interventions.

MS RICHARDS: We'll come back, certainly, in more detail to the question of stigma and discrimination and disclosure. Just turning back to your report at page 4, and you've said this, towards the top of the page:

"The dominant picture [this was the picture that you picked up from the materials you read] is one of a wide range of negative psychological impacts often with devastating effects on day-to-day functioning and quality of life. These impacts occurred in the context of so many negative social effects arising from the relentless health problems and treatment side effects together with the distressing levels of stigma that were experienced."

That was the overall picture you derived from the statements and transcripts and oral evidence you saw.

PROFESSOR WEINMAN: Yeah, I mean, I think --

SIR BRIAN LANGSTAFF: I'm sorry. I didn't mean to interrupt. But please go ahead. I just have a question, because it seems to me we're turning away from the two papers that you've just been looking at.

MS RICHARDS: We are, yes.

SIR BRIAN LANGSTAFF: It had struck me in what the Golics paper says, that it is focusing upon the families. It's not focusing immediately upon the patient. One understands why that is. But is the position perhaps, can it be summarised in this way: that proper care of the patient involves care for the family and support systems?

PROFESSOR CHRISTIE: *(Unclear: multiple speakers)* Sorry, we all said yes.

SIR BRIAN LANGSTAFF: Universal agreement.

PROFESSOR CHRISTIE: Collective, yes.

SIR BRIAN LANGSTAFF: That's what I wanted to ask. Thank you very much.

MS RICHARDS: Thank you. I was just drawing your attention to how you'd summarised from your professional perspective, your understanding of what you'd read.

PROFESSOR WEINMAN: Yeah, I think I wrote that statement and, you know, but I also think that just before that, I had identified the possibility that people could draw some

benefits, so it wasn't all bad news, and I certainly spoke to one or two people yesterday for whom there had been growth, personal growth, and so on, but the dominant picture certainly from all the witness statements and from the literature is one of a whole range of problems compounded by, you know, treatments, failing, further conditions happening, and so on and so on. And by a lot of the other things we are going to talk about, by some of the communication issues.

MS RICHARDS: Yes, absolutely, we're going to come on to all of those. Can I ask, before we leave the topic or the theme of psychological impact, I wanted to ask Professor Christie about some of the particular issues that may arise in relation to children and adolescents because we know significant numbers of children or adolescents were infected, in particular with HIV, but with HIV and hepatitis.

First of all, can I ask you just to talk a little about the impact of long-term illness and in particular a long-term illness and serious illness of the kind we're dealing with on children and adolescents?

PROFESSOR CHRISTIE: Yes. So I would break it into two groups, which the first one is children. So the children who are being very much cared for and looked after. And are often very protected by their parents, so may not be aware of the diagnosis or the full implications of the diagnosis or may not understand fully the long-term implications just by virtue of their level of -- intellectual cognitive level of skill and ability.

However, what children are aware of is the fact that they are limited, that they are prevented from doing things. So they will not be able to do sleepovers. Sometimes that can be because their mum and dad might worry about them being away from home or it might be because the other children's parents don't understand what's needed or required in order to take proper care and so they'll not invite them.

Children with chronic illness often don't get invited to parties, birthday parties, because their parents feel they can't be catered for properly. They might not be allowed to go on school trips. So all of these things that we think of as being really part of our childhood

and part of growing up, just having fun -- because that's your primary job when you're a kid, a little one. Your main job is to just have fun and be looked after. And having a diagnosis of any illness, but particularly one which is potentially life-limiting, is going to stop you being able to do that in the way that your friends are able to do.

The second group is adolescents, which is a really different group, and it's -- in some ways it's the best group, and in some ways it's the most difficult. Because adolescents are going themselves -- without any illness involved, are going through such tremendous change. Their brains are developing rapidly, and changing dramatically, developing decision-making parts of the brain, developing the parts of the brain that allow you to think about your future, and the main job of an adolescent is to decide who I am, who I want to be, and who I want to be with.

And those three questions are what most adolescents spend their adolescence doing, working that out, deciding what they want to go to university and study, deciding what kind of job they want to have, looking at other people, identifying role models.

They spend a lot of their adolescence deciding on their sexuality, on their gender, who it is they want to spend the rest of their life with. They spend a lot of their time completely ignoring their parents. All of us have done this. It's one of our main jobs, is just to ignore your parents and borrow money from them, so that you can, you know -- and that's a dilemma.

And it is kind of funny, but it's also so true, and what happens in an adolescent's life when an illness comes along completely uninvited is that it knocks you off track. It starts to get you to question "Can I be who I'd like to be? Am I ever going to be able to have a long-term relationship?" And that came out through a lot of the transcripts. It came out really strongly that young people -- and I'm thinking of adolescence as going -- if you look at the brain literature, right up to the age of 25, 26, 29, even, a young person's brain isn't fully developed until 29, and that you actually spend so much time trying to work out who you

want to be that the illness completely stops you being able to think about that in a coherent kind of way.

And it can cause you to withdraw, it can cause you to rely so much on your parents that actually, you stop that whole developmental process of becoming independent and moving away. So it's really devastating, an illness. And as we've all -- we all keep adding as a caveat that there are many young people who grow through adversity, and growth through adversity is a really important psychological idea, but even with that growth through adversity, there is still an enormous impact on the decisions that young people can and are able to make when they're faced with living with this. And it's not just them, it's this ripple effect that we've already talked about, because it affects them, and it affects their relationships with their friends. And again, friends are so important when you're an adolescent. They matter so much to you, more than your friendship with your parents.

And your friends will not want to be with you, they will not want to spend time with you.

You will be seen as different. And all of that is going to affect your ability to develop and grow yourself, your picture of who you're going to be.

MS RICHARDS: Some of those from whom we heard very eloquent and powerful testimony who had been diagnosed with HIV as either children or adolescents, had grown up with it effectively all their life. And one of the points they made was they had never known anything different.

PROFESSOR CHRISTIE: Yeah.

MS RICHARDS: So in terms of self-identity, their self-identity was to a very considerable extent almost entirely shaped by the illness.

PROFESSOR CHRISTIE: Yes, and if you think about that, then -- your initial identity, your initial identity as a core human being is not one where illness is involved. And when illness then becomes your identity, it limits you. It can limit you. It doesn't always, but it can limit you. It stops you striving. It can stop you reaching out for things. It can stop you trying to find things that you may have done. It may affect your ability to do something like a gap year. You may -- you know, "Well, a gap

year is not for me because I've got this illness that requires constant medical care."

So it can have that effect on you as well. So it kind of limits you and changes your perspective of what your potential is. And all of us should have this, all of us should have the potential to be as wide-ranging as possible, but living and growing up with an illness like HIV, which has stigma and all of the negative aspects of that attached to it, that's going to completely restrict and give you a much, much narrower focus on what's possible in life.

MS RICHARDS: As may also some of the practical consequences of the condition, in terms of ability to access or complete education.

PROFESSOR CHRISTIE: Oh, absolutely. So we've known -- right back 30 years ago, I remember going on a trip to Washington DC where they were just starting to look at their cognitive effects of HIV in children, and they were just starting to do the very early brain studies, and measuring intellectual ability, and the impact on attention and concentration, and brain function. And very early on, people started to realise that something like HIV has an impact on the developing brain. And as I've said, if you think about the brain as an organic developing process, as something which grows and prunes and develops based on experience, if you have an illness like HIV, or the treatment associated -- it's not just the disease itself, the condition itself, it's the treatment, the medicines -- they affect the brain neurons, they affect the way the brain connects, they affect the way the brain develops. So you might have had aspirations to do something or be something that would require a certain amount of capacity, and the illness will take potentially take some of that capacity away.

MS RICHARDS: You've alluded also in the report to particular difficulties for adolescents with treatment adherence.

PROFESSOR CHRISTIE: Mm.

MS RICHARDS: Can I ask you to just comment upon that?

PROFESSOR CHRISTIE: Yes, and again, this is something which is kind of part of being an adolescent, which is to defy authority, and to not quite believe what your doctors say. So when you go to your doctor as an adolescent and your doctor says, "You need to take this medicine because it will keep you well", as an adolescent, there is a kind of a bit of you that thinks, "Well, yeah, you would say that because you're a doctor, but I'm different", and adolescents have a sense of being bulletproof, that kind of sense of central ego, the kind of like, you know, "Nothing can touch me. Nothing can harm me. It'll happen to other people but it wouldn't happen to me".

That's a really important part of being an adolescent, because that's what helps you take risks. It allows you to do things like experiment, to go out and club until four o'clock in the morning or do all the fun things that adolescents gets to do before they have to grow up and become an adult.

Actually, what happens when you are trying to do all of that with a chronic illness it's going to have a really -- it's going to stop you doing it. It's going to have an impact on you.

MS RICHARDS: Can I ask you about the position for children. Growing up with a parent who is significantly incapacitated by HIV or hepatitis, and who may themselves have -- be carrying a significant psychological burden of their own. You've referred in the report to a paper -- I won't put it on the screen -- it's a paper written by Beardslee which talks about how the children of affectively ill parents are at significantly greater risk of developing psychiatric orders themselves.

PROFESSOR CHRISTIE: Yes.

MS RICHARDS: We have certainly heard evidence which supports that.

PROFESSOR CHRISTIE: Yes, so again, if you think about this, the family unit, so a child depends very much on their parent as a source of emotional care, psychological care, physical care, and financial care, all of those aspects, and when a parent becomes ill, understandably and reasonably, they may struggle to provide all of those aspects of care, and may not be emotionally available because of their on mental health problems.

There's a lot of evidence in other conditions that where, even where there's no physical illness, where a mother who has emotional distress results in the child developing difficulties. So there's difficult with attachment, early attachment, which is really, really important for psychological wellbeing. So the child themselves is affected by the fact that the parent is ill, and will grow up trying to care for their parents, even.

They'll work very, very hard to look after their mum. And in looking -- working so hard to do that, where there's very little support, then and now, very little support, for child carers, that child then becomes separated from their peers. Again, they can't go -- they may well be well physically but they can't go to parties because they'd have to leave Mum at home on her own or leave Dad at home and not be sure whether they'd be able to take care of themselves. They might not be able to go to bed at a time that they should be going to bed because they have to stay up to make sure that Mum or Dad take their medicine. So there are a lot of knock-on effects on effectively a healthy child living with a parent who is struggling with a chronic life-limiting illness.

MS RICHARDS: We've heard certainly some evidence of that ripple effect extending into a third generation --

PROFESSOR CHRISTIE: Yes.

MS RICHARDS: -- with grandchildren as well.

PROFESSOR CHRISTIE: Oh absolutely, yes, and it works all the way down depending on the age of grandparents but again, if you think about middle age, and a teenager, for example, whose grandparents themselves are ill, they may be looking out for their grandparents because their parents were ill, so there's so many complicated possible complications.

If a parent is unwell or a parent has died, then the normal burden, if you like, of looking after elderly parents falls on us, as, you know, we're in our middle age and we've had our kids but now our mums and dads aren't well and so we're looking after them. But if we are taken out of the picture because of something like HIV or hepatitis, then our teenage children or our children in their twenties may then have to step in to look after their grandparents, so it can be multi-generational.

MS RICHARDS: I wanted to explore some of the social impacts and I appreciate there's no bright line between psychological and social, hence psychosocial, but you've identified in the

report, first of all, a range of negative impacts upon an individual's working life, and you've identified that can arise in a number of different ways, inability to work at all, or having to decline promotion or only being able to work part-time.

What can be the impact upon an individual and on a family of those kind of changes having to be made to working life?

PROFESSOR MORGAN: A major impact, of course, is financial, and this was a particular problem for families because over time, as the people's condition got worse, they would have to go from full-time employment to part-time employment and then often come out of employment. So that had a major impact. Then, in many cases, the carer, the partner, also had to reduce their employment or sometimes give up employment, and so the financial impacts were very great. Of course, it varied a bit according to age. It was particularly important for young couples, and people running small businesses and so on and, of course, has impacts all along the line, really, because it's going to affect housing, it's going to affect other opportunities, so

a very, very major impact.

MS RICHARDS: We heard from some witnesses who talked also about how not being able to work or not being able to work in the way or in the job that they would have liked impacted upon their self-esteem, their sense of being of the person who ought to be the provider, and the breadwinner for the family.

PROFESSOR MORGAN: Yes, because, I mean, work often gives you a sense of identity as well as a sense -- as well as of other relationships and opportunities. So all these things were very important and come through very strongly.

MS RICHARDS: And the financial impact, and I'll come back to financial impact in a few minutes, perhaps, but the financial impact can take a further toll in terms of insecurity, a risk of losing the house and the like. That threat of financial insecurity will no doubt exacerbate the other social and psychological impacts and negative effects that the person or family may already be experiencing.

PROFESSOR MORGAN: Yes, it came through as a major source of worry and tension, and it's obviously going to be tensions within the family, and

between partners. And this is a very sort of strong effect.

MS RICHARDS: Could we just put up onscreen, there's just one passage from your report I want to read out, if you put it up onscreen, others can follow it. The report is EXPG0000003, please.

If we go to page 19, please. Henry, it will probably actually come up as page 20 on yours. It's 19 on the one before. If you go on to the next page, please. Thank you. Could you just highlight, please, Henry, the passage halfway down the page beginning "The cumulative effects".

This is what you've said, and I've put it up on the screen so we can see:

"The cumulative effects of limitations in employment potential arising from interruptions in education, together with the continuing health effects, have undoubtedly had negative financial consequences for many infected and affected individuals. Although the extent of this varied across individuals and families depending on their prevailing social circumstances and life stage, the overall costs have been high. A variety of financial payments were available but they were neither universal nor considered sufficient. Many witnesses describe being ground down in their attempts to obtain financial assistance and then giving up. For many, this difficulty in both accessing and receiving financial payments from the trusts and schemes had a range of negative consequences. In addition to the effects of continuing financial hardship, many witnesses report feeling let down, angry and ultimately helpless. It is known that frequent unsuccessful attempts to change an adverse situation typically result in feelings of helplessness and hopelessness, both of which are likely to lead to negative mood and depression."

Is there anything you would want to add on that issue to what you've recorded powerfully in the report there?

PROFESSOR WEINMAN: These are very well-known effects from, you know, when people have to -- whatever the situation is, when people are in adversity, you know, naturally one tries to cope by gaining control, by doing something. But if you're constantly thwarted in your attempts to gain control or to change a situation, this

notion of helplessness or what we refer to as "learnt helplessness", what you learn is whatever you do, nothing is going to work out. That you actually have no control.

We've known for many years that can have a profound effect on people's mood, their wellbeing, and it's a very potent source of depression. So, that's really -- I mean, I think as -- we've said that, but, you know, these effects are profound across a whole range of domains in life, yeah.

MS RICHARDS: You recommended in your report the possibility of obtaining a health economist's input.

PROFESSOR WEINMAN: Yeah.

MS RICHARDS: I should say that is a matter on which Sir Brian invites core participants to make submissions as to what issues could or should be addressed by health economists. But could I ask you from your professional perspective to identify any particular issues or analyses that you think a health economist might be able to undertake?

PROFESSOR WEINMAN: Yeah.

DAME LESLEY: Maybe I can come in here. Certainly

there is a concept now that a lot of us are dealing with, known as financial toxicity. We're used to talking about drug and treatment toxicities but most -- even in a good setting, most treatments and people with illnesses experience a financial toxicity. And one of the problems that health economists sort of tend to focus on is direct drug costs or treatment costs to an institution, to the health service. They rarely deal -- when NICE, for example, are dealing with new drugs or treatment, they rarely deal with the financial toxicity that families actually are experiencing as a result of what's happened to them.

So I think if we do, you do engage a health economist, which would be good, you really do need one that's rooted well in the more social sort of costs of all these sorts of areas.

The other thing that's important to note is that, with the sorts of poverty that we saw some families actually, you know, tumble into because of what happened to them, there's no doubt about it that poverty in itself is linked with poor physical outcomes as well. The Marmot report has just been upgraded today, demonstrating how

well poverty in itself actually does lead to poorer health outcomes.

So even many of the infected and affected individuals that were getting good treatment, if they were plunged into financial toxicity, were likely to experience poorer outcomes physically, not just emotionally.

MS RICHARDS: Can I turn, before the break, to two other aspects of social impact. The first is the impact upon some of the most intimate aspects of private and family life. Again, you've identified in the report gleaned from the witness testimony that the inquiry has received, decisions partners are having to take of opting for lives of celibacy because of the fear of transmitting infection, and then decisions families having to take or couples having to take, women facing decisions about terminations, being advised to have terminations, couples deciding not to have children, or not to have any more children, or couples having to try to obtain funding and go through processes such as sperm washing or other risk reduced conception methods.

Again, I wondered whether any of you have any observations in particular to make upon those issues and those impacts that you saw.

PROFESSOR MORGAN: Well, they were very, obviously, central to people, to life, and they caused considerable emotional upset, which lasted throughout their lives, really, because it also had the effects that they wouldn't have grandchildren and the whole issues. It was in some cases people had abortions because at the time of conception they didn't even know that their partner had HIV, so, you know, they lacked information, and afterwards, they lacked full support, really, in coping with this crisis in their lives.

DR THOMAS: I'd say this is a major area of grief and bereavement that hasn't been addressed for many, many people. I know we're going to talk more about psychological support but an important aspect of psychological support would be to focus on the potential, the loss, actually losses and potential losses and I think for many people, that's when I look at -- looked at the transcript, there's evidence of complicated grief because, you know, how do you come to terms with the difficult losses.

MS RICHARDS: Yes, I will come back to complicated grief, certainly. You've already alluded to it and touched upon it in your report but all of these issues you've been discussing can take their toll on marital relationships, partnerships in particular, and you've picked up in your report on some matters that may have been strengthened but others that have taken an irreversible toll on a marriage and marriages ending, again, is there anything in particular you would want to add to what's in the report in relation to those particular issues?

DAME LESLEY: One of the things I think actually in this area is that not all relationships anyway start from a good stable base, and one of the things certainly you notice in any life-threatening illnesses is that it can really be the final straw to already a struggling relationship. Family dynamics are complicated anyway. Relationships between partners are complex as well.

Particularly when you get reversals of roles and responsibilities as we've been talking about this morning, that really can, I think, impinge hugely on an already shaky relationship.

I think we saw some evidence of that in some transcripts.

PROFESSOR MORGAN: Families were also often quite isolated. They didn't have the support necessarily of a wider group of relatives or close friends, because of all the problems that they were experiencing, so they became very sort of closed units, so I think this puts additional stress and the lack of, as we know, social and psychological support from others is very important.

MS EDWARDS: There's one thing about talking about this within the context of a marriage, but lots of the people who found out that they were hepatitis C and HIV-positive actually just wanted to have sex. It wasn't within necessarily marriage. It was about, as Deborah was saying, about young people who were going off to university and even contemplating a relationship, a physical relationship at all, was very -- could be very fearsome. But also, just having to negotiate when do you tell somebody? How are they going to react? Is it even worth going there, those are huge decision-making processes without that sort of

infectivity, you don't have make in a relationship, normally.

MS RICHARDS: The final question I wanted to ask before we break for the morning break, is again, looking at impacts upon family life. Many statements describe, and you've picked this up in the report, the limitations upon the ability of the person who is ill within the family to participate in ordinary family activities whether walking, going on holiday, playing football with the kids, or caring for their children in the way in which they would want to do so.

Is that likely to increase or compound a person's sense of guilt or helplessness?

PROFESSOR MORGAN: I think that came through very strongly. People were not able to perform the sort of parenting role that they wished to. They were not able to engage in normal family activities, holidays, and other types of things. And this I think this was a major concern, a major concern both in terms of their own identity and the effects on the children.

MS RICHARDS: Picking up I think on an observation you made, Dr Thomas, engendering for some individuals a sense of grief for a family life lost.

DR THOMAS: Absolutely. And, you know, seeing yourself as an incompetent -- I think all of us like to feel in some ways that we're -- some roles that we're good at, a competent mother, father, whatever, and if you can't manage those roles, it adds tremendously to the distress that you're feeling on top of the additional psychological burden you've got already.

PROFESSOR CHRISTIE: I was just going to say, to add very briefly, there's a grief for the future, that on being told -- on being given information, that you may understand completely or maybe not understand completely, but understand that there is going to be a major impact on what you had hoped for, that you go -- that's deeply traumatic. Incredibly traumatic. And the -- and it can last for years and years and years, even with good support. Even with good support. But that grief for the lost future is really impactful.

MS RICHARDS: I'm going to move on to another topic so this may be a suitable opportunity for a break.

SIR BRIAN LANGSTAFF: Yes, I think it will be and we're spot on, 11.30.

MS RICHARDS: Glad to hear it.

SIR BRIAN LANGSTAFF: So 12 o'clock. 12 o'clock, please.

(11.30 am)

(A short break)

(12.02 pm)

MS RICHARDS: One of the most devastating impacts described to this Inquiry and captured in your report is the death of a child, and I wanted to ask a little about that and bereavement and loss more generally, and to do so first of all by reference to one of the papers that you've referred to in your report.

Henry, it's EXPG0000011, and it's a paper by Christ and others called "Bereavement experiences after the death of a child". I just wanted to pick up on a couple of passages and then just ask you about them.

The introduction, if you could highlight the first ten lines or so, please, Henry:

"The death of a child of any age is a profound, difficult and painful experience. While bereavement is stressful whenever it

occurs, studies continue to provide evidence that the greatest stress, and often the most enduring one, occurs for parents who experience the death of a child. Individuals and families have many capabilities and abilities that allow them to respond to interpersonal loss and to emerge from the experience changed but not broken. The few studies that have compared responses to different types of losses have found that the loss of a child is followed by a more intense grief than the death of a spouse or a parent."

Then over the page, please, under the heading "Bereavement, mourning, grief and complicated grief", we can see a number of concepts there discussed:

"Bereavement described as a broad term encompassing the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one, widely recognised as a complex and dynamic process that does not necessarily proceed in an orderly, linear fashion."

At the top of the next page, please, Henry,

then we have grief described, a term that refers to the more specific complex set of cognitive emotional and social difficulties that follow the death of a loved one:

"Individuals vary enormously in the type of grief they experience, its intensity, its duration, and their way of expressing it."

Then we have mourning defined.

"Mourning is often defined as either the individual's internal process of adaptation to the loss of a loved one or as the socially prescribed modes of responding to loss, including its external expression in behaviours such as rituals and memorials."

Then we see the concept of complicated grief, and it says this:

"Complicated grief in adults refers to bereavement accompanied by symptoms of separation, distress and trauma."

Then we see a number of what are called distress symptoms listed:

"Intrusive thoughts about the deceased, yearning for the deceased, searching for the deceased, excessive loneliness since the death, purposelessness about the future, numbness, detachment or absence of emotional responsiveness, difficulty believing or acknowledging the death, feeling that life is empty or meaningless; feeling that part of oneself has died; shattered world view; assuming symptoms of harmful behaviours of the deceased person, excessive irritability, bitterness or anger related to the death."

Then we see the observation of the impact upon siblings.

"Siblings of children who die have also been found to be at greater risk for externalising and internalising problems when compared to norms and controls within 2 years of the death."

Now whether or not a person meets the formal diagnostic criteria for complicated grief, am I right in thinking that the -- what are termed the "distress symptoms" there listed may encompass the kind of response and feelings that many people will experience when they suffer the death of a child or a partner or someone else who they dearly love?

PROFESSOR WEINMAN: Yeah, very much so. I think this paper describes it very clearly. I think the other -- and we heard lots of witnesses

describe exactly these sorts of feelings, both physical, psychological changes following, you know, the sense of loss, and grief and so on.

But I think the really telling thing for me was I went away and looked up, in something called DSM, which is a sort of official classification system that's used for classifying people's psychological mental health problems, I looked up complicated bereavement just -- and tried to think of it in relation to what witnesses had told us. And I just think -- just listen to this, and then think about relating it to our present context:

"Complicated grief obviously is something that's much more intense, much more prolonged."

So it doesn't -- you know, grief, bereavement, is quite variable but this is something which is much more so. Reasons for it, the bereaved person has trouble accepting the death, so clearly issues around a child dying, yeah. If the individual feels unable to trust others. Again, we're going to talk more about trust and about communication. If the individual harbours an excessive bitterness and/or anger related to the death. Again,

thinking about what we talked about yesterday and other factors associated with complicated grief. It's more common with the loss of a child, as we've said. If the nature of the cause and circumstances around the death are complex, or you know sort of beyond the usual, and if the quality of care, palliative care, the sort of support you'd normally give to someone who is in that -- the last days of their life, if that is not -- if that's poor or not available, and if there are concurrent stressors, financial hardships and so on.

If you think about that list of factors and think about what people have told us in their statements, it's really not surprising to me that a lot of people talked about complicated grief, effectively. Grief that's still with them now because a lot of these issues are still there.

What comes out of that is that people ruminate. These things prey on the mind and people ruminate about themselves, their anger maybe they've felt, the guilt that maybe they've felt, and all of those sort of recriminations, if you like, that are linked to that death. So

I think what we have seen and heard from many witnesses really does fall into this, what is a diagnostic category. It's described as a very clear condition that people can experience.

DR THOMAS: I'd like to add to what Professor Weinman has said, and this document is excellent, but one of the things when I read it, and from my experience of working with sickle cell patients, who are predominantly black, that the cultural variables are so strong when you lose a child -- when you lose a child in any culture, and we've all got subcultures anyway, within this community, this sort of basically UK community, so-called white community, we have varying subcultures, but with diverse cultures like African Caribbean cultures, the particular meaning of a child's death is -- it takes on tremendous added proportions. And I think sometimes those things are not given credence within the documents that we have looked at, because it's not been researched fully enough. But I would just like to say, that's a really important thing to say, that we, as a population in the UK, are very diverse, and we should think about those factors as well. And in my work, it's a really important element that comes through.

MS RICHARDS: And if we just turn to the next page of this report, the observations you've made, Professor Weinman, would bear on many of the accounts that we've heard, not simply about the death of a child, but about the deaths of partners as well.

PROFESSOR WEINMAN: Absolutely, yes.

MS RICHARDS: Then there's some specific observations here about some particular additional components in relation to the parental loss of a child. And so I'll just pick it up in the first paragraph, four lines down:

"At various stages in the life-cycle, men and women relate to child-conceiving and child-rearing roles as central to their existence."

And I think, Dr Thomas, that bears upon a point you made before the break about those who are -- do not have children, and the sense of bereavement for the future you've described.

DR THOMAS: Yes.

MS RICHARDS: And then it continues:

"Within the bonds formed within the family,

the parent-child bond is not only particularly strong, it is also integral to the identity of many parents and children."

Then the next paragraph says:

"The parents of children and adolescents who die are found to suffer a broad range of difficult mental and physical symptoms. As with many losses, depressed feelings are accompanied by intense feelings of sadness, despair, helplessness, loneliness, abandonment and a wish to die."

And of course, again, we've heard that from people talking both about the deaths of children and the deaths of partners and other loved ones.

"Parents often experience physical symptoms such as insomnia or loss of appetite as well as confusion, inability to concentrate, obsessive thinking, extreme feelings of vulnerability, anxiety, panic and hyper-vigilance can also accompany the sadness and despair."

And then the passage goes on to talk in particular about anger. Then the next paragraph, please, Henry:

"Children take on great symbolic importance in terms of parents' generativity and hope for

the future. All parents have hopes and dreams about their children's futures. When a child dies, the dreams may die too. This death of future seems integral to the intensity of many parents' responses. Three central themes in parents' experience when a child dies includes: (1) the loss of sense of personal competence and power, (2) the also of a part of the self, and (3) the loss of a valued other person whose unique characteristics were part of the family system. While guilt and self-blame are common in bereavement, they are especially pronounced following the death of a child. The parent's role competence as the child's care giver, protector and mentor is severely threatened by untimely death."

PROFESSOR CHRISTIE: What I'd like to comment on is this is not just an acute reaction. This is not just something that happens when the child dies. It's not just something that is around six months afterwards. These feelings can last for years and years and years and years, and I've worked with parents who lost children 30 years ago who still feel this way. So it's really important to remember that this doesn't just go

away. There's no, you know, neat psychological theory that we all work through our grief and bereavement, and suddenly we'll wake up and we're not feeling that way anymore. Actually, for many people, it changes subtly, it becomes less immediate, but it's always there.

DAME LESLEY: I wonder if we might also talk a little bit about the impact on siblings. Because in any chronic disease situation, where the parents of course have got a major role in caring for the sick child, siblings can respond in a variety of ways, including a sort of resentment towards the sick child that gets all the attention, but then, perversely, when that child dies, extreme guilt, because they almost, like, wished it.

Sometimes the parents, I think, and I know this from work with cancer as well as other chronic illnesses, the parents sometimes hyper-invest in the remaining children, in strange ways that puts huge pressure on them. You know, "These are the ones that are left, I've neglected them, perhaps to a certain extent. I now have even greater expectations of them", which is difficult for them sometimes to deliver on.

And when we get on to talking about care and support services, I think that the grieving siblings, with their mass -- plethora of issues, really need help and support as well.

MS RICHARDS: One of the other features you've alighted upon in your report in relation to the death of a child is in the context of those parents who were administering blood products to their haemophiliac children, the additional component of guilt, the guilt of "I have killed my child."

In your report, at page 9 -- and again, perhaps we could have this up on screen, please, Henry, it's EXPG0000003.

We can see at the top of the page the point I've just referenced. In the first paragraph, last sentence, having talked about the guilt that parents have experienced, you've observed that:

"Guilt and self-blame are both potent precursors of depression and both almost certainly contributed to the considerable levels of negative mood and depression described in many witness statements."

Then in the next paragraph, if we can just highlight the next paragraph, please, Henry, it says this:

"The types of social impacts of HIV and/or hepatitis C on individuals and families were similar in many ways to those experienced with other chronic conditions where partners have to take on major new responsibilities for the family and the provision of care. However, there were aspects of the witnesses' situation that markedly increased the severity of the social impacts for both the affected individuals and family members."

Then you've gone on to identify some of what you've observed as being particularly acute for the groups of individuals with which the Inquiry is concerned.

"These included the relatively young age at which some individuals contracted these conditions, leading to particularly severe financial difficulties and related problems. There was limited availability of effective treatments for HIV or hepatitis C infections and newly researched drugs had many unwanted side effects."

Then you refer to the virus not being cleared and risks of sexual transmission and vertical transmission.

Is it also fair to say that when one is looking at the severity of social impacts for those with whom we're concerned, stigma, discrimination, and lack of support, all of which we're going to come on to shortly, are likely to have compounded and exacerbated the ordinarily severe impacts that flow from long-term chronic illness?

PROFESSOR MORGAN: That's certainly the case. And I've felt in terms of the social impacts, we can see that many of the social impacts are similar for other chronic conditions, but given the number of conditions that people were coping with here, as well as the stigma, the impacts that these groups of people experienced were far more severe and they're more comprehensive. So they would experience nearly all those different types of social impacts that we've been referring to, and to a high degree.

MS RICHARDS: Thank you.

I'm going to come on to stigma next, but before I do so I just wanted to ask Ms Edwards

just to tell us a little about the Haemophilia and HIV life history project in which you were involved.

MS EDWARDS: So the Haemophilia and HIV life history project is an oral history project. Maybe I need to explain that a little.

MS RICHARDS: Yes, please.

MS EDWARDS: So an oral history project is the concept that you would record history by interviewing people who experienced that history. And often history is written by bureaucrats, politicians, historians, academics, but an oral history project would be a collection of memories, testimonies, from the people who experienced that. And certainly, in 2003, a group of us realised -- I, having worked in the Haemophilia Unit as well as in HIV for a long time, realised that this story had not been told. It really hadn't. There was really very little. And we talked briefly yesterday about what research we had looked for around the psychological impacts of HIV, hepatitis C, and people with haemophilia. This was particularly the case for haemophilia, and we all agreed there was very little.

This project is not the types of references we're using here because these are peer-reviewed journals by academics who have analysed, owned this work. What we did was we were funded by the Heritage Lottery to interview people throughout the country who had -- firstly, who had haemophilia and HIV. And it was in 2003, and I don't really believe that we could have done it earlier than that, because I think all of the things that we've already been talking about, the grief, the anger, the confusion, the lack of certainty about what was happening in people's lives, I don't think people were in a position where they would have been very able to be able to verbalise some of the things that they were feeling.

By 2003, that became a little easier, and certainly that's what they told me. And so we went around the country and we invited people to talk about their experiences. And we did it in what's called a life history method, which isn't about asking questions about HIV and haemophilia; it's asking questions about everything, from grandparents to where you live to where you went to school, who was your

girlfriend, what did you play with, you know, everything. So we have a whole life history. So some of these interviews on the average were about 4 hours of recording, and some many more. Many more.

Those interviews were archived in the British Library. They don't belong to me or the team. On the team there was an oral historian, there was an archivist from the British Library, there was myself, a counsellor, somebody with haemophilia and HIV, Rob, who I think you know, and between us this was the work we did for those two years. And so those 30 interviews, very extensive long life history interviews were archived in the British Library.

What of course we realised very soon while we were doing this project was that many people said to us when we asked them about what it was like finding out that you were HIV positive, they would say, "We don't know. Ask my mum, you know, I was two."

And of course the other big area that was missing was the people who had died. We didn't have those stories, and they are a huge story that we were going to be missing out in 2003.

And so we did a second project, for the next two years, between 2005 and 2007, and that project was called HIV in the Family, and that project was interviewing the siblings, the partners, the parents, the mothers, the children of the people who had died over the previous years. There were 35 -- 34 of those interviews, so altogether we collected 64 life history interviews.

Like I said, they don't belong me, they don't belong to anybody. They are in the British Library. They have just gone online and been digitised. They were on tapes, if people remember tapes, C90s, and those tapes have been digitised. There are a number of people in this room who were interviewed for that project, and who I've met over the last two days. And those have gone online and can now be accessed from your home computer. You can listen to the whole recording. They are also summarised so that areas can be found through the, sometimes four, five, six-hour interviews.

Can I just explain sort of an example of one of these interviews?

MS RICHARDS: Yes.

MS EDWARDS: For example I interviewed somebody who had never ever spoken to a single person about his HIV infection. He was infected as a young man. He actually hadn't told his mother, and he hadn't told his sister, who he was actually very, very close to. But he never told them. The only people who knew about his HIV and hepatitis C diagnosis was his HIV doctor, his haematologist, and myself. I happened to also be his community nurse. And I asked him if he wanted to do this interview and he agreed that he would, but that he didn't want anybody to hear it. And I ended up having to do four interviews, four -- four sessions with him, because he was very unwell.

And the last session that I did, in this interview, was in his hospital bed, a matter of days before he died. And he finishes the interview saying, "I know I'm going to die. I'm really sorry that I was unable to share what I've been through through my life with my sister who I love and my mother who I love, but when I die and at my funeral I want you to give these tapes to my sister." And that was the first time that she found out how he actually had died.

So it was, you know -- that was one example. Some of the examples of the interviews that we did were full of laughter and full of resilience, as we talked about yesterday. You know, what comes out is that individuals are very, very diverse.

But if anybody wants to hear these interviews, they are accessible. I may want to reiterate it's the British Library because one person that we interviewed was in an audience like this when I was talking about the project, and he said, "Where are they kept?" And I said, "The British Library, Mick", and he said, "Oh no, I've told everybody I'm in the Natural History Museum!"

[Laughter]

MS RICHARDS: I think it's right that there are a handful of the interviews that are not public in accordance with the wishes of those who gave the interviews.

MS EDWARDS: Yes.

MS RICHARDS: I should also say that the British Library has provided to the Inquiry all the materials that it can provide, and they are

materials that have been read and listened to by the Inquiry, and members of the Inquiry team.

MS EDWARDS: And I believe you have also got the closed interviews.

MS RICHARDS: We do, yes.

MS EDWARDS: Which is very, very, very unusual to have access to an oral history interview that has been closed.

MS RICHARDS: That, I think, leads very naturally to the next theme I wanted to ask you about, which is the theme of stigma and discrimination.

In your report, you say this, on page 20:

"The impacts of medical conditions for individuals and families are profoundly affected by whether they are imbued by a stigma."

I wanted to ask first about two aspects of stigma that are referred to in the report and in the literature: felt stigma and enacted stigma.

Could you explain what those two concepts mean and what the difference is between them?

PROFESSOR MORGAN: Yes, yes. Well first, just to say the stigma, so we're talking about a condition or behaviour which in the view of the wider society marks an individual as unacceptably different, and inferior. With felt

stigma, people are aware of the social meanings of their condition. They're aware that they've got a condition that is regarded as unacceptable in the wider society. This influences their own self-identity.

So felt stigma refers to this understanding of their own possession of the condition which is viewed so negatively and, obviously, it affects their identity and enacted stigma refers to the response of members of the society to people who are identified as possessing a stigmatising condition, and this can take various forms.

It can take particularly avoidance of these people, avoidance in different circumstances, socially, at work, and in other settings, and avoidance and exclusion, and often bullying, children particularly can be subject to bullying. It's very, very painful and it was reported quite extensively by the witnesses.

In addition, some people, even experienced property being vandalised and, you know, a very high level of enacted stigma. Fear of enacted stigma, even if you don't actually experience it the actual fear that you might is in itself

very, very powerful and has a major influence on people's lives.

MS RICHARDS: One of the consequences of stigma may be that individuals do not wish to disclose their condition, and many witnesses reported that, either contemporaneously or still today.

PROFESSOR MORGAN: *(Witness nodded)*

MS RICHARDS: They didn't want to disclose their condition.

That leads to two further concepts I wanted to ask you about and perhaps I can do this by reference to one of the papers in the bundle. Henry it's EXPG0000006, please.

It's a paper by Beales and others. If you go to the next page please, sorry the next one. It's called "Stigma management and wellbeing". There are two parts I wanted to show you and ask you about. On that first page, right-hand column, please, picking it up four lines down, this particular paper it's focus was sexual orientation, but there are some general concepts. We see there reference to a process of stigma management, and it says this:

"This process of stigma management is a major task for individuals with concealable stigmas who weigh the pros and cons of disclosure versus concealment and make decisions based on the circumstances."

Then it refers to another paper, Cain, 1991 "... observed that both options can be taxing because disclosure often entails planning and execution, and concealment requires individuals to attend to many aspects of their social presentation and lifestyle that would ordinarily go unnoticed."

Then Henry, if we can turn on two pages. Right-hand column under the heading, "The role of suppression", we can see again in the first paragraph, it talks about suppression:

"A feeling people may experience if they conceal personal or emotional information they would like to reveal."

Then it refers to another paper:

"Pennebaker and colleagues showed that suppression can be detrimental to both psychological and physical wellbeing."

We can leave that now Henry, thank you.

I want to ask you about these two concepts of stigma management and suppression, please.

PROFESSOR CHRISTIE: I can speak from a child

adolescent perspective, so a young person who may have been aware of their condition. Even with conditions which aren't, we don't think of as being highly stigmatised, something like diabetes, for example, there are many, many adolescents who live with diabetes who don't tell anybody at school. Who keep it an absolute secret at the detriment of their wellbeing and health, so they won't inject insulin, for example, because they don't want their friends to know. They don't want to feel different.

So if you multiply this by a million with something like HIV, where there's masses of ignorance and negative presentation, media presentation, and we weren't in the middle of the social media storm then, but even so on the television, the dreadful adverts and the awful newspaper reports that came out, it would have been impossible for a young person living with haemophilia and HIV to not be acutely aware of the potential for stigma and to have to both manage that but also suppress it, not to tell people too -- and it's exhausting.

That's one of the things in that paper that it doesn't say, it talks about the -- what you

have to do in order to suppress but it doesn't -- the end of the sentence should be, "and it is exhausting", because it is exhausting to constantly be trying to not let people know through what you do, or how you do it, or what you say, or where you go, or you know you don't tell people about hospital appointments, you don't tell people about medication that you're taking, or the fact that you can't go out for an evening because you're exhausted and feeling dreadfully ill and you have to pretend that you just don't want to go, so you get a reputation as somebody who is not much fun rather than people realising that you're actually very ill.

So I think that's -- so from an adolescent perspective, again, that's really, really difficult and challenging for a young person who wants to be part of the world, but who has to prevent themselves participating.

PROFESSOR WEINMAN: I'd like to say something about suppression, really to follow on from what Deborah said. The people who you cite there, Pennebaker, Petrie and so on, are people we work with, and a lot of their work has shown that if you hold on to something, you don't disclose,

you keep it inside you for long periods of time, the costs not only emotionally, but the costs physically can be huge. And there's very good work now looking at people who have really aversive memories or things they've never disclosed to other people, trauma, you know, a whole range of different experiences, including illness-related experiences, and that keeping sort of all those memories inside or keeping those experiences inside comes at a big cost. And what's very interesting about James Pennebaker's work is that he many years ago found that if he said to people, "What I want you to do is write about something that you've never told anybody about, and write your innermost thoughts and feelings, try to contact those", and typically he got people to write over a number of days, and for a number of people, the effects on them were profound. Initially quite uncomfortable, but what happened was that as they began to write and get something out there, they started to make sense of it a bit, understand it. Because when it's all in your head and you haven't disclosed, you haven't spoken to anybody, it's all at that very emotional, that very deep level, and you're not really making sense of it. So again that, you know, failure of disclosure or lack of disclosure comes at that huge cost, and that we know that disclosure, whether it's written emotional disclosure or spoken disclosure, can be very powerful, and some of Pennebaker's studies and a whole lot of other people's have shown that.

MS RICHARDS: We certainly heard from witnesses who have given evidence anonymously because they still have not disclosed information about their health to those who know them, and from witnesses whose close relatives still do not know that they are, for example, HIV positive. And they talked to the Inquiry how they have lived for decades living, in many respects, a lie. The emotional burden of that must be huge.

DAME LESLEY: I think that emotional exhaustion is really interesting because also as a coping strategy, if you like, suppression and concealment have this element of doomed to failure about them, especially if somebody does become progressively sicker, and externally,

they can't disguise anymore what perhaps has been happening.

I think, you know, part of the emotional exhaustion that people feel if they can't talk about these things is due to this anxiety that at any moment it could actually all be revealed, and then the expectation is it's going to be even worse.

It's a terribly, terribly, if you like, tenuous way to actually deal with things that you're scared of.

PROFESSOR CHRISTIE: But in some cases it is actually worse, if -- in some cultures. I mean, we're talking about stigma sort of at a broad level, but I think, echoing what Dr Thomas has said, in certain cultures, the idea -- I mean, in certain cultures the idea of even admitting that you are feeling a little bit low is not appropriate. We have families who will absolutely categorically not allow their children to come and see a psychologist because in that particular culture it's very -- it's highly stigmatised. If you add on to that cultures where things like HIV and even haemophilia itself have -- or any haematological

condition have negative conditions, the fear of telling everybody something because you think something bad is going to happen is actually a true belief, because when you tell people you will be excluded from society. So it's a really, really difficult balance to get right, in terms of disclose or not disclose. It's not simple.

PROFESSOR MORGAN: I think it's very much influenced by the strength of the stigma, and so the likely social reaction, when you do disclose. And for -- our witnesses were describing situations in which they -- some people disclosed to trusted friends but in fact found that the enacted stigma was so strong that they were completely cut off and isolated.

So I think there are different situations according to the sort of strength of the stigma, and so the strength of the social reaction, because what we're hoping with disclosure is these positive benefits for the individual and some of these benefits come from greater social support. But that can be limited.

MS EDWARDS: Can I just add the fact that we talk a lot about HIV stigma, I think further is

evidence of the extraordinary stigma of hepatitis C. And we tend to talk about HIV stigma because it is very much in our lives and because of the health promotion that went round it, the fact that Freddie Mercury died, that Princess Diana held people's hand, that actually the stigma is something we verbalise and talk about. There has been no such thing for hepatitis, and I think the stigma of that today is huge. And people find it very difficult to verbalise and to talk about that because they don't know what reactions people are going to be, because it's not something that society talks about very much.

MS RICHARDS: Dr Thomas?

DR THOMAS: Just picking up on that point around psychological support, and for me coming out of the documents that I've read was the lack of support that was offered. People, some people did get good support, and it was variable across the country, but another barrier to people accessing psychological support is a stigma that's attached to psychological services. And, you know, I remember just an anecdotal conversation I've had with one of our consultants, and I sort of talked about, you know, the notion that I might sort of extend psychological support in an area, and he said, "Well, you know, Nicky, I don't really want you to do this touchy-feely nonsense with our patients", because actually it's still seen as a woolly concept, providing support for people.

So if the establishments out there see it as not an acceptable form of support, it's also another barrier for people to overcome. And I just felt it important just to say that at this moment in time.

MS EDWARDS: Can I add one thing to that, with regard to talking about the Life History Project, it's very interesting how many young men said to me it was an enormous step to access support when it was there. So I think it's an internal thing as well. And without making huge generalisations, these was young, male patients who'd had haemophilia, and now HIV and hepatitis C, and, you know, we talk a lot about did they access psychological support and counselling. For many people, that step was enormous, and we have some very amusing clips of -- on a website that we made about this,

about people saying, "I wasn't going to go to Birchgrove and sit around with the chitty chatty stuff and start talking to people about my feelings."

Of course he went and it was amazing, but verbalising that idea that it's not manly to access support. It's not only coming from institutional -- it's coming from within us, you know.

MS RICHARDS: We're going to look at a couple of HIV and then hepatitis C-specific materials in relation to some of the particular aspects of stigma associated with those conditions, but just picking up on what you've said about Birchgrove, could we have up on screen, please, Henry, HSOC0005046.

So this a report, "Keeping it in the family, access to information and service provision, findings from a study on behalf of the Birchgrove Group and The Haemophilia Society".

For present passages there is one passage I'd like to ask you to note on the next page, please, Henry. It's halfway down the page beginning, "Then there is paradox", fifth paragraph down. If you could highlight that and

the following paragraph. Could you highlight the second paragraph adds well, if possible, Henry, one after that. Thank you.

So this really, in the words of those who are living with the condition and with the dilemmas, it encapsulates some of what you've described, I think.

"Then there is paradox. In the first and probably second phase of the epidemic in the UK [this is talking about the HIV AIDS epidemic] raising the profile was seen to be the way to connect disease with human beings; to reduce the stigma and discrimination. People came out to raise the profile. If the stigma and discrimination associated with HIV are not challenged prevention won't work, people will not come forward for testing, and the move will be to drive it underground -- with all that that means.

"So those living with HIV have had to manage something of a dilemma: to come out and perhaps experience profound discrimination or to remain closeted about their HIV status and thus perpetuate the view that 'It doesn't exist, it's the province of queers and junkies'; and if they

do have it they should stay outside the norms of the rest of society, including the right to have children. Confidentiality or coming out, challenging social attitudes against the discrimination and stigma associate with HIV infection or protecting the individual's right to privacy."

That captures the dilemma for many. In terms, specifically, first of all, of the stigma associated with HIV and AIDS, I just wanted to again put up one of the materials that you've referenced in your report on the screen, and just look briefly at the 1980s and then come forward to the present day. Henry, it's EXPG0000033, please. This is a paper about heroin, it says it in the title:

"Heroin injecting and the introduction of HIV/AIDS into a Scottish city."

Just one passage, page 3, please, Henry, at the bottom right-hand corner of the page. It's the last paragraph on the right-hand side, please. This refers to the advertising campaigns of the 1980s.

"It was in 1987 that the famous UK campaigns were launched involving TV adverts which showed the tip of the iceberg and tomb stone images. Leaflets delivered to every household proclaimed 'AIDS. Don't die of ignorance. Anyone can get it, gay or straight, male or female. Already 30,000 people are infected'. The major influence on this was the fear that the infection would spread into the heterosexual community as a result of sexual contact with drug users. There was much less regard for the hapless human beings who were already infected. There was little information about what might happen to them, and estimates of illness and mortality were guesstimates based on widely differing reports from around the world."

Do you know if there's been any research or study about the impact of those public health campaigns in the second half of the 1980s.

PROFESSOR MORGAN: I don't know of any direct evidence of that but certainly witnesses referred to these campaigns as having the effect of increasing general fear and stigma. The campaigns were obviously trying to change behaviours, but by emphasising that HIV was something anybody could get, and so on, and knowing about the high death rates, this really

increased the fear which stoked the stigma, so it was an unintended sort of consequence, really.

DAME LESLEY: In fact much of the research that has been done, looking at public health campaigns, sort of does demonstrate that very often they are ill-informed, rarely actually do influence behaviour, because they don't come from, by and large, any theoretical underpinnings that we know about, and then they sort of die a natural death without people really looking and thinking: well how did smoking get reduced or have we actually tackled the obesity crisis in a sensible way?

This campaign in particular, the only research I am aware of is the fact that it really portrayed exactly the wrong messages if you wanted to get behavioural change. Fear rarely works in terms of changing behaviours.

MS RICHARDS: In your report at page 20, you've observed that the campaigns contributed to widespread public fear, and to the popular notion that HIV/AIDS could be caught through normal social interaction.

Now, you've observed in your report from the

statements and the evidence that the Inquiry has heard, number of examples of enacted stigma, really quite severe examples of enacted stigma.

I don't know whether you can answer this, but are there any kind of steps or response that you think could or should have been taken in the 1980s and 1990s, specifically dealing with this what's called the HIV or AIDS epidemic that might have reduced the stigma associated with the condition or mitigated its effects?

PROFESSOR MORGAN: I don't know if my ...

DAME LESLEY: I guess one of the problems was that people were starting from a rather uneducated basis anyway, in interpreting what was seen to be happening. So you had a dual problem, really, of the people who were trying to launch campaigns and provide information didn't actually always have it or did it in a rather cack-handed fashion, and that just created a sense of further panic amongst the sort of general population.

PROFESSOR CHRISTIE: I also think that we didn't have the psychological knowledge that we have now about nudge and behaviour change. So the ideas that we have now about getting people to

eat differently, shop differently, behave differently -- those campaigns are underpinned by very different psychological theories, and as Lesley said, fear was the -- you know, the anti-smoking -- I mean, the anti-smoking campaigns didn't work. They didn't reduce people smoking. A few people maybe. But the majority of people don't change their behaviour because you tell them not to. You know, if we yell at somebody and say, "Cut the grass", or "Paint the spare bedroom", or "Tidy your room", the response is "Not now, I'm busy", "I don't want to", "I'm not doing anything you tell me to do", and that whole governmental thing of "I'm going to wag my finger at you and tell you not to do it" was how we used to think that we could educate and control public behaviour, but we know that it doesn't work now. So, you know, educational campaigns now are much cleverer, they're about motivating people to feel that they have the capacity to change their behaviour, and the campaigns in the eighties and nineties just didn't do that. They just didn't have that ability. And as everybody has said here, what they did was they created more fear, you know, that people who did that were bad. "I don't do it, I'm good, so those that do are bad." And it created that polarity between good people and bad people.

MS EDWARDS: I think the other thing with this campaign, it did actually massively increase people going for testing who were not at risk of HIV at all. There was a huge, huge amount of testing that was undertaken in the hospitals in those early days, for people's fear who, despite the fact that these leaflets -- if you remember, the leaflet that went round everybody's house as well as the television adverts actually did have a lot of information on them. Whether people read that and actually heard what they were reading, is another matter. Because as said, fear came up, and everybody rushed off to be tested.

I think the thing that was particularly difficult about this is watching these adverts and reading these leaflets when you were already infected. And I think, you know, what Roy Robertson says then about the guys in Edinburgh, and whether it was them or it was here, it was gay men, it was people with

haemophilia, if you had HIV, you were seeing this: everybody's going to die, there is no help. Which is such a distressing message to have.

It was obviously to educate the public who were uninfected but the impact it had on people who were already infected and unwell was enormous.

MS RICHARDS: Yes, Professor Morgan?

PROFESSOR MORGAN: I'd say that in some cases we find that sort of media celebrities can be very important in actually challenging the stigma. And if you think about it, the late Princess Diana actually shaking hands with somebody with AIDS, I mean that seemed to be more important to people in thinking about these issues and recognising that you couldn't just contract AIDS so easily, rather than just endless sort of printed word and so on. So I think that we have to think in different ways of communicating to actually challenge the stigma.

MS EDWARDS: Mark Fowler on Eastenders, remember? Great job.

MS RICHARDS: Many of the most severe descriptions

of enacted stigma in the witness statements describe events in the 1980s and the 1990s, but bringing matters forward to the 21st century, you've referenced in your report some papers which describe the ongoing stigma and discrimination, first of all, in relation to HIV. I'm not going to -- I'm going take you to one of them but I'm going to ask you first to note, you've referred to a paper which looked at discrimination, HIV-related discrimination in 2004, 2005. But for anyone who wants -- sitting behind me who wants a note of it, it's EXPG0000014.

You don't need to put it up on the screen, Henry.

But that was a survey in London -- and one of the authors of it is Professor Anderson, who will be coming on Thursday to talk about HIV, so we may be able to ask her about it -- and nearly a third respondents in 2004, 2005, reported HIV-related discrimination. Almost half of those reported some form of discrimination in the healthcare sphere, and I'll come on to that in a moment. But bringing it on, then, 10 years further on, to 2015, you've referred in your

report to the HIV Stigma Survey.

And we will put that onscreen, please. Henry, it's EXPG0000027, please.

So we can see it's Stigma Survey UK 2015, and it's titled "HIV in the UK: Changes and Challenges; Actions and Answers The People Living With HIV Stigma Survey". So this only four or five years ago, and we only need to look at couple of passages -- if we go to the next page, please, Henry -- we can see it says this:

"The landscape for people living with HIV in the United Kingdom is dramatically different from what it was ten or twenty years ago. Advances in treatment mean the life expectancy of HIV positive people can be the same as that of the general population. Living with HIV in the age of undetectability and reduced risk of transmission should mean a better quality of life for people living with HIV.

"However, despite some shifts in public attitudes a considerable number of people in the UK still hold stigmatising attitudes towards people living with HIV. Consequently, stigma remains a significant obstacle for many people living well with diagnosed HIV."

Then if we just have the next page, please, Henry, and we need look only at the summary of the findings, I think, rather than the detail of the report.

"In 2015 people living with HIV in the United Kingdom continue to feel stigmatised and experience HIV-related discrimination.

"The survey findings show that while two-thirds of 1,576 participants felt overall positive about their life and in control of their health, in the past year around half reported feeling shame, guilt or self-blame in relation to their HIV status and one in five had felt suicidal."

Then the report observes those feelings were more likely to affect those who were recently diagnosed.

Then two paragraphs further down:

"Experiences of stigma in the healthcare setting were common and one in eight participants had avoided seeking care in the past year. Similarly, about one in eight people had decided not to apply for, or turned down, employment or a promotion due to their HIV status."

Then the last paragraph in that section:

"A considerable number of participants had sought support in the last 12 months, including from a local HIV support organisation. Participants believe that education and awareness campaigns are necessary to challenge the stigma and discrimination experienced by people living with HIV in the UK today."

So this not a phenomenon of the past.

Can I ask you in particular to comment upon the suggestion there about the continuing need for education and public awareness campaigns, please.

PROFESSOR CHRISTIE: I mean, I'll start. I'm sure other members of the panel will add on to this. There is something about how conditions are perceived as being your fault. So if, in the world of eating disorders, for example, working with people who are overweight, there's enormous stigma, because generally people think that people who are overweight are lazy and it's their fault that they're fat. It's their fault, they've done it to themselves, and that they haven't tried to do anything to stop it.

Whereas at the other end, if you look at

somebody who is living with anorexia nervosa, there's this enormous outpouring of sorrow and distress and feeling of sympathy for this person who is ill and, therefore, it's not their fault they're ill. It's because they have a mental illness and eating disorder.

The same is true for HIV, this feeling of blame that on the whole, the population, the public, feel that it's something that you have done to yourself, or somebody, you know, in the case of sort of, if you're a child, and because of the medication nowadays, children aren't born with HIV, but when children were being born with HIV it was their mother had done something and so they came from a bad family and again there's this use of the words "bad" and "good".

Nowadays I think we still have that concept of blame. If you've got something that everybody thinks is your fault because there's not enough education to demonstrate that you can't help it, it's nothing that you've done to yourself, then people kind of disrespect you or there's going to be that worry about stigma and the impact of stigma, so that's how I would start.

DAME LESLEY: I think also we ought to mention actually the role of religion here, and different cultures, because for some it is seen as divine retribution for your, you know, misdemeanours and that, of course, in certain parts of the world like South Africa, for example, led to a huge explosion of HIV, even when in fact most of the rest of the world were able to contain it and treat it. Because of a sort of perception by a lot of people over there that either it didn't exist, which was just plain ignorance, or that if people did get it, it was due to their, you know, sort of failure to follow the rules of the good book.

MS RICHARDS: Professor Morgan?

PROFESSOR MORGAN: I think you've not mentioned one aspect underlying it, which is the blame, and I think a second aspect is fear, and there is still fear, and I think this is something that needs to be addressed because the notion of fear is sort of amplified and once you fear that HIV could be more easily contracted than it is, and so on, there is bound to be barriers and discrimination. So I think it's both. It's the issues of blame and the issue of fear.

MS RICHARDS: Thank you. Sir, I note the time. I'm going move on to stigma and hepatitis C, but we can do that after lunch.

SIR BRIAN LANGSTAFF: Well, let's do that after lunch. We'll take a break now until two o'clock. So two o'clock, please.

(1.02 pm)

(Luncheon adjournment)

(2.03 pm)

MS RICHARDS: I think we have one additional member of the panel to be sworn in.

DAME THERESA MARTEAU (affirmed)

Examination of Panel by MS RICHARDS (continued)

MS RICHARDS: So we were looking before lunch at the question of stigma for those suffering from HIV. Before we leave the topic of stigma I wanted to look at one of the materials you've referred to in your report relating to stigma and hepatitis C.

Henry, could we have up, please, onscreen EXPG0000028, please. This is a 2017 paper by Northrop, headed:

"A dirty little secret: stigma, shame and hepatitis C in the health setting."

If we just look down to the bottom of the

left-hand column, please, on that page, under the heading "Introduction", four lines in:

"Illnesses tainted by the stigma of questionable lifestyles present specific challenges particularly in health settings when treatments are sought. Hepatitis C provides one such example. Within the high-income world, the hepatitis C virus, replete with connotations of illicit behaviour and self-infliction, is most commonly associated with injecting drug use (IDU)."

Then the paper goes on to talk about an Australian study with individuals, none of whom had engaged in injecting drug use, and it says this at the bottom of that column:

"Despite this, the association between HCV and IDU was found to be highly problematic, impacting all aspects of life, personal relationships, employment opportunities and, significantly in this instance, access to health services. Because hepatitis C is often concealable, the decision to disclose one's blood status and to whom emerged as a centrally important consideration. Participant accounts underline shame, stigmatisation, fears of

potential stigmatisation, and extreme caution around disclosure."

Then it refers to:

"In keeping with subsequent research health settings emerged as one of the most vulnerable sites for experiencing stigma."

This paper goes on to narrate various experiences very similar to the experiences described by witnesses to the Inquiry. So I won't dwell upon the detail of the paper. But this exemplifies the continuing stigma associated to this day with hepatitis C; is that fair?

Can I ask someone to answer because the transcribers wouldn't pick up a nod.

PROFESSOR MORGAN: As we know, hepatitis C is more prevalent than HIV and it's still associated with some stigma, yes.

MS RICHARDS: And it's very much -- for similar reasons to those you discussed before lunch, it's that question of seeing certain types of behaviour associated with it that are seen as bad by society and then the aspects of fear that you described earlier.

PROFESSOR MORGAN: Yes, both, as you say, the shame

from -- seen to be associated, the sort of stereotype of deviant behaviour, plus fear that you might contract it.

MS RICHARDS: The way you put it in your report was to say that:

"Hepatitis C is a stigmatised condition and shares some characteristics of HIV with its normal route of transmission thorough handling blood, particularly in the context of illicit drug use, linking it with publicly acceptable behaviour."

Then you go on to say this:

"The main difference was that no educational campaigns specifically targeted hepatitis C. The public therefore had very limited knowledge about hepatitis C and they therefore drew on their knowledge of HIV which they thought would be very similar and this frightened them."

PROFESSOR MORGAN: Yes, several people said that explicitly, "I don't really know but I think it's a bit like HIV", and then had their image of HIV.

MS EDWARDS: Can I say one thing: that underlying this of course is the society that we live in that has such a judgement, and I suppose from a nursing perspective -- you know, when you're a nurse, you don't make judgements about why people are sick. And I think we live in this society where we make judgments about people's behaviour with sometimes a very poor empathy and a poor understanding of what got them into that position, and whether that be drug users, whether that be anything else. And I think the stigma that we're talking about, you know, it hasn't just arrived. We make that stigma. You know, we've created this society.

I think it is a really important thing, and especially with this article which talks about stigma within the healthcare service, and about whatever reason that you go into the healthcare service, you should be cared for as a human being and not be judged for whatever behaviour you're there for. But that comes from a very nursing perspective, which I think we need to have as nurses.

MS RICHARDS: Witnesses have commented on, and relayed, and you've picked up on this in the report, a number of different ways in which they have experienced stigma, at least felt stigma, if not enacted stigma, within healthcare

settings. And I just wanted to explore a little the potential consequences of that. That can be obviously distressing and upsetting for the patient, but it can presumably have a longer term impact in terms of engagement with clinicians, trusting clinicians and healthcare advisers, adherence to treatment and matters such as that.

PROFESSOR WEINMAN: Yeah, very strikingly, I think we -- (a) we could see that, and that's consistent with research. I think when people lose faith in a system, lose that sense of trust, then (a) -- well, there are two things likely to happen: either they will try and avoid or work their way around different parts of the system, and there's a paper that we talked about following medical errors, how people tried to navigate their way around the bits of the system that they've been offended by.

Or people go into slightly more passive, sort of resigned, "Well, there's nothing I can do", you know, and feel that somehow -- again, the blame gets internalised. You know, "Well, clearly I've got something that they really don't want to be bothering with."

So I think, you know, there are a number of ways in which that can happen. And I think -- it's interesting, before the break you talked about that was then, this is now, well, just a couple of weeks ago I read a study on looking at a large trial in America where they were offering PrEP, which is, you know, a treatment for prevention of HIV and AIDS to a large, you know, relatively socially excluded population, and it was a very large study from Chicago, and the study that the uptake of PrEP was low. And they started to look at it thinking it was going to be this excluded group and it wasn't. It was the failure of family doctors to really recommend it. And some actually said out loud things like, "Well, you know, I'm not sure, you know, whether it's right to encourage the sort of behaviour that this is going to allow people to have", ie, you know, more frequent sexual contact and so on.

So, again -- and that's, you know, a 2019 paper. So there's still a lot of big issues out there in terms of, you know, judgement that's being made by healthcare professionals, negative judgement.

MS RICHARDS: Specifically within the healthcare setting, are there any suggestions that you can make, either now or, if not now, perhaps in the supplemental report that you're kindly undertaking to provide, about how stigma within a healthcare could be addressed? If it was something you would like to think about and reflect upon and put in the report, that's fine, but it's obviously an important -- (overspeaking) --

PROFESSOR WEINMAN: Unless anybody has any immediate --

DAME LESLEY: The only immediate thing that I can mention is the fact that if you actually associate different groups of people with things, prejudices, and what we're talking about here, they are so ingrained over years and years, and it doesn't matter which professional group you belong to, we all have different prejudices that sometimes are very overt, other times they're hidden and I think they're very difficult to change. They're very, very difficult to change. And you can do all sorts of online surveys to see how ageist you are, how racist you are, and even if we think, "Oh, I'm not ageist, I like old people as much as young people", "I'm not racist, I like Asian people as much as, you know, sort of Caucasian people", you do some of these surveys and you see how subliminally you've got a lot of these features yourself.

So all I'm trying to say is that it's very difficult to help people change behaviours that they have developed over years or attitudes that they have developed over years, belief systems about certain groups, you know, being less honourable or less reliable than others, all these sorts of things. They're difficult to shift.

PROFESSOR CHRISTIE: There is a move I think within, well, perhaps the NHS but in other areas to address racism with unconscious bias training, where rather than sending people on a diversity training which everybody hates to go on, and doesn't think it applies to them, if people are helped to understand their unconscious bias, because we all have it. Every single person in this room has it, towards the other. And it's about recognising that when we see people as the other, that we have that unconscious bias which

then leads to stigma or discrimination.

And I think that that's, for me, that would be one direction that we can think about in relation to something like this, because I agree with Sian that as healthcare professionals we should behave in a certain way, and one thinks, "Well, why did you go into the healthcare profession and the helping profession if you're going to behave in a way that isn't helpful", but we also have other contexts in which we live our lives. So we've already discussed the idea of religion and faith, and there will be many healthcare professionals who hold a very strong position because of their faith. We have positions according to our ethnicity, there's many contexts, whether we're a mother, a father, as to how we react to people.

If we didn't reflect on that then we never change it. I would say that one of the things that I think changes healthcare professionals the most is the opportunity to have supervision, good supervision, and right now, medical doctors don't get supervision, and nurses very rarely get supervision. The people who get the most supervision are psychologists, who spend their

whole life talking to people and then talking to people about what they've talked to people about.

DAME LESLEY: We like talking, yeah.

PROFESSOR CHRISTIE: As you can see, but that then means that we then have an opportunity to reflect on what we said, and was that hurtful, was that the right thing to have said, and should we do that the same way the next time we're in an interaction with somebody?

So I think that would be a very good and relatively -- well, not simple, but it would be a good start to get people to have some greater degree of reflective practice.

MS RICHARDS: And then Theresa, you ...

DAME THERESA: I was just going to add to what's already been said, to say that people working in a healthcare system are part of society, and so our prejudices will be revealed through the people working in the health service, so I think it points to two targets for change. One is society more broadly, and perhaps where there would be faster change would be as has already been said, unconscious bias training, which, as a university teacher, I undergo. It's very

important in terms of recruiting students to university as well as in teaching, so it is possible.

I don't know what is -- what happens in the NHS, but I would have thought that this would be an absolutely core part of effective and sensitive communication training, which I presume we will be coming on to.

MS RICHARDS: We will in just a moment. Doctor Thomas, was there something you wanted to say?

DR THOMAS: Just to add to what everybody has just said, that communication training is a really important way of helping people, but involving key participants who are, if you like, hepatitis C sufferers, to be part of that training programme, so that they are communicating that experience at firsthand.

From my experience of working in another area, it's a really powerful message that you're sitting there and you're actually saying, "This is how you make me feel", and those exchanges are really helpful to get people to think about their biases and to think about how they might change.

SIR BRIAN LANGSTAFF: Before we just move on to what is going to be, I think, another topic, can I ask you, when you do consider this question in a supplementary report, you address a couple of things. One is that it's been suggested earlier, and has been suggested by a number of people, that the answer to a lot of bias, a lot of prejudice, a lot of stigma, is education. That presumably is education about the disease, it's natural progress, how you get it, what it is, therefore replacing ignorance with information.

That is particularly -- it is particularly, therefore, worrying, perhaps, that some of those who are currently in the health service are suffering stigma when they ought to be the most informed. Does that in any way invalidate or cast any doubt upon education as such on its own being an answer?

And secondly, if the NHS is a caring profession, which ought to be fully educated, how best do we prevent the societal -- it's not, I think, an answer to say that society stigmatises because it may be, might it, that people in society have their attitudes affirmed because they know somebody who works in

a hospital who has exactly the same attitude.

[Witnesses all agree]

So there may be an element of cross-affirmation going on but which affirms prejudice or stigma as it's perceived and is therefore unhelpful, and a way at least of addressing society's stigmatising might be to start with the health service. But it's a suggestion which you might want to consider and the pros and cons of it. It's just a thought which has occurred to me as I've listened to you.

MS RICHARDS: And we'll write to you and set that out. You don't need to try to remember it.

I want to move to the question of communication which a number of you have alluded to in your answers already. In the report, you say this:

"Good quality communication is an essential element of healthcare practice."

And I wondered if you could just elaborate upon why that is the case.

DAME LESLEY: Me?

MS RICHARDS: Yes, I'm looking at you.

DAME LESLEY: Yes, good quality communication is

absolutely pivotal to everything that happens within medicine, because if you are a poor communicator, you're probably a poor listener as well, so you don't hear what patients say, you don't actually ask questions in ways that permit them to be accurate givers of their history. You probably don't communicate well with your colleagues either. And all healthcare now is a serious team business, the days of, you know, a patient going and seeing one individual who then offers a prescription and everything sort of is all hunky dory are long over.

People are treated within teams, and so good communication lies at the heart of absolutely everything that is done within healthcare. And sadly, it's one of the areas of health education that probably receives scant training. In the course of a clinical career spanning, if they're lucky, about 40 years, the average consultant within a hospital will have 240,000 interviews at least with patients, which is more times than they'll do anything else in their career. It's more times than they'll wield a scalpel, take a blood pressure, feel a pulse. Yet if you contrast the amount of time that is given over

to practical skills, in most of our medical schools, with the amount of time given to communication skills training, it's easy to see why we have a major problem.

MS RICHARDS: We've obviously heard examples that go back to the 1970s, through the 1980s, to the present day, and from what you say, Dame Lesley, it sounds as though, from your perspective, it is still very much a present day problem.

DAME LESLEY: Yes, it is. Although certainly within most of our medical schools there has been an increase, and also schools of nursing, in communication skills training, very often even the format of the training is poor. You cannot possibly -- rather as Nicky was just saying, you can't possibly learn an experiential skill such as communicating merely by reading a book about it, or listening to a lecture. And yet that still is how a lot of our communication skills training is done.

You have to do it. You have to have feedback from experienced facilitators, from patients themselves, if you're going to actually change the way you communicate in beneficial ways.

MS RICHARDS: One of the papers you'd referred to, I won't -- don't need to put it up onscreen but if anyone wants to know where to find it, it's EXPG0000016, and it's a paper by Elder 2017, and it talks about empathy and the importance of empathy in the clinician-patient relationship. Again, many of the statements that we have received describe a lack of empathy.

DAME LESLEY: Yes.

MS RICHARDS: What role does that play in modern medicine and is that something that can be taught or assisted?

DAME LESLEY: That's a very interesting question because there are lots of debates that go on about whether or not you can actually teach people to feel, to care, to walk in the same shoes as the person in front of them. That's what empathy is about. And if you don't naturally possess those sorts of feelings as an individual, is it actually possible to teach it to people?

I suspect it's difficult to teach empathy to people who are just -- you know, their personality disposition is that they are not empathic. However, one can teach them skills of conveying at least a sense of empathy when they're dealing with people. It's all in the nuance of the way you say things. You can always manage to say something that sounds callous and indifferent, or you can actually say precisely the same words but say them with a sort of empathy that is conveyed by either their non-verbal facial movements -- the fact that people even look at you when they're talking to you conveys "Hey, I'm listening to you. I feel what you're actually saying is really an important problem for you."

And there's a very interesting paper that I read a few years ago that I give medical students and other healthcare professionals who come on training courses, and it's called "You me and the computer makes three". Because a lot of interaction now that takes place within our sort of, I don't know, GP surgeries as well as at hospitals, is with somebody in front of a computer typing things up, and that's when you also lose all the, you know, key non-verbals. You know -- and it looks as though somebody doesn't care if they're just looking at their computer.

MS RICHARDS: Dr Thomas?

DR THOMAS: Yes. And the flip side of empathy is compassion, and there's quite a lot of work being done at the moment within the NHS to try to instil more compassionate healthcare professionals, and an important element of that is enabling people to actually have feedback about their skills. And I think together, hopefully, those methods down the line will impact. But the transcripts were really clear that some of the experiences that people have had has been really unempathic and definitely without compassion.

MS RICHARDS: Do you know, any of you -- Dame Lesley, you may know the answer to this, I hope, but any others who may assist -- to what extent is any of this -- communication skills training, work on compassion and empathy -- part of any of the basic medical training that the medical schools deliver as part of a degree?

DAME LESLEY: Most curricula do have some of that within it. As I've said before, though, I think very often the methods that are used are not always the most appropriate. And also the time that is devoted to it is just pathetic, really.

And I -- you know, one of the things that I think is important is that -- and this actually, I think, is particularly pertinent as modern medicine becomes more and more complex -- is that you can meet very good communicators who appear very empathic and, you know, sort of have the patient's needs right up front there, but they become so inured to the terminology that is used within the health service that they might just as well be talking Chinese to the person in front of them. And one of the other skills that I think we need to help people develop is how to put complex information into easy layman's terms, without being patronising, because people are not giving informed consent to tests or treatments if they haven't actually understood a word of what somebody has been saying, no matter how kind, compassionate or empathic they might appear.

PROFESSOR CHRISTIE: I was going to say there's a very recent paper which has come out which has been very important in diabetes care, which is called Language Matters -- and those of you that are Twitter followers can read all about it on hashtag language matters, and it tells you --

and it's really about the kind of words that you use when you are thinking about somebody, when you are communicating with somebody. It's really powerful, powerful document, that the diabetes world is trying to get everybody that's providing care for the thousands and thousands of people with diabetes to start using when they talk to and about people.

And it's not just about the talking to the people that you work with, it's not your clients, it's not just about that, it's to get people to think differently, to stop thinking of people as -- in some ways as patients, but people that you owe a service to, and that it should be a responsible, accountable service to.

But it's also about thinking about how you talk about people when they're not there, when they're not in the room, because how we think about people when they're not there, when we then go out and communicate with them, it communicates through our faces and through our body language. If we think of somebody as a nuisance and talk about them as a nuisance in our little private consultations and then go and speak to somebody, that comes across. People

know if you don't like them. People know if you have a judgemental attitude towards them. So I think definitely the communication is really, really important.

And we looked at a -- we did a review in 2017, so just two and a half years ago, which looked at what communication training was available to haematologists, and it was non-existent. It's -- there's guidelines, there are loads of guidelines, but guidelines aren't mandatory, guidelines are just suggestions. And there's no consistency. So one medical school may do more than another one, and one will do hardly any at all. And as already has been said, there's no real pedagogy attached to these trainings, there's no real thought about the education. And how you educate people, you have to train people properly in order to do it. And you have to keep monitoring them. Once you've done it -- you might do as a key medical student, but once you become a consultant, nobody ever checks your communication skills. Medical students get monitored but nobody ever sits in and says to a consultant, "You know that last conversation you had with somebody was

really very poor." That doesn't happen. And that's another thing that needs to happen, is that senior doctors who think they know how to do it, they need to be held to account as well as training up the junior ones.

PROFESSOR WEINMAN: Yes.

MS RICHARDS: Dr Thomas?

DR THOMAS: We're going to talk about that later on, I know, about embedding psychological services, and an important role that psychologists have when they're part of a medical team, you see the doctor, you see the nurse, you see the psychologist, is normalising psychology, but it's also about having those conversations which challenges those negative views of patients in a closed room. So, "When you say that, what exactly are you meaning about that individual?"

So those conversations, we call them cross-fertilisation of ideas, because -- the doctor's conversation -- we learn from them and they learn from us. And I think that's a really important way -- that psychology service, embedding them. It's not only a benefit to the patient when they have therapy, but for the wider team as well in learning how to put those

prejudices aside.

MS RICHARDS: I'm going ask about some of the potential psychosocial consequences of poor communication in a number of different respects. Taking, first of all, consent, and I'm not asking about the legal requirements for informed consent, but can you just perhaps assist us with the importance, in psychosocial terms, of informed consent, and conversely, the impact of being treated or tested or entered into research or clinical trials without informed consent. Whoever wants to answer?

DAME LESLEY: Well, informed consent, I mean obviously again, it's a sort of pivotal thing within the practice of medicine generally, because any procedure, any test, at least the patient has got to have given tacit consent to, if not written consent to. So if you hear that a healthcare professional has done something to you that you were unaware of ever having an option at least to express whether or not you wanted this done or not, you're going to feel deeply mistrustful of absolutely everything else that follows.

And I think certainly my readings of many of the transcripts, when I attended some of the hearings as well, it made my hair stand on end actually seeing how often people reported that they never even knew that they had been tested for something, so obviously hadn't given any overt consent to it, let alone sort of some of the treatments, particularly when we came to clinical trials. And that's probably another topic you might want to move on to.

So I think if somebody does something to you, because that's what was happening. People were doing stuff to patients, and they had no knowledge of having given at least some verbal consent to it, no understanding of why something was being done, or had an opportunity to express whether or not their preferences would be for one treatment or one procedure rather than another, if they had different burdens and consequences associated with them, then that is deeply, deeply troubling for the rest of the relationship that that individual will have, not only with the healthcare professional that they were initially treated by, but everybody else in the system as well.

MS RICHARDS: Dame Theresa.

DAME THERESA: If I could just add to that, Lesley has described how this could erode/undermine trust. The other thing that consent does is it provides what we could think of as psychological preparation for a test result, so some of the harrowing evidence that people describe that they'd undergone testing for HIV, they had no idea that they had, and then suddenly learnt that they were infected. So with appropriate consent comes talking through not only the nature of the test, but the potential results giving people the opportunity to think through and prepare, and have support at the time of testing for the different outcomes, so all of that is lost through not having appropriate consent procedures.

MS RICHARDS: Then you've addressed in the report the consequences potentially and the importance of adequate information and accurate information being provided. If insufficient information is provided about whether it's a test result or a condition or treatment or side effects, is it fair to assume that patients may then have to take on the burden of researching themselves what the condition means, and we heard lots of

testimony about that, and they may find information alarmist or inaccurate or not relevant to them and they have no means of knowing what the correct position is as regards to their own health.

DAME LESLEY: Absolutely, and I think that leads to even deeper anxiety amongst patients. Dr Google has a lot to answer for. We're talking about some doctors that you've all actually had indifferent experiences with, but Dr Google is universally I think responsible for causing a great deal of anxiety and confusion.

Patients who have not been adequately informed about the consequences of things, the need for different treatments, the, you know, side effects and, as I said, different burdens associated with different types of treatment, if they then go online, they fall prey to all manner of purveyors of snake venom and whatever else.

That I think in itself just exacerbates the confusion that they're already sort of experiencing. Guiding somebody through the tranche of information they need to make truly, not just informed -- I don't like the informed

consent. I think it's educated consent that allows a patient to pull in their own lifestyle preferences and choices and so forth. That actually takes time, and some online stuff is quite good, but it still needs somebody to direct the patient towards, and I think it was very alarming, again, in many of the transcripts, to read how people were just so desperate to try and find out things that they went online and, of course, we are dealing with a time when knowledge in itself about particularly HIV/AIDS was a little scanty.

MS RICHARDS: Doctor Thomas, was there something you want to say?

DR THOMAS: Just to say that in addition to what Professor Fallowfield has said, is really that if you have got poor information or scant information, then how -- you're not supported to go forward to take on board what are very complex healthcare treatments, and we know they also have some difficult and unwanted side effects. So if you've got poor information to start with, you're not going to be supported to actually adhere to medicines comfortably.

PROFESSOR WEINMAN: I think there's an additional element to this, which is again something we saw in the witness reports, is that information was actually withheld on the grounds, apparently, at the time, that people didn't want to know. And that was a view -- and I know when I started teaching medical students, there was a strong belief out there that people didn't really want to know the bad stuff. And I can remember seeing a really good paper very early on with a title "No news is not good news, it's an invitation to fear". So if you don't get adequately prepared or you don't have that information and you're feeling bad, you fear the worst. All sorts of, you know, perceptions and interpretations go on inside people's heads.

So again, you know, I think going back -- it's still an issue now, but I think back in the old days information was withheld because people really genuinely believed -- I think out of complete ignorance -- that somehow it was not helpful for people to receive information. Which is worrying, you know.

PROFESSOR CHRISTIE: Just one small thing I think also, that there's often an idea that communication is like the doctor holds all the

knowledge, and the patient is a sort of receiver, and the doctor transmits information and the patient receives it, and so therefore communication must have taken place. And I think it was George Bernard Shaw said something about the greatest illusion in life is that communication has taken place. We'll correct it if I've misquoted it slightly. But the -- but actually, you can't just communicate something like that in one go. You have to come back and say: what did you understand? What do you need me to go over again?

And it's an organic ongoing process with giving anybody bad news, or any news, actually, about your medical condition, because you hear the first two minutes and if it's devastating or difficult, you don't hear the rest of the 15-minute consultation. You don't remember anything. You walk out there, and it's all gone apart from the big words that were in capital letters. And then you go in again and it's almost like, "Well, I can't ask again because they've told me everything, so I'll just -- I'll go and look for myself." So there's got to be an understanding that communication isn't

a one-off, it's an ongoing process of you checking and checking again.

And I think that's where nurses serve such an amazingly valuable purpose because they're often the ones who pick up the pieces, who sit down and say, "What did the doctor tell you?"

Most of the young people I work with will say, "The doctor said, 'Blah, blah, blah, blah, blah, blah, blah', because I have no idea what they just said to me", and then somebody will have to go through it again, and use different words and visual images, or -- you know, and different materials and different media. So it's a really interactive process. It's not just "I'm going to say something and you're going to understand it."

MS RICHARDS: You've set out very helpfully in your report good principles or good practice of how to communicate bad news.

PROFESSOR CHRISTIE: Yes.

MS RICHARDS: I'm not going to take time going to that because we've got it in the report, but you've also drawn attention to a particular paper, Bernacki, which we've also got, and some elements of best practice when discussing a

diagnosis of serious illness.

Can I then come on to about candour, openness, about when things have gone wrong, where there has been -- whether you call it medical error or an adverse incident, whatever terminology you want to use.

Again, you've set out some principles in your report, on page 11 in section 13.4.2. I'm not going to, again, take time to just repeat what you've set out, but I wanted to ask you if you can, please, help us with, again, the psychosocial impact upon patients of not being told that something serious has happened to them as a result of the care or treatment that they have been given or not been given. How does that impact upon a patient's experience?

PROFESSOR WEINMAN: Well, you cited the Elder paper earlier, which actually was exactly about that. It was on primary care and it was looking at when things have gone wrong from a patient's point of view, from sometimes quite minor things, like being treated badly, to, you know, treatments going wrong, adverse drug reactions. There, they showed very clearly that, first of all, there were big emotional impacts. People felt angry, they felt resentful. They felt -- the thing that really bugged them, and this comes out in the other paper that we've cited, the Southwick paper, that lack of accountability. That, you know, that people (a) were not saying what had happened, they weren't even acknowledging that actually, you know, "It was us, we did this. We had a role in this, or the healthcare system in some way."

So there are very clear emotional reactions there. And that was -- the Elder paper was relatively minor errors, problems. The Southwick paper, which I think is a really informative one, was about a survey of something like 700 people where there had been serious medical error, and then looking at two things, really. First of all, people's emotions. And people's emotions were really, you know, very highly affected. They were things like, you know, surgery that had gone wrong, adverse drug reactions, treatments that had failed and so on.

Again, lack of accountability, a lack of explanation, lack of apology, all those sorts of things really emerged in that. And the effects on people were 90% of people talked about

serious emotional consequences and major financial impacts, as a result of all of that happening. And so the impacts there were huge. Absolutely huge.

You know, it was in the US where the financial aspects of health are fortunately, from our point of view, a little bit different to they are here, but even so, the impacts are huge. I mean that review, or that survey I think is a very powerful one, a very powerful indictment.

MS EDWARDS: Can I add something to that?

MS RICHARDS: Yes.

MS EDWARDS: I think that -- moving on from what John is saying is that also -- that was the emotional impact but the paper also goes on as well to discuss the behavioural impact, and the behavioural impact where somebody feels that they -- the acknowledgment of error at whatever level is not being made, that people stop going to the doctor.

PROFESSOR WEINMAN: Yes.

MS EDWARDS: And they do things like go -- not them, but on Google, you know, you do search for your answers elsewhere, and you avoid going back to

that doctor, and often you avoid going back to the whole system. So the healthcare system becomes something very negative in one's life, and whether that be the nurses, the hospital itself, whatever. And so your healthcare is therefore going to be compromised because you're no longer going to get the care and help that you need and you deserve because of your behavioural anger towards that doctor, nurse, you know, whoever.

DR THOMAS: Just to add that justifiable anger, which the paper actually speaks about quite well, it comes through very clearly from the transcripts. And if you are stuck with that anger, you're sort of -- you can't move on with some aspects of your life, really, because nobody has acknowledged or taken responsibility for what has happened to you. So I think that just adds to -- goes on top of all this, all the psychological distress and psychosocial concerns that our population have gone through.

MS RICHARDS: Dame Lesley?

DAME LESLEY: I was actually going to say something rather similar. I mean when I did quite a bit of work with what was then called the National

Patient Safety Agency, when we were trying to encourage more open disclosure -- in fact the programme ended up being called at the time Being Open -- we were very struck when we spoke to patients who had been the victims of sometimes some very serious medical errors, including sort of infected blood, but there were many other sorts of things, operations that had gone wrong, wrong drugs being administered and so forth, we were very struck with how those who were stuck with the anger. They were so incensed that people had never just 'fessed up and said right at the outset, "This was our error. We apologise wholeheartedly. We are going to investigate exactly what went wrong here. In the meantime we're going to do everything possible to try to help you," and furthermore -- and this becomes the important thing for many of the people that we spoke to -- they wanted to know that something would be done to stop it happening to others.

And it was the failure, I think, for people to first of all acknowledge the problem, but then not actually try and put in place measures that would ensure it would never happen to another person. And look at the hundreds of you, who I'm quite sure actually also experienced exactly the same feelings: anger not just for what had happened to you, but anger that it continued to go on.

That's one of the reasons that the National Patient Safety Agency actually sort of changed their name to the National Reporting and Learning System, because at the very least, apart from personal acknowledgment and recompense for what had happened, people so wanted the system to learn so it wouldn't keep on happening to others.

MS RICHARDS: Just in relation to that guidance being open, which was 2009 guidance, I should say it's guidance that relates now to England, but there is guideline in Wales, Scotland and Northern Ireland, and we will obtain those and provide them to core participants. You talked also about the Australian study and about the legal duties of candour, and again, we'll provide information to core participants about the duties as they apply in different parts of the United Kingdom, but I understand that duty of candour worldwide is not necessarily a new thing, and that there's at least one country that recognised it in legal form decades ago.

Could you tell us about that, Dame Lesley?

DAME LESLEY: Absolutely. I mean in New Zealand 40 years ago there was a duty of candour that at the moment an error was spotted, there was a legal responsibility, a mandatory responsibility, to report it, and set in process not only treatment for the individuals affected, but also the, you know, legal means to get some recompense for this.

I think Australia and New Zealand actually were probably ahead of us, but New Zealand it was 40 years ago they first published their work on a duty of candour to investigate, learn, and recompense the people that had actually been affected in whatever way it was.

MS RICHARDS: Dame Theresa, was there something you were going to add?

DAME THERESA: I was just going to mention that really in this context, and some of the witness statements emphasised this, that insult was added to injury where sometimes people were encouraged in a hostile way to take blood products and were falsely reassured that they would not be infected. So not only was there, if you like, an error in terms of an adverse medical outcome, but they were falsely reassured that what they were being given was completely safe and that they should not be making such a fuss.

So I don't doubt that that would further contribute to the psychological toll on those individuals.

MS RICHARDS: Then can I just ask you a little about -- apologies -- what they mean, who they might need to come from, how they might need to be expressed.

First of all, an acceptance of responsibility or some kind of comprehensive apology, if made promptly, is presumably likely to be of greater benefit than if it's made begrudgingly or many years after the event.

DAME LESLEY: Absolutely. I mean there is so much evidence that really what people require is an immediate hands up, something went wrong here, rather than, "Well what's going on here? I don't think this is right. Why isn't anybody actually talking this through with me?"

There are several things about apologies, though, that are quite interesting to look at. First of all, a formulaic, "The hospital are all extremely sorry that this has happened to you" in a letter, that does not work. That really does not cut it. The apology has to be personal. It has to be face-to-face. It's not necessarily the doctor/nurse that was responsible for administering the drug or cutting the wrong arm or leg off, or whatever it was, who has to be there. It should be, though, somebody who is experienced in some way. They have as many facts as they -- as are available, in front of them, but they can personalise the apology.

Because too many people report that it's just a sort of cut and paste letter, and that is not an apology. Even with the apology, "We are so, so sorry that this has happened to you", there has to be a, "Look, we still don't know all the facts", because you can't always identify exactly what went on, "but we will put in place now an investigation. We will keep you appraised of how that goes as more facts emerge, but, first of all, I want to know how you at the moment are actually feeling, what we can do, how we can best support you and, by the way, this is the treatment that you're now going to actually really need."

Now, that sounds a lot to do, but it can be handled well, and one of the things that again the National Patient Safety Agency "being open programme" started, it wasn't just that we wrote a big report; we actually did develop some training modules that were meant to be used by all hospitals, where individuals would take responsibility for, you know, sort of dealing with medical errors of different sorts of severity. They'd come to the training programmes, we'd train them, and part of that, the most important part of it, was how to do the apology.

The other thing is that when you're dealing with a family, of course they're likely to want very different types of apology. And so that's what I meant by the personalising it, rather than just a formulaic, "I'm sorry this happened to you, it wouldn't happen again."

MS RICHARDS: Your report and your evidence obviously focuses upon apologies, candour within the healthcare setting for obvious reasons. But

would the basic principles that you describe, of the importance of there being acceptances of responsibility, candour about mistakes, potentially also apply to Government, to other public bodies and institutions, and politicians and individuals?

DAME LESLEY: You're getting into very sort of touchy sort of ground here, because obviously there are levels at which the buck should stop. And sometimes the people that actually really have to be made the sacrificial lambs are not really the people who were responsible. And I guess, with certain sorts of -- I mean, I use this term -- well, I don't think you can describe it as anything other than scandals -- one of the problems with scandals such as this is that there were probably people who knew a long time ahead, for a long time, what was happening, and yet for whatever reason, this was concealed.

And I think that there does need to be a very public apology at the highest level, but meant. But meant sincerely.

MS RICHARDS: Just one further aspect of candour and communication, but a slightly different one.

Significant numbers of witnesses to the Inquiry have reported either lost or missing medical records, incomplete records, destroyed records, or they've reported difficulties in accessing records, either their own records or the records of deceased relatives.

Some might view it as deliberate. That may be their view. Some may see it as evidence that they are unimportant, that what's happened to them doesn't matter to the organisations that they're asking for this information from. How might that again impact upon the psychosocial experiences of the individuals?

DAME LESLEY: I think that's likely to have a serious sort of impact on them in terms of trust and confidence. Even something such as this Inquiry, sadly.

You know, if things go missing and it was the people, you know, who call all the shots, people in power who actually allowed this to happen, I mean it's funny how similar sorts of documentation appear to have all gone missing at the same time in wildly different hospital situations, schools and whatever, isn't it?

But if people feel there has been an

institutional concealment or cover-up of things, it's going to make them -- really, really difficult for them to trust even, I guess, what we're saying.

MS RICHARDS: I'm going to move on to the -- my penultimate topic is difficulties in accessing treatment, which I can take shortly, and then there's a slightly longer topic in relation to care and support, which is an important one and we'll need some time. So if I may, I'll just trespass into the break for two or three minutes to deal with the penultimate topic.

The question of difficulties in accessing treatments, for example, drug treatments for hepatitis C, is a theme of many statements. Now I'm not going to ask you to comment upon what the reasons for that might have been. We know there are issues about rationalisation, funding, and the like. There may have been all sorts of other impediments to giving people treatment.

I wanted to ask you what -- again, the psychosocial consequences for individuals, particularly individuals who have been infected as a result of NHS treatment, then being denied the treatment or having that treatment deferred that might address the consequences of that, how might that affect them?

DAME LESLEY: You'd feel victimised, wouldn't you? Doubly victimised, I think.

PROFESSOR WEINMAN: I think the whole issue of access to treatment is quite a complicated one because there are lots of reasons or lots of different sorts of access problems, as you've alluded to, and some involve, you know, just the fact that the centre was some way away, people had distances to travel when they were feeling fatigued, nauseous, whatever. So I think some of those impacts were horrendous, in -- just the toil that that took -- the toll, rather, that it took on people.

I think where you're looking at sort of other -- what I would call more pernicious aspects of access, difficulty, I think where the problems really compound. So where people talked about feeling that they were not prioritised, feeling that they were being discriminated against, maybe there was rationing. You know, they weren't -- or even when there are sort of perhaps cost-related issues, that, you know, there, I think, what

that really added to was -- a little bit like what Lesley was saying -- a real sense of discrimination and stigma. You know, you are part of a group who actually somehow were not worthy of the sort of healthcare you should be getting.

And I think those two very -- there were two very different -- you know, there are access issues which the individual experiences, and then the ones which are the more practical ones. And I think that's the secondary of that more pernicious group, where people felt that they were not getting the sort of -- you know, they were being blocked off, in various ways, from the sort of treatment they should be getting, could be getting. I think the impacts there are huge. You know, the negative mood, distrust, dissatisfaction -- you know, a large amount of work looking at patient satisfaction with healthcare. Huge dissatisfaction there. Lack of confidence in the whole healthcare system, reluctance to follow advice and treatment.

I think, you know, all sorts of behavioural, psychological impacts of being blocked off in that way, or finding it difficult to access --

and again, it's consistent with literature. There's a big literature on HIV, again, which are very parallel to that -- just HIV on its own or in the context of, you know, infected blood.

MS RICHARDS: Thank you.

Sir, the final topic, which I'll deal with after the break, is about psychosocial care and support, and also picking up on some issues in relation to vCJD notification. I would ask any core participants, through their recognised legal representatives or otherwise, if they have additional questions arising out of what they've heard so far that they would like to have put, to raise those with their recognised legal representatives who will raise them with Ms Scott during the course of the break, and, to the extent that time permits, we may be able to ask some additional questions.

SIR BRIAN LANGSTAFF: I would ask, in that case, to make sure that you know in good time in order to work out what you're going to ask in what remains of today's hearing time.

MS RICHARDS: Yes. Ultimately it means that the lawyers behind me will have to miss their break, but so will we.

SIR BRIAN LANGSTAFF: Well, everyone else won't, and if you can be back, please, by 3.30, so slightly shorter break, 25 minutes.

(3.05 pm)

(A short break)

(3.35 pm)

SIR BRIAN LANGSTAFF: Yes.

MS RICHARDS: I want to ask you now about the question of psychological and social care and support. Starting with psychological support and counselling.

First of all, do you consider that the provision of counselling and psychological support would have been of benefit to patients infected with hepatitis and HIV in the way that we've heard?

PROFESSOR CHRISTIE: Yes, absolutely. Absolutely. Without question. Without question.

There's very good evidence that when somebody receives a diagnosis that is challenging and distressing, that proper, adequate psychological counselling and support can make a significant difference to their ability to develop coping strategies, to the family's ability to manage. So there's absolutely no question.

MS RICHARDS: And family support, informal support networks, through groups such as a number of the groups that we've heard described, are clearly very, very important, but they are important in their own right rather than as a substitute for psychological and professional assistance?

PROFESSOR CHRISTIE: Yes, there's a difference between a support group, which is there to, like, activate political support in some ways, to have the condition recognised -- what I would say is that what's needed is a number of different therapeutic kinds of support groups. So there are therapeutic groups where there's -- are facilitated and supported using psychological theory and psychological therapy techniques to help people share. It's really important not to re-traumatise people. We know that just getting people to tell their story, again and again and again and again, just creates a re-traumatising situation and is not helpful.

There's got to be a way of people working that through, of transforming a distressing emotion, recognising their own resilience.

There are lots of different ways that people can be supported, and people can and deserve to choose the kind of therapeutic support that works for them, and when it's the right time for them. So at the immediate point of diagnosis it can be too raw, too painful, and too difficult to sit down and talk with the psychologist, but there will be a point at which -- they should continually be asked, "How are you doing right now? How are you dealing with it right now? Would you like to talk things through and work out what would work for you?"

And that might be individual work or it might be family work, it might be couples work. There are a vast range of psychological approaches and psychological therapies that will fit different people in different ways and have good outcomes.

MS RICHARDS: And in the absence of formal psychological support, is there a risk that patients may develop their own coping and adjustment strategies? And that might include strategies that are damaging or harmful. We've had some accounts for example of people turning to alcohol and drugs [all witnesses nod] as

a means of coping in the absence of any other form of support?

DR THOMAS: That's absolutely right. They can utilise unhelpful coping strategies which undermine their own physiological health systems and mental health systems, but I think it's really important that for us, as a group of psychosocial experts, what's come out again, is that individuals have found important ways of transforming that experience, and making that experience a positive one, and so resilience has been a really important thing that's come out, that they have found ways, individual ways, of -- without support, of becoming resilient. That's not to say support isn't important, but we must acknowledge that they've found ways of doing that.

Just to add to what my colleague was saying here about there's quite a lot of research that shows with adding psychological care in the context of the medical setting, that you can reduce psychological distress, you can reduce -- improve the coping mechanism, and the frequency people are hospitalised and how long they're staying in hospital are enormously benefited

from having -- adding psychology to the team.

I think it's absolutely right what you were saying about how -- what kind of psychology services are available, and in my experience and certainly when I was doing the work, trying to do the literature search around this, we found very little evidence for hepatitis C patients who had been infected or haemophilia patients, and the large support literature has come from the HIV literature, which -- you know, people were infected -- and MSM literature, which in some ways, although they had support structures there, people with haemophilia didn't necessarily feel that they could access those. And I think that's -- that was also an added problem, and I don't know whether you want to say something about that, Sian, because you've got more direct experience of that.

MS EDWARDS: It's interesting because we cannot pretend in this era that HIV psychological support was absent. In many areas, there was enormous support. There was fabulous communication, things that we have talked about and that witnesses have expressed. In some areas, in the HIV specialist areas, there was a lot of resources. There was a lot of money being put into this area. You know, when we think about healthcare services, we think about -- when you want a good healthcare system to work for you, you need somebody who has in-depth knowledge, who has expertise, and who has experience. And in the early days of the eighties, nobody had any of that. And so what happened in many of the HIV specialist centres, where people were coming into the service because they wanted to be there as healthcare professionals, the question was: tell me, as a patient, how you want to be nursed and how you want me to care for you. And actually, that was very transformative in the HIV specialist services. And in that area, there was huge psychological support.

On our discussion earlier all about communication, communication -- on one level it's about patient and doctor; on another level it's between healthcare professionals. I think in some ways we didn't access some of the support that was around for all sorts of reasons. Because much of the support was seen as HIV specialist care, that was seen as

something that was focused on gay men who were infected with HIV, and therefore inappropriate or not targeted, not sympathetic. The Birchgrove report that we mentioned earlier on talks about this a lot.

And in retrospect, did we do -- you know, did we do something wrong? Did the healthcare workers -- we talked about prejudice within the healthcare working -- workers' areas, there were many doctors who would not refer to specialist areas of HIV, and I think -- we can't pretend it wasn't there. I think what we do know, that it wasn't accessed, and often referrals weren't appropriately made, and it may be that it was not appropriate.

MS RICHARDS: Is there still the potential for benefit for patients to access psychological support services now, so many years after some of the initial events?

DR THOMAS: Absolutely.

MS EDWARDS: Absolutely.

DAME LESLEY: Absolutely.

DR THOMAS: I mean, it's -- in the break I was speaking to a hepatitis C sufferer and who was talking to me about how she had managed to hold

on to a lot of her information and the secret around carrying hepatitis C, managing herself and also her daughter and her family, and how this has been -- on one hand, she sees herself as being quite strong and has brought out her resilience, but actually, you know, that's sort of -- a loneliness of carrying that has actually meant that she hasn't had a space where she's given permission to kind of debrief and look at, you know, all of this, the stress that she's had.

So I think it's immensely important going forward.

PROFESSOR CHRISTIE: I mean, every single transcript that I read, and I can't remember how many I went through, but I went through a lot of the transcripts, and every single one that I read I could see the potential for support and help from psychological therapy. In every single transcript. For some people, I felt that there was the opportunity to work with an individual to help them with some of the guilt that they'd experienced. There was opportunities for families, to support the family and help the family see what an amazing job they had done.

There was the opportunity for parents to help them think about how they'd managed to parent despite the difficulties that they'd had. For young people to realise that despite having lived with this really awful challenging, challenging condition, throughout their teenage years, how they had turned into amazing individuals.

And therapy can be about good stuff too. Therapy doesn't have to be -- you don't have to be sad, bad or mad to see a psychologist. You can just be living with stuff that you'd like to work through, and the service that I work in, we see people to celebrate. We see people to celebrate and witness their triumphs, not just to talk about the miserable stuff.

And there's some very good work in the narrative field which is around people who have lived -- a lot of it actually, interestingly, coming from New Zealand -- with people who have lived with trauma and lived with abuse, which is what a lot of people effectively have experienced, they've experienced abuse, iatrogenic abuse, abuse by the medical system, for them to actually come together to witness and to celebrate the fact that they have survived, and that they are survivors and should be really proud of being a survivor.

DAME LESLEY: I think Professor Christie has made some good points there, but one of the things that I'm mulling over is just that there isn't a generic form of support that would be appropriate for everybody, it's got to again be very individualised and personalised. And sometimes it might be groups, and sometimes it might just be one person.

But I feel from all the sorts of things I've read and the spontaneous conversations I've had with some of the affected and infected, that until particularly this Inquiry comes to some conclusion, the reconciliation process that will bring a great deal of comfort and support to people can't be achieved.

You can talk and talk and talk about how you feel, you can talk about methods to, you know, manage your anger, your resentment, your feelings of guilt, you can do all that, but I think the greatest form of support for a large number of people is going to be achieved by a successful outcome from this Inquiry, and

reconciliation.

MS RICHARDS: One issue that has -- or one concern that's been expressed by a number of people is about the variability amongst different parts of the United Kingdom and the different schemes within the United Kingdom, different elements of both psychological and social support being available, and that's engendered in some further sense of discrimination or stigmatisation. Is it fair that they understand it in that way or experience it in that way?

PROFESSOR CHRISTIE: It's absolutely accurate. There is a postcode lottery for mental health care across the whole of the UK, and depending where you live will determine whether or not you have quick or, indeed, any access to child and adolescent mental health service or an adult mental health service, whether or not you have access to increased psychological therapy, access via your GP. Some GPs will pay for a counsellor, others won't.

There is a -- it's appalling that there is, but there is a really significant postcode lottery in relation to support for emotional wellbeing.

MS RICHARDS: A common theme -- I'm sorry, Dr Thomas?

DR THOMAS: Just that where there are psychologists within haemophilia or hepatitis C services, their access is very, very variable as well, so you may have, say -- I can speak for my centre -- you know, psychologists providing three or four days to Haemophilia Centre, and then you go to Ireland or Scotland and find that you've got one psychologist doing half a day. So how does it possibly meet the need? And I think it's disingenuous sometimes of healthcare providers to say that they've got access when the calibre of access or the quantity that they've got is extremely limited. And it's those things, I think, that need challenging.

MS RICHARDS: One of the common concerns expressed by witnesses has been where they've attempted some form of psychological support -- accessing some form of psychological support, it's been at a level of general mental health services, and they have found themselves having to explain the history of infection through blood and blood products, and so a number of witnesses have said

what they would want is a service which is sufficiently specialist and focused that those who are delivering the service understand and have a good knowledge of the history as well as of the particular conditions of HIV and hepatitis C and its consequences. Would you agree with that?

DR THOMAS: Absolutely. And again, I draw on my experience, and certainly some of my patients who are in the audience here, where we provide what we call a dedicated service for people with haemophilia. So you have an expert knowledge of haemophilia, as well as hepatitis C and HIV. And there are joint clinics that are run within the Haemophilia Centre with all these professionals who come to the department, and that involves a psychologist as well. So I do think, if you -- if the psychologist -- the psychologist needs to have that history of infected blood disorder as well, infected blood products, and -- so that the individual feels that they can go and they're in a safe pair of hands, they don't have to start explaining themselves all over again. Which is very, very distressing and wearing, you know, takes its toll. So I do think embedding a psychology service within the medical team, so the doctor, the nurse, the psychologist is there, normalises psychology, so there isn't a sense of, oh -- you know, you see the psychologist and you can have informal conversations, and when individuals are ready to have that referral and see a psychologist for one-to-one and detailed psychological support, they've already sort of bridged some of those initial conversations, and then it doesn't feel like it's something that's foreign and unusual.

I think the other thing to say about that is just that we have spent a lot of time demystifying what psychology is. You bring to us -- you are the experts with your health problem and we're learning from you as psychologists. We're novices. So they may initially feel like there are power dynamics in the room where we, the psychologists, are powerful, but the important role is to educate the individual patient to say, "Actually, you know more about this than I do, what is it you want from this therapy? It's not what I'm going tell you you need; it's about what you feel you

want to get."

And that's a really important way, I think, services should be structured.

MS RICHARDS: You've referred in the report to UK quality standards for haemophilia and for haemoglobin disorders. Now obviously at the risk of perhaps stating the obvious, that's only going to be available for individuals who are accessing those centres, and because they have either a bleeding disorder or a haemoglobin disorder. So that's not a service that's open to those, for example, infected through transfusion.

You've also, I think, alluded to the fact that there is very different availability in different centres across the country in relation to that.

For some -- and some witnesses, not all, have said this -- for some, receiving psychological support at the centre where they were infected, albeit involving treatment from different individuals a number of years before, is itself problematic.

DR THOMAS: Yes. And an important dimension in terms of how a haemophiliac -- and I can only

speak for haemophilia obviously, and it is absolutely right that other people who are infected also need support, and that sort of specialist focus work in an area that is non-stigmatising is very important. That in a way it's important that, going forward, we are actually taking account of what people are bringing to sessions, and -- I've lost my thread of what the question is now. Can you repeat that last question for me?

MS RICHARDS: I'm going to have to check. No, I can't even see it on the transcript. I was asking, I think, about the -- people having to go back to the same centre where they had been infected.

DR THOMAS: Yeah, so Haemophilia Centres have actually then provided kind of outreach work, and certainly one recommendation would be, and within our centre, we would go out to centres to see patients there. And of course this is not always possible because it comes back to resources again, if you don't have adequate psychology resources you can't provide that. But that would be an ideal way of meeting people within the community or linking them up with

appropriate people in the community to get that support.

MS RICHARDS: Dame Lesley?

DAME LESLEY: I wonder if I could slightly disagree in the sense that it for many people, what has happened is they've lost trust and if you're going to re-establish trust you can't actually do that by sending them somewhere else. And also some people live, certainly parts of the devolved nations, Scotland, you're miles and miles away from specialist centres, you're likely to actually experience other sorts of illnesses and ailments or your family will, where you'll have to be treated in your local centre. And so I guess I'm sort of thinking about a little more widely as we're talking about this, that perhaps also there are some support services that are required for the healthcare professionals who inadvertently have been actually involved in these errors. It's not been their fault, not their responsibility. It might have happened years before they ever even joined the service and unless we -- again I'm coming back to this reconciliation -- it works both ways. There are some probably quite damaged healthcare professionals out there who feel desperate about the situation of the families, and also have a sort of corporate guilt themselves, that their institution or hospital did this to people, wittingly or unwittingly.

And I think, unless we can try and re-establish the trust factor, it doesn't matter if you're sending somebody a million miles away, they might still feel mistrustful of healthcare professionals there.

MS RICHARDS: Professor Christie?

PROFESSOR CHRISTIE: I suppose I wanted to suggest something slightly in the middle because I think I agree absolutely with both positions. As a psychologist, you don't have to have diabetes in order to work with a young person with diabetes. You don't have to have a particular condition. You don't also -- what you have to have is an understanding of the impact of illness.

Now, I think one of the things that's really striking for me was, when I started to read, to start to get a sense of understanding how many other people there are out there who have

developed these infections as a result of having something other than haemophilia, so the people you are referring to who aren't going to a Haemophilia Centre because they became infected through a pregnancy transfusion or an accident or something like that.

So I think it is possible to think more widely. I think it's possible to have a trained workforce, and I think you would need to think about how people are trained in order to start to help people think about these really unusual -- this is not usual. You don't come across people who have been infected by a healthcare service in your everyday work, but it is possible for psychologists to work, if they have an overall understanding, and I think -- and Lesley has also said this -- that actually it's not going to be possible to have "The Infected Psychology Service". It's just not going to work, because everybody here in this room is different, and everybody here in this room will have a different thing that they need to think about or work through.

So, again, the workforce has got to be of an adequate calibre -- and Nicky used that word,

"calibre", it's so important -- it's got to be people who can work with difference, with diversity, with uncertainty, and not quite know where they're going to go, but be able to be driven by what the person coming to them is -- needed. So I'm not entirely sure that it does need to just be in Haemophilia Centres. I do think there needs to be some embedding within a medical service. I think psychology for chronic illness and emotional distress is very different to just mental health. You know, that's why we don't have good evidence for what kind of treatments are needed. We know what works for people who just have depression but we don't know what works for people who have diabetes and depression or HIV and depression. We don't have the clinical trials to tell us. But we have the clinical skills to know what might work.

We need to be flexible and we need to be adequately resourced, because without adequate resourcing what we will get is an unqualified workforce that will provide unhelpful, low-quality services, and people will say, "Well, we're doing something", and that's not

good enough.

MS RICHARDS: Dame Theresa, was there something you want to add?

DAME THERESA: Yes, just to say it's not my area of expertise so I defer to what I'm hearing here, but I'd just like to add that I would want to think about this not just in terms of psychologists, there are other healthcare professionals who can provide expert counselling, and I think we also need to look at this in the context of the lack of parity between mental and physical health, and Sir Simon Wessely, who produced a report for the Government before last, I think it was under the Prime Minister Theresa May, he wanted to see a levelling up, if you like, of resource for mental health services. So I would see this as part of that, as well as having the particular colour that it has here.

And we've talked about medical errors, and I don't know what provision there is within the NHS for managing that. So there are going to be very, very expert services, such as the kind that Nicky is providing, but I would want to see a response that goes across the piste for all the reasons that we've discussed.

MS RICHARDS: Would you also expect psychological care and support to be available to affected individuals, in the sense that the Inquiry has used that term: family members, partners, children, et cetera?

PROFESSOR CHRISTIE: We opened this morning by stating very, very clearly that nobody lives on their own with this, that the illness, the condition, the infection, is in the family. One person may carry it, sometimes more than one person may carry it, but everyone in that family lives with it, and you cannot provide good psychological care by just focusing on that one person. You have to think about their wider system. You have to think about whether there's siblings, friends, aunties, uncles. You have to think about everybody, parents, grandparents, everybody needs to be considered and included, because one person may be infected but everybody is affected.

MS RICHARDS: Dame Theresa?

DAME THERESA: Just to add: infected; affected; and a very important point not to lose sight of that Lesley has already mentioned, the healthcare

providers. I think it's absolutely key that any kind of training that we talk about continues through in terms of providing support for those individuals to be able to manage the situations that they have found themselves in.

MS RICHARDS: A number of those that have given evidence about bereavement have pointed to an absence of psychological support for them, either in the weeks or months preceding death or in the weeks, months and years after death. Would that be another important part of any service offered?

DAME LESLEY: Yes, and actually some of those things exist. Certainly when I worked at the London Hospital, we had a bereavement service that was actually run not by specialist psychologists, myself and a psychiatrist called Colin Murray Parkes used to train up very good counsellors, because we just didn't have funding or enough personnel to offer the service, but they were very good at actually visiting people, compassionate friends. There are quite a few bereavement services that I think, with a little extra support and training, you could realistically help to do this job.

MS RICHARDS: Can I ask, if an individual is reluctant to access psychological support -- and there may be all sorts of reasons, many of which you'd discussed why that might be the case -- how active should healthcare professionals be in trying to encourage that individual to access support services?

DR THOMAS: I think everybody has to get to that place where they feel ready and able to take that kind of support, but if you don't know that that support exists within your vicinity of where you're getting the care, then that's just such a travesty, you know, that we healthcare professionals are not doing a duty to our population of patients. So educating our patients about what the service entails is a really, really important thing to do. And what it means. So normalising it, again. I remember when I started working in sickle cell all those years ago, this -- psychology was seen as such a stigmatising area, and one of the biggest advocates for it, and enabling patients to access it, were the clinical nurse specialists. They would talk about it in a way that was useful and helpful, that the patients

could access, about all kinds of things that they found that -- that they would find it useful for. So there's a role for the healthcare professional to sell it, if you like, in a way, so that they know it's there, it's part of the service they can access, but if you don't know it's there, you won't -- it's another barrier, and you struggle for years. And then you suddenly discover, oh, yes, it's there. So I think that's an important role.

PROFESSOR CHRISTIE: You should just never stop asking because you just never know when people are going to be ready. So some people will want support immediately when something traumatic happens. Other people will be ready in six months. Other people, six years. And some people maybe 20 years. So, you know, there will be young people I'll see who will categorically refuse to see me, and will -- I know, can you believe that -- and they will say, you know, "I can't see the point of this, there's no point in talking", and we'll say, "That's fine, let's try this again in six months' time", and we start at 12, and when they're 18, just before they're about to be transferred to adult services, they go, "Oh, I've changed my mind, I'd like some psychology now." But there are equally people who get in touch with me six, seven years later after I saw them in their early twenties, and say, "I just wanted you to know I finally did what you suggested and I went and saw a psychologist. I wish I'd done it earlier."

So it's never ever, ever too late, if you feel that you -- that there's something that's not quite right. If you feel that you need help and support, then go and ask, and keep asking. Keep asking, because you will get it eventually, but you just have to persevere, just persevere.

MS RICHARDS: If we just broaden out the discussion from psychological support to other forms of support more broadly, social support, what other kinds of support might alleviate some of the kinds of psychosocial impacts that you've identified?

PROFESSOR CHRISTIE: Decent financial support, yes.

PROFESSOR WEINMAN: Definitely.

PROFESSOR CHRISTIE: Decent financial support so people aren't -- we heard this morning and earlier this afternoon about the massive impact

socioeconomic financial hardship has on people, on their physical wellbeing and on their mental wellbeing, so appropriate and adequate financial support can make such a difference to people. It can help a family go on holiday, something as simple as that, but that could make such a difference to people's wellbeing, so I think financial support, very, very important.

And social support is a major mediator of physical wellbeing, so creating good social support systems and, again, asking people. It is absolutely essential for healthcare professionals to keep asking the people that they're working with, "How are you doing? How are you doing? What can I do to help you?" Not, "Tell me what your blood levels are". That's not the question. "What can I do to help you today? What is it that will make your life better?"

The question that needs to be asked, and when somebody tells you, it's your job then to do it. Often it's not psychology. We will get families we see where actually what they need is a decent house to live in, decent accommodation, a decent school. They don't need a psychologist

to fix. They're not depressed. They're living in squalor and a psychologist can't fix that, so good social care, decent social care.

DAME LESLEY: There is one other thing of course that we are slightly forgetting, and that is that not everybody lives in a warm family environment. There are lots of people who anyway contracted all these awful sort of diseases who are already socially quite isolated anyway, and I have a slight concern that the only people who usually knock on doors asking for help are those who are already actually in receipt of some of it.

I think it would be quite useful to be a bit more proactive in seeking out those who had lost loved ones when they were already socially quite isolated and who don't have any existing supports. If we have to focus our efforts on individuals because of a lack of different sorts of resources, manpower, money and everything else, I think there's a very needy group who don't have a voice at all. They don't have a friend. They don't have a family who will shout and beat the drum for them.

MS RICHARDS: Dame Theresa, can I ask you now

a slightly different topic about the consequences of vCJD notification. Your report very properly draws attention to what I think is the only study that has looked at the psychological or emotional consequences of being told about the possibility of exposure to vCJD.

That study, which was a small one of 11 individuals, found in those 11 individuals, no evidence of particular long-term emotional psychological disturbance.

As the panel know, the evidence that the Inquiry has received from in excess now of 2,000 statements paints a different picture. Not everybody obviously responds in a different way, each -- people respond in their own way, but we know from what we've been told that it is something that has weighed very heavily on a number of individuals, and has been a cause of considerable fear, anxiety, psychological distress.

Dame Theresa, I think you have some observations about why the study which you spoke about wouldn't be representative of the broader group with whom we're concerned.

DAME THERESA: That's absolutely right, and thank you for giving me the opportunity to expand on that. So the only study that has been conducted looking at people who have been notified that they have a risk of about 1% of having become infected with variant CJD, so there's a very low risk, so the only resource that was available was to interview 11 people, and those individuals, as far as I know, had not already had experience of being infected through healthcare.

So these were individuals who were being informed of a real but theoretical -- you know, a low risk -- for a condition for which there was no test and no treatment. And what we know from those individuals -- so they're selected -- they're self-selecting, so they were approached, but if you were feeling pretty ropey about that notification, you would be unlikely to come forward to be interviewed. We know from other research that those who respond to life-changing risk information, how they respond is very much predicted by their psychological and emotional resources before being notified.

So the main study in this area which we cite in the report was a study which might feel very

removed from your experiences, of those who were found to be at risk of an inherited condition of Huntington's disease, and undergoing testing. And the thought always was that if you were found to have inherited the gene, and you would go on to develop this condition for which there was no treatment, you would be understandably depressed and anxious. And if you found you hadn't inherited the gene, you would be not anxious and depressed.

Whereas what the evidence told us was that how you felt before the testing predicted how you felt afterwards. So if you were depressed and anxious before, regardless of your test results, you felt like that afterwards. So that's a long way of saying that initial vulnerability is extremely important in affecting how people respond to being given risk information about their health. So for those who had already been informed that they were infected, through treatment that they'd been receiving, whether it's HIV or hep C, to then learn that they had a chance that they had been exposed to another infection, that would lead me to predict, on the basis of what we know, the

impact would be very, very different.

MS RICHARDS: Then going back to questions of communication, how does what you told us earlier about good communication inform what should be the right approach to this situation, where you're not telling somebody that they have been diagnosed with a condition; you're telling them that they may have been exposed to something that cannot be tested? Are there any recommendations or observations that any of you have about how that should be approached?

DAME THERESA: I think, again, it would depend on the individuals. So for those such as the infected and the affected that are the focus of this Inquiry, so already within a healthcare system where people are dealing with the damaging consequences of having already received blood or products or undergone surgery where they have been exposed to infection, I think, as Lesley has already outlined, face-to-face communication, explaining. And as Deborah has already stated, it's not sort of one-way. So there's an interaction with an individual, with a healthcare professional, who has all the information at their hands, being able to

explain in a way that is effective and sensitive. So checking that people have understood what this information means, and providing them with the support that they need to adjust, to yet more information about a potential infection.

MS RICHARDS: Dame Lesley.

DAME LESLEY: I'm always very interested in individual differences and how different people respond in ways that you think, you know: this is really strange. Why is one person devastated by the news? Why is another entirely, you know, sort of cool about it?

And there's a very interesting test you can give people, quite a quick one, called the intolerance of uncertainty test, and it's quite robust. And it really is highly predictive as to how well people are going to cope with different sorts of risky information that involves uncertainty. So if you have a high intolerance to uncertainty, you are likely to find it very, very difficult to live with that, and will need a lot of really quite intensive support services to help you through it. But if you're someone who actually has a high tolerance to uncertainty, then living with this information is probably not, in the order of things, as difficult as, you know, thinking about whether or not your football team will win on Saturday or not.

DAME THERESA: But critically, it will -- to add to that -- depend on your pre-existing -- how you are feeling, what your emotional resources are. So added on to that.

DAME LESLEY: Added to it, yes.

DAME THERESA: So not everybody, but many of those, as we've read from the accounts of the witnesses in this Inquiry, these were individuals who had already had to deal with errors that were being made. So to add to that with something else that, for those who haven't previously had that experience, actually in the ordinary course of events, they could deal with it. But actually it's like the final straw for many people.

DAME LESLEY: There is also, when you're looking at people communicating about risk and uncertainty to patients, something that's quite interesting: the same words can be received very differently by patients because of the nuance, the way that people actually express themselves.

And I think that's another reason why we feel quite often, in certain situations about -- when an error has occurred, when an adverse event has occurred, you should actually have somebody talking through the implications of this with a patient who has actually had some specific training, and will recognise when they are offering that information in a way that actually biases, if you like, things to over-optimism or over-pessimism. Being objective about the information you're giving can sometimes sound quite cold, but you really don't need somebody to either over or under-egg it. And again, healthcare professionals have different tolerances to uncertainty and risk as well.

DAME THERESA: Can I also add that, having sat on one of the many panels that were set up by Government to deal with variant CJD and the implications of it, it was very much informed by what was considered to be -- and I would have to choose my words advisedly, so not a scandal, but a recognition that what has happened to many people in this room should not be repeated.

So you could tell by the communications that

were happening with people who were at risk of variant CJD, there was going to be no sitting on hands. People were going to be giving the information. And a lot of care went into the communication of that.

So little comfort, I suspect, to many in this room, but already there was some learning that was happening as a result of the experiences of you in this room.

MS RICHARDS: We have heard from one witness whose son died in consequence of vCJD. His son's experience of the care and support that was available, and your report alludes to the specialist provision that was made for people diagnosed with a prion disease, his experience was very different from the experience that the majority of infected individuals and their families have described of their own experiences of the trusts and schemes set up to support them. I think you've drawn attention in your report to that specialist service, the specialist guidance for social workers dealing with vCJD and a national service that has been established.

I've one further question and then a handful

of questions that others have asked to be put to you. You will have heard from what you've read and those of you who heard the evidence yesterday from intermediaries, that there are a number of individuals who, in giving their witness statements, giving their oral testimony, if they've done that, or speaking to intermediaries, are speaking for the very first time about deeply personal and deeply traumatic experiences.

Some have reported that that has in some respects felt cathartic but is it fair to say that for some that very experience may also be traumatic? And, if so, what kind of care or support should potentially be being made available for people who are reliving distressing events?

PROFESSOR CHRISTIE: I mean I would say that the research does say that asking victims of trauma to recount their experience creates a re-traumatising situation and one where you could re-experience the distress that you went through the first time, so just as you asked the question about what we should do, we should offer what we can. So we need to make sure that anybody who has been brave enough to stand up and tell their story needs to know that help and support is available, and it should be offered. It may not be taken up, but that's somebody's preference. But it should be. It should be offered.

MS RICHARDS: Again this is, as I say, a handful of questions from various core participants and their various legal representatives. One is question for clarification of something Dame Lesley said when we were talking about consent earlier, and you used a phrase "tacit consent", and I wondered if you could explain what you meant by that phrase.

DAME LESLEY: Ah, well, we have written consent, for example if you're going to go into a clinical trial or you're about to have a knee replacement or an operation. But for certain sorts of treatments or procedures, the doctor will just say, "I think we should just run a few blood tests", and the patient nods, and that's taken as tacit consent, which I think has been potentially a big issue here in this particular problem that patients have had.

A lot of the people who actually claim --

and I don't doubt them for a second -- that tests were done without their knowledge, I bet you'd find most of the healthcare professionals would argue that you had provided at some stage some tacit content. I can see somebody shaking their head, and that's exactly it. They would have picked up, or thought that they had actually got your approval. Some of them would have done. And that's what I mean by tacit consent. If somebody doesn't actually put their hand up and say, "Excuse me, but what exactly are you doing here? What does this involve?", and they just nod, they've given tacit consent sometimes, some healthcare professionals would say. I don't agree with the practice, but that's what I meant by it.

MS RICHARDS: And that reinforces the importance, perhaps, of two things. One is the provision of full information by the healthcare clinician as to what they are doing, or what they are asking the patient to agree to. And the second is the importance of written consent, of recording that.

DAME LESLEY: Yes, absolutely.

PROFESSOR CHRISTIE: Yes.

DAME LESLEY: And checking that people have understood what they've just signed. Because that's another thing. Many consent forms are actually written demanding a health literacy skill that most of the population don't have. The health literacy in the UK is probably about that of -- 25% of the population have health literacy skills of a 10-year old. And if you look at most informed consent forms that people sign, they are way beyond that. They're graduate level reading skills required.

I don't think it's just that we need written consent from people, somebody should go through the form with them and say, "Have you got any further questions? What does this mean to you?" Those sorts of open questions.

MS RICHARDS: Then the next question is about care plans for treatment. What are the benefits, the psychological benefits, of having an agreed care plan and of having input into that care plan as an individual?

DR THOMAS: So an important benefit from that is that the care plan is individualised to that patient's needs, and if it's been drawn up as an effective care plan, the patient or, you know,

the impacted or infected person would be party to that, so they would be collaborating in developing that care plan and identifying their needs. Because as we said before, they are the expert in terms of their physiological and psychological needs. So it's important that they are saying to us what it is. And of course, added to that is a medical and nursing dimension that goes into that, as well. But a care plan is useless if you don't have signed and -- sort of collaboration from the person who is going to be impacted on.

PROFESSOR CHRISTIE: I was just going to say very quickly, in terms of adherence or concordance, which is a phrase that we prefer, where people are part of their medical treatment, you're much more likely to get people to take their medication more regularly, you're more likely to get people to follow recommendations for physiotherapy or any -- anything that you ask somebody to do, if they have created a co-created care plan, then the chances of that happening then are much, much higher than if you don't have one.

MS RICHARDS: The next question is about psychological impact again. And it's this: would you expect there to be an additional adverse psychological impact for someone who has been infected as a result of treatment that wasn't for a life-saving event, but may have been treatment that wasn't essential or even appropriate because they'd been misdiagnosed or because they were, for example, a mild haemophiliac for whom other treatment methods were well established. Is an additional sense of injustice or harm that people in those situations might experience?

PROFESSOR WEINMAN: I don't think there's any direct evidence on that, because that was something I was interested in. It was bought up by one of the questions you gave us.

Off the top of my head one would say yes, it is most likely. But as we said yesterday, you know, with additional problems, you don't necessarily get additional or some sort of linear psychological impact. So terribly difficult to answer. And my sort of gut, you know, from what I read and what I've read around it is yes, you would expect that, because of the sort of shock and all those other issues that came out of something that was possibly unnecessary.

MS RICHARDS: Then again we explored yesterday a number of different psychological and indeed psychiatric impacts arising from illness and treatment and so on. Does the risk of those impacts also include the risk of other harmful behaviours such as addictions or behavioural issues?

PROFESSOR WEINMAN: We certainly heard that from some of the witnesses. You know, because it's -- we talked about illness having an impact on, you know, one's sense of oneself and so on and how one deals with that. And the ways in which one deals with the sort of demands that are on you now can vary hugely, and this sort of heading of what we call coping. So, you know, a large amount of coping is attempting to deal with things directly, but a lot of coping is around dealing with things that actually you can't change, or you can't prepare yourself, or whatever. It's out there, it's some enduring problem.

And I think a lot of people go for a sort of an avoidant type of coping which might involve

blanking oneself off, you know, turning towards alcohol, turning towards comfort eating, turning to whatever it is to, you know, avoid that awfulness that's in you. And it's all part of that avoidant type of coping that we talked about that can be very harmful in the long run.

MS RICHARDS: Dr Thomas, yes.

DR THOMAS: There is this existing literature in NICE guidance suggesting that people with physiological long-term health problems, so chronic health problems that a haemophiliac or hepatitis C or HIV already have, what we call -- they are twice if not three times more likely to be psychologically depressed. So this is the -- again, it's a background. And many people are not necessarily aware that they're depressed, but there's a low level of depression that's there. And some people are really quite severely depressed, which then interferes with people's motivation, ability to live life, then they might turn to other means of coping, like drugs and alcohol and so on and -- as a way of coping. But I think it's something that -- when I was doing this work, I was thinking really, that we already -- people are already compromised because of having to cope with two long-term conditions.

MS RICHARDS: Ms Edwards.

MS EDWARDS: We mustn't forget as well that the things that we're dealing with are also extraordinarily painful, so we're dealing with haemophilia, which can be very painful, for men, for women with von Willebrand, we know there are people with haemophilia who are women as well, these are very, very, very painful situations. HIV also can be a very painful debilitating illness, the treatments that go with that. Then you've got your hepatitis C treatments that come in on top of that. There's an enormous amount of treatments. Drugs and alcohol take some of that pain away, as well as the psychological pain. It would be very unsurprising in many ways that people don't turn to those methods of relief.

MS RICHARDS: Then moving on to the theme of communication, some of the evidence we've heard suggests that people were given their diagnosis or information about their diagnosis either in a group setting or in a non-confidential setting of some other kind, being -- something being called out across a corridor or a clinic. Is that appropriate, and what are the psychological consequences of it?

DAME LESLEY: I don't think any of us even need to answer that directly, but just -- I mean, I was totally shocked at the number of reports that we read where people had been told what had to be life-shattering information in the most callous, insensitive manner, with a total lack of privacy. I mean, to be told the sorts of information -- particularly as we also have the backdrop of, you know, the stigmatisation, the lack of knowledge about things such as HIV/AIDS and Hep C at the time -- to be told that in a corridor, to be told it on the telephone by a receptionist in a GP surgery, that just violates every principle of common decency, let alone sort of how medical professionals should behave.

[Applause]

This is starting to feel like Question Time!

The other thing, actually, on a serious note that I feel sort of is really important to sort of say here, and that is that we've already mentioned that part of the process of coping

with a serious diagnosis that's got prognostic sort of implications, lifestyle implications for you, part of the, you know, thing that we should always do to help people is give them some warning. Fire a warning shot. The realisation that you have a life-changing diagnosis, that you're going to have expectations, sort of no longer -- realise that you're going to need lengthy treatments, and a lot of this might never get better. That's a process, and it needs to be done over time with the right pacing, with the right sort of information, at the right level of complexity for the person in front of you. And no one should ever be told a serious diagnosis like this by somebody just who happenchance to come across the information. People lying on trolleys in an A&E department being told, "Oh, I think we're dealing with full-blown AIDS here", I think I remember reading one transcript. That is just utterly totally unacceptable. I'm sure that no one could ever forgive somebody who did that to them.

And you will find, certainly in the world of cancer, which is primarily my area, people will

recall verbatim the words that somebody used when it was done insensitively. Bad news is always bad news. You can't make it good news if it's bad, but the way in which people receive it is totally dependent on the person who's actually giving it.

MS RICHARDS: Sir, I'm going turn my back and see whether there are any other pressing matters which legal representatives would wish to have raised.

No one, I'm happy to report, is popping their hand up, so those are the questions I had, sir.

SIR BRIAN LANGSTAFF: I have one, but it's a question which is addressed -- although I'm putting it to all of you, it's one which you may prefer, in due course, to answer individually. I'm not asking you to answer it now, for reasons which I shall explain.

You've given a lot of thought and a lot of suggestions, and you've demonstrated a number of important changes that there might be, which would make matters -- would improve the health service, would help to make sure that something like this never happens again. Could you please

just think of the single biggest improvement you think could be made to stop this happening again.

Secondly, the second part to the same question is I've asked what could be made, should be made. There may be a difference between those two. But it may be very much an individual reaction to that. If it's a collective reaction, that's fine. But it is your expert views which I'm looking for.

PROFESSOR WEINMAN: Now?

SIR BRIAN LANGSTAFF: I'm going leave that with you and it can be answered with the supplementary questions.

PROFESSOR WEINMAN: Okay.

SIR BRIAN LANGSTAFF: But can I now let you into a bit of a secret. When we were planning, we thought that the evidence overall that you would give would last a little bit into this afternoon, and we're very glad that it did because we were worried that we might not get full value from Dame Theresa and her availability. I'm very glad to say we have done. But the reason it's gone on beyond the 16.30 -- I'd better not make it too late, but we've had, is because it has been so valuable, and indeed, leading counsel said to me at the last break that she might go on, but I'm very happy that that should be the case, because I don't think there's -- I think it's unlikely to be any one of us who has not found your evidence riveting, not found it resonant with many people who are here.

It has certainly added a dimension to the evidence that we've heard over weeks from and about those who have been infected or affected by the infection of others, and when it comes to communication, you have demonstrated how it should be done, in your own way.

So can I thank you very much for that. You've shown us as well, I think, the proper place of your expertise. It isn't an add-on, it certainly isn't airy fairy, as one of you put it earlier, but it seems to me that you've made the most powerful case there could be for it being an integral part of care. Because it meets a need. Not just the -- well, a need for just that sort of care. For those -- and you've emphasised this too -- for those who want to take advantage of it, because you've emphasised the importance of choice.

Can I thank you enormously for that, and all the more so because I know that you have busy lives. I know that for instance -- and I'm singling out one only, the same probably applies to all of you -- but Professor Christie, this is her day off, would you believe? And this is how she spends it, instead of with her 2-year old grandchild. So that is a sacrifice, I can tell you.

PROFESSOR CHRISTIE: Am I allowed to say that for me personally it's been an enormous privilege to have been part of this process, and I would like to thank everybody for allowing me to have taken part in this. I've been really, really moved, and it has been a tremendous privilege, and I feel very inspired.

SIR BRIAN LANGSTAFF: Well, the privilege is ours. Thank you.

Well, Ms Richards. Tomorrow?

MS RICHARDS: Hepatitis, sir.

SIR BRIAN LANGSTAFF: And 10.30.

(4.43 pm)

(Adjourned until 10.30 am the following day)