

<p style="text-align: right;">1</p> <p style="text-align: center;">Tuesday, 25th February 2020</p> <p>(10.34 am)</p> <p>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.</p> <p>As for today, can I welcome Professor Christie to the panel. We have to swear you in, so let that be done, please.</p>	<p style="text-align: right;">2</p> <p>PROFESSOR DEBORAH CHRISTIE (affirmed)</p> <p>PROFESSOR MYFANWY MORGAN (continued)</p> <p>DR NICKY THOMAS (continued)</p> <p>DAME LESLEY FALLOWFIELD (continued)</p> <p>MS SIAN EDWARDS (continued)</p> <p>PROFESSOR JOHN WEINMAN (continued)</p> <p>Examined by MS RICHARDS</p> <p>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.</p> <p>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?</p> <p>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?</p> <p>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</p>
<p style="text-align: right;">3</p> <p>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.</p> <p>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.</p> <p>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</p>	<p style="text-align: right;">4</p> <p>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.</p> <p>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.</p> <p>PROFESSOR WEINMAN: Actually to say a little bit</p>

<p style="text-align: right;">5</p> <p>1 more about this, because I think the way you've 2 phrased the question was this sort of shared 3 response, people responding in a similar way, 4 and we certainly heard that, that some families, 5 you know, had this very solid response. They 6 pulled together, they coped.</p> <p>7 But we also did read, and I know from other 8 work I've done, where there were really 9 important discrepancies between family members. 10 And if you remember what I was talking about at 11 the beginning of yesterday, I talked about the 12 way people make sense of illness, and certainly 13 there's quite a lot of work around that, looking 14 at what we call dyads, say a parent and a child, 15 or partners or whatever, where one has 16 a particular way of thinking about the illness 17 and coping with the illness and it's not matched 18 in the other person, and that -- where you get 19 those rifts it can be really distressing, where 20 maybe the person who is affected rather than 21 infected perhaps in some way blames the other 22 for not coping in a certain way, and some of 23 those rifts that you can see, because of the 24 different ways of processing and thinking about 25 the illness, can be very powerful and actually</p>	<p style="text-align: right;">6</p> <p>1 very hurtful because you don't get that power of 2 the support within the family and that cohesion 3 which, you know, we've seen some work so well, 4 but it also can break down, pretty -- and we 5 certainly read and heard a number of witnesses 6 talk about that they just couldn't take it 7 anymore, you know, they felt the other person 8 somehow wasn't involved, might have been within 9 a couple and so on. So we need to remember 10 that. It's not always a good group response in 11 that way from a family perspective.</p> <p>12 MS RICHARDS: One of the additional burdens 13 potentially for family members will be 14 additional caring responsibilities, either 15 directly for the person who is infected or 16 having to take on additional caring 17 responsibilities, for example for children, 18 because their partner is not able to do that. 19 What kind of toll can that take in practical, 20 emotional, and psychological terms, both on 21 individuals and on families as a whole?</p> <p>22 PROFESSOR CHRISTIE: Well, it can have a significant 23 impact, psychologically. So it can have an 24 impact on your identity. So if you imagine you 25 having -- if you've got a job that you love and</p>
<p style="text-align: right;">7</p> <p>1 you enjoy, and you have to give that job up to 2 look after somebody that you love and want to 3 care for, there's still that dilemma of having 4 to give that job up and what that means for who 5 you identify as. Because a lot of us see 6 ourselves as the job. The job that we do is how 7 we describe ourselves when we introduce 8 ourselves to people. And that can get lost.</p> <p>9 There can be enormous financial implications 10 obviously if somebody has to stop working. We 11 see this a lot in families where there's chronic 12 illness where one of the -- somebody in the 13 family has to give up a job, so there's 14 a financial impact.</p> <p>15 And socially, if -- again, if you think 16 about most of the -- most people who have jobs 17 have relationships within their workplace, they 18 have friends that they go for a drink with 19 afterwards or they have the -- you know, the 20 Christmas party, and that might seem really 21 minor, but actually is a big thing, because 22 you've lost that whole social circle and your 23 life becomes condensed and focused on -- just 24 into that very small sort of family unit.</p> <p>25 So there's a -- and there can be resentment</p>	<p style="text-align: right;">8</p> <p>1 as well. There's all these complicated feelings 2 that need to be thought about and processed and 3 understood and spoken about. And as 4 Professor Weinman said, you very often find it 5 difficult to talk about it because you want to 6 protect somebody. You don't want them to know 7 that you're resentful. You don't want them to 8 know that you're sad that you've given up your 9 job or angry or you don't want people to know 10 that you haven't got money to do things. So 11 there's also that sort of closing down on 12 communication, which has an impact on family 13 relationships.</p> <p>14 MS RICHARDS: We talked yesterday about the process 15 of adjustment for the person who is unwell, and 16 the impact upon the concept of self-identity for 17 the person who is unwell. But what you're 18 describing is those same two processes or ideas 19 impacting as well upon family members.</p> <p>20 PROFESSOR CHRISTIE: Absolutely. Because when we -- 21 as we grow, throughout our lives we go through 22 various developmental phases and -- becoming 23 a parent, becoming a partnership, becoming 24 a grandparent, all those different developmental 25 phases comes with certain expectations, our own</p>

<p>9</p> <p>1 expectations from our families, from society, 2 from films, from everything that we read about 3 what it means to be a good grandparent or to be 4 a good mother or a good wife or husband. 5 And that identity then gets disrupted by the 6 introduction of an illness and particularly by 7 an illness that is potentially life-limiting. 8 It kind of just cuts you off at the knees and 9 throws -- can throw you under the bus. 10 If you've got a good support system, then 11 you can be amazingly resilient and you can pull 12 together, as John said, and many, many people do 13 that. Many people do that in an amazing way, an 14 inspiring way, but equally, it's very, very 15 difficult. 16 MS RICHARDS: There are two pieces of literature 17 I just want to refer you to there, materials 18 you've referenced in the report, which provide 19 confirmation of what you're saying. 20 Henry, could we have EXPG0000022, please. 21 It should come up on the screen in front of you. 22 It's a paper called -- by Golics and others 23 2013, and it's called: 24 "The impact of patients' chronic diseases on 25 family quality of life: an experience from 26</p>	<p>10</p> <p>1 specialities." 2 We can see from the abstract, methods, it 3 talks about semi-structured interviews being 4 carried out with 133 members of mostly 5 chronically ill patients from 26 medical 6 specialities, family members invited to discuss 7 all areas of their lives that have been affected 8 by having an unwell relative. 9 Then if you look just over halfway down that 10 page, please, Henry, at "Conclusion", you can 11 see it says: 12 "This large scale multi-speciality study has 13 demonstrated the significant yet similar impact 14 that illness can have on the quality of life of 15 patients' family members. Family quality of 16 life is a previously neglected area of 17 healthcare which needs to be addressed in order 18 to provide appropriate support for the patient 19 and family unit." 20 Then there are just a couple of references 21 within the paper I wanted to show you, and then 22 ask you to comment on. On the same page under 23 the heading "Background" we can see it said 24 there: 25 "The quality of life of family members as</p>
<p>11</p> <p>1 well as patients, can be hugely reduced in terms 2 of physical effects, psychological distress and 3 social problems." 4 Then the last sentence of that paragraph: 5 "Previous work has shown that family members 6 of patients can be more emotionally affected by 7 illness than patients themselves." 8 Then if we turn, please, Henry, to -- it 9 should be the fourth page. It's headed page 790 10 in the article itself. That's the one. 11 Towards the bottom of that page, please or 12 the bottom half of that page. Thank you. 13 So we see there under the heading "Emotional 14 impact" it records: 15 "92% of the family members interviewed were 16 affected emotionally by the patient's illness, 17 mentioning worry (35%), frustration (27%), anger 18 (15%), and guilt (14%). Worry was reported when 19 the family members were thinking about the 20 future or the patient's death. Less common 21 psychological effects included feeling upset, 22 annoyed, helpless, stressed and lonely." 23 Then it's reference to support, some people 24 finding it difficult to find someone to talk to, 25 and this resulting in them blocking up their</p>	<p>12</p> <p>1 feelings, finding it very difficult to cope, 2 with many describing breaking down in tears when 3 alone. 4 Then if we just go -- the study then looks 5 at number of different impacts: daily 6 activities, family relationships, the family 7 members own health, work and financial impacts. 8 But we'll pick it up, please -- it should be 9 page 8, Henry -- in the discussion towards the 10 end of the article. 11 We can see there: 12 "The impact of a patient's illness on 13 families is widespread and profound. Family 14 members are affected in multiple ways across all 15 medical specialities. This study has identified 16 the major ways in which family lives can be 17 affected by disease and the commonality of 18 issues across all diseases." 19 Then if we can go down the left-hand column 20 on that page to the second paragraph, thank you. 21 If you could highlight the paragraph beginning 22 "Family members", thank you. 23 "Family members of patients from all 24 specialities felt a great emotional impact, the 25 most widely previously reported topic. They</p>

<p>13</p> <p>1 often felt they had to hide their feelings from 2 the patient in order to provide support - for 3 many this was very difficult. This emotional 4 impact has a major influence on many areas of 5 their lives, eg on health and sleep. Family 6 members of patients can be more emotionally 7 affected than the patients themselves, 8 particularly in the area of oncology. This may 9 be because attention is mainly focused on the 10 patient and much consideration given to the 11 patient's needs. In contrast, the family member 12 and their concerns are usually ignored or not 13 understood."</p> <p>14 Then if we look at the right-hand column on 15 that page, this is the last reference, second 16 paragraph down, please, Henry, thank you, 17 beginning "The impact on family finances": 18 "The impact on family finances and 19 employment were major issues. Family members 20 described the financial impact of having to 21 reduce or give up work as a result of the 22 patient's illness, often compounded by the 23 patient also giving up work. Looking after an 24 unwell patient is expensive." 25 Then the next paragraph, please, Henry, the</p>	<p>14</p> <p>1 first three lines of that: 2 "Family members described their own existing 3 medical conditions worsening, several developed 4 depression. This study identifies family 5 members as a hidden patient group, with an 6 apparent 'ripple effect' of illness; one patient 7 being unwell has the potential to create several 8 more 'patients' in the family. This can then 9 magnify problems with finances and family 10 relationships in a vicious cycle. This hidden 11 burden has a potentially huge financial impact 12 on the healthcare system that could potentially 13 be reduced by appropriate family support." 14 Any observations or comments about those 15 findings? 16 PROFESSOR WEINMAN: I think they fit exactly, 17 really, with what we're saying. And this is, 18 you know, part of the very strong evidence that 19 we've drawn on. There's a huge literature on 20 the stress of caregiving, generally, whether 21 it's with, you know, a very sick child or an 22 elderly parent. And that literature shows 23 really strongly that, you know, you not only see 24 psychological changes, you see physical changes, 25 changes in immune function. There are even</p>
<p>15</p> <p>1 studies looking at how quickly -- you know, if 2 people have wounds, if they are caregivers, 3 those wounds are slower to heal because the 4 immune system is compromised because of that 5 really long chronic stress that's not going 6 away. It's pretty uncontrollable in that way, 7 it's something that's always going to be there. 8 So I think, you know, these sorts of 9 findings really underline how -- you know, how 10 much of a burden it can be. But again, as we 11 said yesterday, for some people, it's a powerful 12 and important thing to do, and the roles they 13 take on, as caregivers become really important 14 to them, become part of that new self, that new 15 identity. So although it's pretty bleak, pretty 16 negative, there is that other side that we 17 shouldn't forget. 18 MS EDWARDS: Yes. Just to say, of course, that this 19 study was done in 26 specialities, and none of 20 those specialities are ones where people hide 21 their diagnosis, and I think that makes an 22 additional, very profound difference, because 23 this is a distressing report, and it shows how 24 awful it can be for people, physically and 25 emotionally. But these people generally will be</p>	<p>16</p> <p>1 people who can share the stories and what 2 they're going through with their friends and 3 their neighbours and healthcare workers, and 4 I think when you take that part away, it has an 5 even greater impact on the conclusions that this 6 report has made. 7 MS RICHARDS: And that's picked up in the second 8 piece of literature I wanted to just ask you to 9 look at, which is a World Health Organisation 10 analysis of the impact of HIV on families. 11 Henry, that's EXPG0000039, please. 12 This is a 2005 paper by the World Health 13 Organisation entitled "What is the impact of HIV 14 on families?" Again, referenced in your report. 15 If we could go, please, Henry, to page 4. 16 Under the heading "Findings", if we could just 17 highlight the first paragraph, please. It picks 18 up on one of the very points that Ms Edwards has 19 made: 20 "Human Immunodeficiency Virus has a large 21 psychological, physical and social impact on 22 infected individuals and their families. 23 Stigmatisation worsens this impact. It hinders 24 the prevention and treatment of HIV and hampers 25 social support and HIV disclosure."</p>

<p style="text-align: right;">17</p> <p>1 It is that latter point I think you were</p> <p>2 emphasising then.</p> <p>3 If we could go on, please, Henry, to -- it's</p> <p>4 the page numbered 8 at the bottom of the page.</p> <p>5 Yes, it should be page 8.</p> <p>6 So if you look under the heading "HIV and</p> <p>7 families", the second paragraph beginning "In</p> <p>8 the first 15 years of the AIDS epidemic", could</p> <p>9 you highlight that, please, Henry. This records</p> <p>10 that:</p> <p>11 "In the first 15 years of the AIDS epidemic,</p> <p>12 families had to deal with the death and the loss</p> <p>13 of family members. Since the introduction of</p> <p>14 HAART in 1996, however, their widespread use has</p> <p>15 reduced the number of AIDS related deaths in</p> <p>16 Australia, Europe and United States. Now</p> <p>17 families must deal with the HIV infection as</p> <p>18 a chronic disease to be managed for the lifetime</p> <p>19 of infected members."</p> <p>20 Now. If we just go on, please, to the</p> <p>21 page 10, Henry. There's a passage "Psychosocial</p> <p>22 issues" which covers much of what we said</p> <p>23 yesterday, but if we then look at "Families" at</p> <p>24 the bottom of the page, please, Henry, at the</p> <p>25 heading "Families", it talks about:</p>	<p style="text-align: right;">18</p> <p>1 "The social stigma that surrounds HIV may</p> <p>2 have adverse repercussions not only for the</p> <p>3 individual, but also for their family.</p> <p>4 "HIV has an impact on partners and on the</p> <p>5 dyadic relationship. Care giving is associated</p> <p>6 with stress and AIDS-related stigma."</p> <p>7 If we go over the page, please, to page 11,</p> <p>8 we see in the second paragraph, please, Henry,</p> <p>9 beginning with "Children", you see a discussion</p> <p>10 there of the emotional distress that:</p> <p>11 "... children may experience due to the HIV</p> <p>12 infection of a parent."</p> <p>13 Then if we go on, please, to page 12, Henry,</p> <p>14 under the heading, "The impact of disclosure on</p> <p>15 the family", halfway down the page. We pick it</p> <p>16 up in the second paragraph:</p> <p>17 "A review of the evidence in the early 1990s</p> <p>18 showed that when people disclosed their HIV</p> <p>19 status, family members experienced a range of</p> <p>20 emotions, including feelings of helplessness,</p> <p>21 fear of the loved one dying, concern about care</p> <p>22 and fear of becoming infected. A recent</p> <p>23 qualitative study, with mainly European</p> <p>24 participants, showed that even in the post-HAART</p> <p>25 era disclosure of an HIV infection may have an</p>
<p style="text-align: right;">19</p> <p>1 emotional impact on the family members; they may</p> <p>2 be surprised and saddened by the disclosure.</p> <p>3 The potential for terminal illness -- as well as</p> <p>4 the impact of medical treatments and constant</p> <p>5 adjustment of hopes and fears -- can affect both</p> <p>6 the individuals infected with HIV and their</p> <p>7 families."</p> <p>8 I think that's all we probably need to look</p> <p>9 at from that paper, but again, perhaps invite</p> <p>10 you, Ms Edwards, to comment upon what we see set</p> <p>11 out there.</p> <p>12 MS EDWARDS: Well, maybe one of the others whose</p> <p>13 social context --</p> <p>14 PROFESSOR MORGAN: I think --</p> <p>15 MS EDWARDS: -- the report.</p> <p>16 PROFESSOR MORGAN: It brings out very clearly that</p> <p>17 the impact extends beyond the individual to the</p> <p>18 family, and in terms of stigma the family is</p> <p>19 often also stigmatised. They have an</p> <p>20 associative stigma by their close association.</p> <p>21 So they share very much in the whole</p> <p>22 stigmatisation process, as well as in these</p> <p>23 other social impacts. Originally the emphasis</p> <p>24 was very much on the, just the patient, but</p> <p>25 I think that a lot of the recent work is very</p>	<p style="text-align: right;">20</p> <p>1 much emphasising the family unit, and the</p> <p>2 importance of taking that through in terms of</p> <p>3 interventions.</p> <p>4 MS RICHARDS: We'll come back, certainly, in more</p> <p>5 detail to the question of stigma and</p> <p>6 discrimination and disclosure. Just turning</p> <p>7 back to your report at page 4, and you've said</p> <p>8 this, towards the top of the page:</p> <p>9 "The dominant picture [this was the picture</p> <p>10 that you picked up from the materials you read]</p> <p>11 is one of a wide range of negative psychological</p> <p>12 impacts often with devastating effects on</p> <p>13 day-to-day functioning and quality of life.</p> <p>14 These impacts occurred in the context of so many</p> <p>15 negative social effects arising from the</p> <p>16 relentless health problems and treatment side</p> <p>17 effects together with the distressing levels of</p> <p>18 stigma that were experienced."</p> <p>19 That was the overall picture you derived</p> <p>20 from the statements and transcripts and oral</p> <p>21 evidence you saw.</p> <p>22 PROFESSOR WEINMAN: Yeah, I mean, I think --</p> <p>23 SIR BRIAN LANGSTAFF: I'm sorry. I didn't mean to</p> <p>24 interrupt. But please go ahead. I just have</p> <p>25 a question, because it seems to me we're turning</p>

<p style="text-align: right;">21</p> <p>1 away from the two papers that you've just been</p> <p>2 looking at.</p> <p>3 MS RICHARDS: We are, yes.</p> <p>4 SIR BRIAN LANGSTAFF: It had struck me in what the</p> <p>5 Golics paper says, that it is focusing upon the</p> <p>6 families. It's not focusing immediately upon</p> <p>7 the patient. One understands why that is. But</p> <p>8 is the position perhaps, can it be summarised in</p> <p>9 this way: that proper care of the patient</p> <p>10 involves care for the family and support</p> <p>11 systems?</p> <p>12 PROFESSOR CHRISTIE: <i>(Unclear: multiple speakers)</i></p> <p>13 Sorry, we all said yes.</p> <p>14 SIR BRIAN LANGSTAFF: Universal agreement.</p> <p>15 PROFESSOR CHRISTIE: Collective, yes.</p> <p>16 SIR BRIAN LANGSTAFF: That's what I wanted to ask.</p> <p>17 Thank you very much.</p> <p>18 MS RICHARDS: Thank you. I was just drawing your</p> <p>19 attention to how you'd summarised from your</p> <p>20 professional perspective, your understanding of</p> <p>21 what you'd read.</p> <p>22 PROFESSOR WEINMAN: Yeah, I think I wrote that</p> <p>23 statement and, you know, but I also think that</p> <p>24 just before that, I had identified the</p> <p>25 possibility that people could draw some</p>	<p style="text-align: right;">22</p> <p>1 benefits, so it wasn't all bad news, and</p> <p>2 I certainly spoke to one or two people yesterday</p> <p>3 for whom there had been growth, personal growth,</p> <p>4 and so on, but the dominant picture certainly</p> <p>5 from all the witness statements and from the</p> <p>6 literature is one of a whole range of problems</p> <p>7 compounded by, you know, treatments, failing,</p> <p>8 further conditions happening, and so on and so</p> <p>9 on. And by a lot of the other things we are</p> <p>10 going to talk about, by some of the</p> <p>11 communication issues.</p> <p>12 MS RICHARDS: Yes, absolutely, we're going to come</p> <p>13 on to all of those. Can I ask, before we leave</p> <p>14 the topic or the theme of psychological impact,</p> <p>15 I wanted to ask Professor Christie about some of</p> <p>16 the particular issues that may arise in relation</p> <p>17 to children and adolescents because we know</p> <p>18 significant numbers of children or adolescents</p> <p>19 were infected, in particular with HIV, but with</p> <p>20 HIV and hepatitis.</p> <p>21 First of all, can I ask you just to talk</p> <p>22 a little about the impact of long-term illness</p> <p>23 and in particular a long-term illness and</p> <p>24 serious illness of the kind we're dealing with</p> <p>25 on children and adolescents?</p>
<p style="text-align: right;">23</p> <p>1 PROFESSOR CHRISTIE: Yes. So I would break it into</p> <p>2 two groups, which the first one is children. So</p> <p>3 the children who are being very much cared for</p> <p>4 and looked after. And are often very protected</p> <p>5 by their parents, so may not be aware of the</p> <p>6 diagnosis or the full implications of the</p> <p>7 diagnosis or may not understand fully the</p> <p>8 long-term implications just by virtue of their</p> <p>9 level of -- intellectual cognitive level of</p> <p>10 skill and ability.</p> <p>11 However, what children are aware of is the</p> <p>12 fact that they are limited, that they are</p> <p>13 prevented from doing things. So they will not</p> <p>14 be able to do sleepovers. Sometimes that can be</p> <p>15 because their mum and dad might worry about them</p> <p>16 being away from home or it might be because the</p> <p>17 other children's parents don't understand what's</p> <p>18 needed or required in order to take proper care</p> <p>19 and so they'll not invite them.</p> <p>20 Children with chronic illness often don't</p> <p>21 get invited to parties, birthday parties,</p> <p>22 because their parents feel they can't be catered</p> <p>23 for properly. They might not be allowed to go</p> <p>24 on school trips. So all of these things that we</p> <p>25 think of as being really part of our childhood</p>	<p style="text-align: right;">24</p> <p>1 and part of growing up, just having fun --</p> <p>2 because that's your primary job when you're</p> <p>3 a kid, a little one. Your main job is to just</p> <p>4 have fun and be looked after. And having</p> <p>5 a diagnosis of any illness, but particularly one</p> <p>6 which is potentially life-limiting, is going to</p> <p>7 stop you being able to do that in the way that</p> <p>8 your friends are able to do.</p> <p>9 The second group is adolescents, which is</p> <p>10 a really different group, and it's -- in some</p> <p>11 ways it's the best group, and in some ways it's</p> <p>12 the most difficult. Because adolescents are</p> <p>13 going themselves -- without any illness</p> <p>14 involved, are going through such tremendous</p> <p>15 change. Their brains are developing rapidly,</p> <p>16 and changing dramatically, developing</p> <p>17 decision-making parts of the brain, developing</p> <p>18 the parts of the brain that allow you to think</p> <p>19 about your future, and the main job of an</p> <p>20 adolescent is to decide who I am, who I want to</p> <p>21 be, and who I want to be with.</p> <p>22 And those three questions are what most</p> <p>23 adolescents spend their adolescence doing,</p> <p>24 working that out, deciding what they want to go</p> <p>25 to university and study, deciding what kind of</p>

<p>25</p> <p>1 job they want to have, looking at other people, 2 identifying role models.</p> <p>3 They spend a lot of their adolescence 4 deciding on their sexuality, on their gender, 5 who it is they want to spend the rest of their 6 life with. They spend a lot of their time 7 completely ignoring their parents. All of us 8 have done this. It's one of our main jobs, is 9 just to ignore your parents and borrow money 10 from them, so that you can, you know -- and 11 that's a dilemma.</p> <p>12 And it is kind of funny, but it's also so 13 true, and what happens in an adolescent's life 14 when an illness comes along completely uninvited 15 is that it knocks you off track. It starts to 16 get you to question "Can I be who I'd like to 17 be? Am I ever going to be able to have 18 a long-term relationship?" And that came out 19 through a lot of the transcripts. It came out 20 really strongly that young people -- and I'm 21 thinking of adolescence as going -- if you look 22 at the brain literature, right up to the age of 23 25, 26, 29, even, a young person's brain isn't 24 fully developed until 29, and that you actually 25 spend so much time trying to work out who you</p>	<p>26</p> <p>1 want to be that the illness completely stops you 2 being able to think about that in a coherent 3 kind of way.</p> <p>4 And it can cause you to withdraw, it can 5 cause you to rely so much on your parents that 6 actually, you stop that whole developmental 7 process of becoming independent and moving away. 8 So it's really devastating, an illness. And as 9 we've all -- we all keep adding as a caveat that 10 there are many young people who grow through 11 adversity, and growth through adversity is 12 a really important psychological idea, but even 13 with that growth through adversity, there is 14 still an enormous impact on the decisions that 15 young people can and are able to make when 16 they're faced with living with this. And it's 17 not just them, it's this ripple effect that 18 we've already talked about, because it affects 19 them, and it affects their relationships with 20 their friends. And again, friends are so 21 important when you're an adolescent. They 22 matter so much to you, more than your friendship 23 with your parents.</p> <p>24 And your friends will not want to be with 25 you, they will not want to spend time with you.</p>
<p>27</p> <p>1 You will be seen as different. And all of that 2 is going to affect your ability to develop and 3 grow yourself, your picture of who you're going 4 to be.</p> <p>5 MS RICHARDS: Some of those from whom we heard very 6 eloquent and powerful testimony who had been 7 diagnosed with HIV as either children or 8 adolescents, had grown up with it effectively 9 all their life. And one of the points they made 10 was they had never known anything different.</p> <p>11 PROFESSOR CHRISTIE: Yeah.</p> <p>12 MS RICHARDS: So in terms of self-identity, their 13 self-identity was to a very considerable extent 14 almost entirely shaped by the illness.</p> <p>15 PROFESSOR CHRISTIE: Yes, and if you think about 16 that, then -- your initial identity, your 17 initial identity as a core human being is not 18 one where illness is involved. And when illness 19 then becomes your identity, it limits you. It 20 can limit you. It doesn't always, but it can 21 limit you. It stops you striving. It can stop 22 you reaching out for things. It can stop you 23 trying to find things that you may have done. 24 It may affect your ability to do something like 25 a gap year. You may -- you know, "Well, a gap</p>	<p>28</p> <p>1 year is not for me because I've got this illness 2 that requires constant medical care."</p> <p>3 So it can have that effect on you as well. 4 So it kind of limits you and changes your 5 perspective of what your potential is. And all 6 of us should have this, all of us should have 7 the potential to be as wide-ranging as possible, 8 but living and growing up with an illness like 9 HIV, which has stigma and all of the negative 10 aspects of that attached to it, that's going to 11 completely restrict and give you a much, much 12 narrower focus on what's possible in life.</p> <p>13 MS RICHARDS: As may also some of the practical 14 consequences of the condition, in terms of 15 ability to access or complete education.</p> <p>16 PROFESSOR CHRISTIE: Oh, absolutely. So we've 17 known -- right back 30 years ago, I remember 18 going on a trip to Washington DC where they were 19 just starting to look at their cognitive effects 20 of HIV in children, and they were just starting 21 to do the very early brain studies, and 22 measuring intellectual ability, and the impact 23 on attention and concentration, and brain 24 function. And very early on, people started to 25 realise that something like HIV has an impact on</p>

<p style="text-align: right;">29</p> <p>1 the developing brain. And as I've said, if you</p> <p>2 think about the brain as an organic developing</p> <p>3 process, as something which grows and prunes and</p> <p>4 develops based on experience, if you have an</p> <p>5 illness like HIV, or the treatment associated --</p> <p>6 it's not just the disease itself, the condition</p> <p>7 itself, it's the treatment, the medicines --</p> <p>8 they affect the brain neurons, they affect the</p> <p>9 way the brain connects, they affect the way the</p> <p>10 brain develops. So you might have had</p> <p>11 aspirations to do something or be something that</p> <p>12 would require a certain amount of capacity, and</p> <p>13 the illness will take potentially take some of</p> <p>14 that capacity away.</p> <p>15 MS RICHARDS: You've alluded also in the report to</p> <p>16 particular difficulties for adolescents with</p> <p>17 treatment adherence.</p> <p>18 PROFESSOR CHRISTIE: Mm.</p> <p>19 MS RICHARDS: Can I ask you to just comment upon</p> <p>20 that?</p> <p>21 PROFESSOR CHRISTIE: Yes, and again, this is</p> <p>22 something which is kind of part of being an</p> <p>23 adolescent, which is to defy authority, and to</p> <p>24 not quite believe what your doctors say. So</p> <p>25 when you go to your doctor as an adolescent and</p>	<p style="text-align: right;">30</p> <p>1 your doctor says, "You need to take this</p> <p>2 medicine because it will keep you well", as an</p> <p>3 adolescent, there is a kind of a bit of you that</p> <p>4 thinks, "Well, yeah, you would say that because</p> <p>5 you're a doctor, but I'm different", and</p> <p>6 adolescents have a sense of being bulletproof,</p> <p>7 that kind of sense of central ego, the kind of</p> <p>8 like, you know, "Nothing can touch me. Nothing</p> <p>9 can harm me. It'll happen to other people but</p> <p>10 it wouldn't happen to me".</p> <p>11 That's a really important part of being an</p> <p>12 adolescent, because that's what helps you take</p> <p>13 risks. It allows you to do things like</p> <p>14 experiment, to go out and club until</p> <p>15 four o'clock in the morning or do all the fun</p> <p>16 things that adolescents gets to do before they</p> <p>17 have to grow up and become an adult.</p> <p>18 Actually, what happens when you are trying</p> <p>19 to do all of that with a chronic illness it's</p> <p>20 going to have a really -- it's going to stop you</p> <p>21 doing it. It's going to have an impact on you.</p> <p>22 MS RICHARDS: Can I ask you about the position for</p> <p>23 children. Growing up with a parent who is</p> <p>24 significantly incapacitated by HIV or hepatitis,</p> <p>25 and who may themselves have -- be carrying</p>
<p style="text-align: right;">31</p> <p>1 a significant psychological burden of their own.</p> <p>2 You've referred in the report to a paper --</p> <p>3 I won't put it on the screen -- it's a paper</p> <p>4 written by Beardslee which talks about how the</p> <p>5 children of affectively ill parents are at</p> <p>6 significantly greater risk of developing</p> <p>7 psychiatric orders themselves.</p> <p>8 PROFESSOR CHRISTIE: Yes.</p> <p>9 MS RICHARDS: We have certainly heard evidence which</p> <p>10 supports that.</p> <p>11 PROFESSOR CHRISTIE: Yes, so again, if you think</p> <p>12 about this, the family unit, so a child depends</p> <p>13 very much on their parent as a source of</p> <p>14 emotional care, psychological care, physical</p> <p>15 care, and financial care, all of those aspects,</p> <p>16 and when a parent becomes ill, understandably</p> <p>17 and reasonably, they may struggle to provide all</p> <p>18 of those aspects of care, and may not be</p> <p>19 emotionally available because of their on mental</p> <p>20 health problems.</p> <p>21 There's a lot of evidence in other</p> <p>22 conditions that where, even where there's no</p> <p>23 physical illness, where a mother who has</p> <p>24 emotional distress results in the child</p> <p>25 developing difficulties. So there's difficult</p>	<p style="text-align: right;">32</p> <p>1 with attachment, early attachment, which is</p> <p>2 really, really important for psychological</p> <p>3 wellbeing. So the child themselves is affected</p> <p>4 by the fact that the parent is ill, and will</p> <p>5 grow up trying to care for their parents, even.</p> <p>6 They'll work very, very hard to look after</p> <p>7 their mum. And in looking -- working so hard to</p> <p>8 do that, where there's very little support, then</p> <p>9 and now, very little support, for child carers,</p> <p>10 that child then becomes separated from their</p> <p>11 peers. Again, they can't go -- they may well be</p> <p>12 well physically but they can't go to parties</p> <p>13 because they'd have to leave Mum at home on her</p> <p>14 own or leave Dad at home and not be sure whether</p> <p>15 they'd be able to take care of themselves. They</p> <p>16 might not be able to go to bed at a time that</p> <p>17 they should be going to bed because they have to</p> <p>18 stay up to make sure that Mum or Dad take their</p> <p>19 medicine. So there are a lot of knock-on</p> <p>20 effects on effectively a healthy child living</p> <p>21 with a parent who is struggling with a chronic</p> <p>22 life-limiting illness.</p> <p>23 MS RICHARDS: We've heard certainly some evidence of</p> <p>24 that ripple effect extending into a third</p> <p>25 generation --</p>

<p>33</p> <p>1 PROFESSOR CHRISTIE: Yes.</p> <p>2 MS RICHARDS: -- with grandchildren as well.</p> <p>3 PROFESSOR CHRISTIE: Oh absolutely, yes, and it</p> <p>4 works all the way down depending on the age of</p> <p>5 grandparents but again, if you think about</p> <p>6 middle age, and a teenager, for example, whose</p> <p>7 grandparents themselves are ill, they may be</p> <p>8 looking out for their grandparents because their</p> <p>9 parents were ill, so there's so many complicated</p> <p>10 possible complications.</p> <p>11 If a parent is unwell or a parent has died,</p> <p>12 then the normal burden, if you like, of looking</p> <p>13 after elderly parents falls on us, as, you know,</p> <p>14 we're in our middle age and we've had our kids</p> <p>15 but now our mums and dads aren't well and so</p> <p>16 we're looking after them. But if we are taken</p> <p>17 out of the picture because of something like HIV</p> <p>18 or hepatitis, then our teenage children or our</p> <p>19 children in their twenties may then have to step</p> <p>20 in to look after their grandparents, so it can</p> <p>21 be multi-generational.</p> <p>22 MS RICHARDS: I wanted to explore some of the social</p> <p>23 impacts and I appreciate there's no bright line</p> <p>24 between psychological and social, hence</p> <p>25 psychosocial, but you've identified in the</p>	<p>34</p> <p>1 report, first of all, a range of negative</p> <p>2 impacts upon an individual's working life, and</p> <p>3 you've identified that can arise in a number of</p> <p>4 different ways, inability to work at all, or</p> <p>5 having to decline promotion or only being able</p> <p>6 to work part-time.</p> <p>7 What can be the impact upon an individual</p> <p>8 and on a family of those kind of changes having</p> <p>9 to be made to working life?</p> <p>10 PROFESSOR MORGAN: A major impact, of course, is</p> <p>11 financial, and this was a particular problem for</p> <p>12 families because over time, as the people's</p> <p>13 condition got worse, they would have to go from</p> <p>14 full-time employment to part-time employment and</p> <p>15 then often come out of employment. So that had</p> <p>16 a major impact. Then, in many cases, the carer,</p> <p>17 the partner, also had to reduce their employment</p> <p>18 or sometimes give up employment, and so the</p> <p>19 financial impacts were very great. Of course,</p> <p>20 it varied a bit according to age. It was</p> <p>21 particularly important for young couples, and</p> <p>22 people running small businesses and so on and,</p> <p>23 of course, has impacts all along the line,</p> <p>24 really, because it's going to affect housing,</p> <p>25 it's going to affect other opportunities, so</p>
<p>35</p> <p>1 a very, very major impact.</p> <p>2 MS RICHARDS: We heard from some witnesses who</p> <p>3 talked also about how not being able to work or</p> <p>4 not being able to work in the way or in the job</p> <p>5 that they would have liked impacted upon their</p> <p>6 self-esteem, their sense of being of the person</p> <p>7 who ought to be the provider, and the</p> <p>8 breadwinner for the family.</p> <p>9 PROFESSOR MORGAN: Yes, because, I mean, work often</p> <p>10 gives you a sense of identity as well as</p> <p>11 a sense -- as well as of other relationships and</p> <p>12 opportunities. So all these things were very</p> <p>13 important and come through very strongly.</p> <p>14 MS RICHARDS: And the financial impact, and I'll</p> <p>15 come back to financial impact in a few minutes,</p> <p>16 perhaps, but the financial impact can take</p> <p>17 a further toll in terms of insecurity, a risk of</p> <p>18 losing the house and the like. That threat of</p> <p>19 financial insecurity will no doubt exacerbate</p> <p>20 the other social and psychological impacts and</p> <p>21 negative effects that the person or family may</p> <p>22 already be experiencing.</p> <p>23 PROFESSOR MORGAN: Yes, it came through as a major</p> <p>24 source of worry and tension, and it's obviously</p> <p>25 going to be tensions within the family, and</p>	<p>36</p> <p>1 between partners. And this is a very sort of</p> <p>2 strong effect.</p> <p>3 MS RICHARDS: Could we just put up onscreen, there's</p> <p>4 just one passage from your report I want to read</p> <p>5 out, if you put it up onscreen, others can</p> <p>6 follow it. The report is EXPG0000003, please.</p> <p>7 If we go to page 19, please. Henry, it will</p> <p>8 probably actually come up as page 20 on yours.</p> <p>9 It's 19 on the one before. If you go on to the</p> <p>10 next page, please. Thank you. Could you just</p> <p>11 highlight, please, Henry, the passage halfway</p> <p>12 down the page beginning "The cumulative</p> <p>13 effects".</p> <p>14 This is what you've said, and I've put it up</p> <p>15 on the screen so we can see:</p> <p>16 "The cumulative effects of limitations in</p> <p>17 employment potential arising from interruptions</p> <p>18 in education, together with the continuing</p> <p>19 health effects, have undoubtedly had negative</p> <p>20 financial consequences for many infected and</p> <p>21 affected individuals. Although the extent of</p> <p>22 this varied across individuals and families</p> <p>23 depending on their prevailing social</p> <p>24 circumstances and life stage, the overall costs</p> <p>25 have been high. A variety of financial payments</p>

<p>37</p> <p>1 were available but they were neither universal 2 nor considered sufficient. Many witnesses 3 describe being ground down in their attempts to 4 obtain financial assistance and then giving up. 5 For many, this difficulty in both accessing and 6 receiving financial payments from the trusts and 7 schemes had a range of negative consequences. 8 In addition to the effects of continuing 9 financial hardship, many witnesses report 10 feeling let down, angry and ultimately helpless. 11 It is known that frequent unsuccessful attempts 12 to change an adverse situation typically result 13 in feelings of helplessness and hopelessness, 14 both of which are likely to lead to negative 15 mood and depression." 16 Is there anything you would want to add on 17 that issue to what you've recorded powerfully in 18 the report there? 19 PROFESSOR WEINMAN: These are very well-known 20 effects from, you know, when people have to -- 21 whatever the situation is, when people are in 22 adversity, you know, naturally one tries to cope 23 by gaining control, by doing something. But if 24 you're constantly thwarted in your attempts to 25 gain control or to change a situation, this</p>	<p>38</p> <p>1 notion of helplessness or what we refer to as 2 "learnt helplessness", what you learn is 3 whatever you do, nothing is going to work out. 4 That you actually have no control. 5 We've known for many years that can have 6 a profound effect on people's mood, their 7 wellbeing, and it's a very potent source of 8 depression. So, that's really -- I mean, 9 I think as -- we've said that, but, you know, 10 these effects are profound across a whole range 11 of domains in life, yeah. 12 MS RICHARDS: You recommended in your report the 13 possibility of obtaining a health economist's 14 input. 15 PROFESSOR WEINMAN: Yeah. 16 MS RICHARDS: I should say that is a matter on which 17 Sir Brian invites core participants to make 18 submissions as to what issues could or should be 19 addressed by health economists. But could I ask 20 you from your professional perspective to 21 identify any particular issues or analyses that 22 you think a health economist might be able to 23 undertake? 24 PROFESSOR WEINMAN: Yeah. 25 DAME LESLEY: Maybe I can come in here. Certainly</p>
<p>39</p> <p>1 there is a concept now that a lot of us are 2 dealing with, known as financial toxicity. 3 We're used to talking about drug and treatment 4 toxicities but most -- even in a good setting, 5 most treatments and people with illnesses 6 experience a financial toxicity. And one of the 7 problems that health economists sort of tend to 8 focus on is direct drug costs or treatment costs 9 to an institution, to the health service. They 10 rarely deal -- when NICE, for example, are 11 dealing with new drugs or treatment, they rarely 12 deal with the financial toxicity that families 13 actually are experiencing as a result of what's 14 happened to them. 15 So I think if we do, you do engage a health 16 economist, which would be good, you really do 17 need one that's rooted well in the more social 18 sort of costs of all these sorts of areas. 19 The other thing that's important to note is 20 that, with the sorts of poverty that we saw some 21 families actually, you know, tumble into because 22 of what happened to them, there's no doubt about 23 it that poverty in itself is linked with poor 24 physical outcomes as well. The Marmot report 25 has just been upgraded today, demonstrating how</p>	<p>40</p> <p>1 well poverty in itself actually does lead to 2 poorer health outcomes. 3 So even many of the infected and affected 4 individuals that were getting good treatment, if 5 they were plunged into financial toxicity, were 6 likely to experience poorer outcomes physically, 7 not just emotionally. 8 MS RICHARDS: Can I turn, before the break, to two 9 other aspects of social impact. The first is 10 the impact upon some of the most intimate 11 aspects of private and family life. Again, 12 you've identified in the report gleaned from the 13 witness testimony that the inquiry has received, 14 decisions partners are having to take of opting 15 for lives of celibacy because of the fear of 16 transmitting infection, and then decisions 17 families having to take or couples having to 18 take, women facing decisions about terminations, 19 being advised to have terminations, couples 20 deciding not to have children, or not to have 21 any more children, or couples having to try to 22 obtain funding and go through processes such as 23 sperm washing or other risk reduced conception 24 methods. 25 Again, I wondered whether any of you have</p>

<p style="text-align: right;">41</p> <p>1 any observations in particular to make upon 2 those issues and those impacts that you saw. 3 PROFESSOR MORGAN: Well, they were very, obviously, 4 central to people, to life, and they caused 5 considerable emotional upset, which lasted 6 throughout their lives, really, because it also 7 had the effects that they wouldn't have 8 grandchildren and the whole issues. It was in 9 some cases people had abortions because at the 10 time of conception they didn't even know that 11 their partner had HIV, so, you know, they lacked 12 information, and afterwards, they lacked full 13 support, really, in coping with this crisis in 14 their lives. 15 DR THOMAS: I'd say this is a major area of grief 16 and bereavement that hasn't been addressed for 17 many, many people. I know we're going to talk 18 more about psychological support but an 19 important aspect of psychological support would 20 be to focus on the potential, the loss, actually 21 losses and potential losses and I think for many 22 people, that's when I look at -- looked at the 23 transcript, there's evidence of complicated 24 grief because, you know, how do you come to 25 terms with the difficult losses.</p>	<p style="text-align: right;">42</p> <p>1 MS RICHARDS: Yes, I will come back to complicated 2 grief, certainly. You've already alluded to it 3 and touched upon it in your report but all of 4 these issues you've been discussing can take 5 their toll on marital relationships, 6 partnerships in particular, and you've picked up 7 in your report on some matters that may have 8 been strengthened but others that have taken an 9 irreversible toll on a marriage and marriages 10 ending, again, is there anything in particular 11 you would want to add to what's in the report in 12 relation to those particular issues? 13 DAME LESLEY: One of the things I think actually in 14 this area is that not all relationships anyway 15 start from a good stable base, and one of the 16 things certainly you notice in any 17 life-threatening illnesses is that it can really 18 be the final straw to already a struggling 19 relationship. Family dynamics are complicated 20 anyway. Relationships between partners are 21 complex as well. 22 Particularly when you get reversals of roles 23 and responsibilities as we've been talking about 24 this morning, that really can, I think, impinge 25 hugely on an already shaky relationship.</p>
<p style="text-align: right;">43</p> <p>1 I think we saw some evidence of that in some 2 transcripts. 3 PROFESSOR MORGAN: Families were also often quite 4 isolated. They didn't have the support 5 necessarily of a wider group of relatives or 6 close friends, because of all the problems that 7 they were experiencing, so they became very sort 8 of closed units, so I think this puts additional 9 stress and the lack of, as we know, social and 10 psychological support from others is very 11 important. 12 MS EDWARDS: There's one thing about talking about 13 this within the context of a marriage, but lots 14 of the people who found out that they were 15 hepatitis C and HIV-positive actually just 16 wanted to have sex. It wasn't within 17 necessarily marriage. It was about, as Deborah 18 was saying, about young people who were going 19 off to university and even contemplating 20 a relationship, a physical relationship at all, 21 was very -- could be very fearsome. But also, 22 just having to negotiate when do you tell 23 somebody? How are they going to react? Is it 24 even worth going there, those are huge 25 decision-making processes without that sort of</p>	<p style="text-align: right;">44</p> <p>1 infectivity, you don't have make in 2 a relationship, normally. 3 MS RICHARDS: The final question I wanted to ask 4 before we break for the morning break, is again, 5 looking at impacts upon family life. Many 6 statements describe, and you've picked this up 7 in the report, the limitations upon the ability 8 of the person who is ill within the family to 9 participate in ordinary family activities 10 whether walking, going on holiday, playing 11 football with the kids, or caring for their 12 children in the way in which they would want to 13 do so. 14 Is that likely to increase or compound a 15 person's sense of guilt or helplessness? 16 PROFESSOR MORGAN: I think that came through very 17 strongly. People were not able to perform the 18 sort of parenting role that they wished to. 19 They were not able to engage in normal family 20 activities, holidays, and other types of things. 21 And this I think this was a major concern, 22 a major concern both in terms of their own 23 identity and the effects on the children. 24 MS RICHARDS: Picking up I think on an observation 25 you made, Dr Thomas, engendering for some</p>

<p style="text-align: right;">45</p> <p>1 individuals a sense of grief for a family life</p> <p>2 lost.</p> <p>3 DR THOMAS: Absolutely. And, you know, seeing</p> <p>4 yourself as an incompetent -- I think all of us</p> <p>5 like to feel in some ways that we're -- some</p> <p>6 roles that we're good at, a competent mother,</p> <p>7 father, whatever, and if you can't manage those</p> <p>8 roles, it adds tremendously to the distress that</p> <p>9 you're feeling on top of the additional</p> <p>10 psychological burden you've got already.</p> <p>11 PROFESSOR CHRISTIE: I was just going to say, to add</p> <p>12 very briefly, there's a grief for the future,</p> <p>13 that on being told -- on being given</p> <p>14 information, that you may understand completely</p> <p>15 or maybe not understand completely, but</p> <p>16 understand that there is going to be a major</p> <p>17 impact on what you had hoped for, that you go --</p> <p>18 that's deeply traumatic. Incredibly traumatic.</p> <p>19 And the -- and it can last for years and years</p> <p>20 and years, even with good support. Even with</p> <p>21 good support. But that grief for the lost</p> <p>22 future is really impactful.</p> <p>23 MS RICHARDS: I'm going to move on to another topic</p> <p>24 so this may be a suitable opportunity for</p> <p>25 a break.</p>	<p style="text-align: right;">46</p> <p>1 SIR BRIAN LANGSTAFF: Yes, I think it will be and</p> <p>2 we're spot on, 11.30.</p> <p>3 MS RICHARDS: Glad to hear it.</p> <p>4 SIR BRIAN LANGSTAFF: So 12 o'clock. 12 o'clock,</p> <p>5 please.</p> <p>6 (11.30 am)</p> <p>7 (A short break)</p> <p>8 (12.02 pm)</p> <p>9 MS RICHARDS: One of the most devastating impacts</p> <p>10 described to this Inquiry and captured in your</p> <p>11 report is the death of a child, and I wanted to</p> <p>12 ask a little about that and bereavement and loss</p> <p>13 more generally, and to do so first of all by</p> <p>14 reference to one of the papers that you've</p> <p>15 referred to in your report.</p> <p>16 Henry, it's EXPG0000011, and it's a paper by</p> <p>17 Christ and others called "Bereavement</p> <p>18 experiences after the death of a child". I just</p> <p>19 wanted to pick up on a couple of passages and</p> <p>20 then just ask you about them.</p> <p>21 The introduction, if you could highlight the</p> <p>22 first ten lines or so, please, Henry:</p> <p>23 "The death of a child of any age is</p> <p>24 a profound, difficult and painful experience.</p> <p>25 While bereavement is stressful whenever it</p>
<p style="text-align: right;">47</p> <p>1 occurs, studies continue to provide evidence</p> <p>2 that the greatest stress, and often the most</p> <p>3 enduring one, occurs for parents who experience</p> <p>4 the death of a child. Individuals and families</p> <p>5 have many capabilities and abilities that allow</p> <p>6 them to respond to interpersonal loss and to</p> <p>7 emerge from the experience changed but not</p> <p>8 broken. The few studies that have compared</p> <p>9 responses to different types of losses have</p> <p>10 found that the loss of a child is followed by</p> <p>11 a more intense grief than the death of a spouse</p> <p>12 or a parent."</p> <p>13 Then over the page, please, under the</p> <p>14 heading "Bereavement, mourning, grief and</p> <p>15 complicated grief", we can see a number of</p> <p>16 concepts there discussed:</p> <p>17 "Bereavement described as a broad term</p> <p>18 encompassing the entire experience of family</p> <p>19 members and friends in the anticipation, death,</p> <p>20 and subsequent adjustment to living following</p> <p>21 the death of a loved one, widely recognised as</p> <p>22 a complex and dynamic process that does not</p> <p>23 necessarily proceed in an orderly, linear</p> <p>24 fashion."</p> <p>25 At the top of the next page, please, Henry,</p>	<p style="text-align: right;">48</p> <p>1 then we have grief described, a term that refers</p> <p>2 to the more specific complex set of cognitive</p> <p>3 emotional and social difficulties that follow</p> <p>4 the death of a loved one:</p> <p>5 "Individuals vary enormously in the type of</p> <p>6 grief they experience, its intensity, its</p> <p>7 duration, and their way of expressing it."</p> <p>8 Then we have mourning defined.</p> <p>9 "Mourning is often defined as either the</p> <p>10 individual's internal process of adaptation to</p> <p>11 the loss of a loved one or as the socially</p> <p>12 prescribed modes of responding to loss,</p> <p>13 including its external expression in behaviours</p> <p>14 such as rituals and memorials."</p> <p>15 Then we see the concept of complicated</p> <p>16 grief, and it says this:</p> <p>17 "Complicated grief in adults refers to</p> <p>18 bereavement accompanied by symptoms of</p> <p>19 separation, distress and trauma."</p> <p>20 Then we see a number of what are called</p> <p>21 distress symptoms listed:</p> <p>22 "Intrusive thoughts about the deceased,</p> <p>23 yearning for the deceased, searching for the</p> <p>24 deceased, excessive loneliness since the death,</p> <p>25 purposelessness about the future, numbness,</p>

<p>49</p> <p>1 detachment or absence of emotional 2 responsiveness, difficulty believing or 3 acknowledging the death, feeling that life is 4 empty or meaningless; feeling that part of 5 oneself has died; shattered world view; assuming 6 symptoms of harmful behaviours of the deceased 7 person, excessive irritability, bitterness or 8 anger related to the death." 9 Then we see the observation of the impact 10 upon siblings. 11 "Siblings of children who die have also been 12 found to be at greater risk for externalising 13 and internalising problems when compared to 14 norms and controls within 2 years of the death." 15 Now whether or not a person meets the formal 16 diagnostic criteria for complicated grief, am 17 I right in thinking that the -- what are termed 18 the "distress symptoms" there listed may 19 encompass the kind of response and feelings that 20 many people will experience when they suffer the 21 death of a child or a partner or someone else 22 who they dearly love? 23 PROFESSOR WEINMAN: Yeah, very much so. I think 24 this paper describes it very clearly. I think 25 the other -- and we heard lots of witnesses</p>	<p>50</p> <p>1 describe exactly these sorts of feelings, both 2 physical, psychological changes following, you 3 know, the sense of loss, and grief and so on. 4 But I think the really telling thing for me 5 was I went away and looked up, in something 6 called DSM, which is a sort of official 7 classification system that's used for 8 classifying people's psychological mental health 9 problems, I looked up complicated bereavement 10 just -- and tried to think of it in relation to 11 what witnesses had told us. And I just think -- 12 just listen to this, and then think about 13 relating it to our present context: 14 "Complicated grief obviously is something 15 that's much more intense, much more prolonged." 16 So it doesn't -- you know, grief, 17 bereavement, is quite variable but this is 18 something which is much more so. Reasons for 19 it, the bereaved person has trouble accepting 20 the death, so clearly issues around a child 21 dying, yeah. If the individual feels unable to 22 trust others. Again, we're going to talk more 23 about trust and about communication. If the 24 individual harbours an excessive bitterness 25 and/or anger related to the death. Again,</p>
<p>51</p> <p>1 thinking about what we talked about yesterday 2 and other factors associated with complicated 3 grief. It's more common with the loss of 4 a child, as we've said. If the nature of the 5 cause and circumstances around the death are 6 complex, or you know sort of beyond the usual, 7 and if the quality of care, palliative care, the 8 sort of support you'd normally give to someone 9 who is in that -- the last days of their life, 10 if that is not -- if that's poor or not 11 available, and if there are concurrent 12 stressors, financial hardships and so on. 13 If you think about that list of factors and 14 think about what people have told us in their 15 statements, it's really not surprising to me 16 that a lot of people talked about complicated 17 grief, effectively. Grief that's still with 18 them now because a lot of these issues are still 19 there. 20 What comes out of that is that people 21 ruminate. These things prey on the mind and 22 people ruminate about themselves, their anger 23 maybe they've felt, the guilt that maybe they've 24 felt, and all of those sort of recriminations, 25 if you like, that are linked to that death. So</p>	<p>52</p> <p>1 I think what we have seen and heard from many 2 witnesses really does fall into this, what is 3 a diagnostic category. It's described as a very 4 clear condition that people can experience. 5 DR THOMAS: I'd like to add to what 6 Professor Weinman has said, and this document is 7 excellent, but one of the things when I read it, 8 and from my experience of working with sickle 9 cell patients, who are predominantly black, that 10 the cultural variables are so strong when you 11 lose a child -- when you lose a child in any 12 culture, and we've all got subcultures anyway, 13 within this community, this sort of basically UK 14 community, so-called white community, we have 15 varying subcultures, but with diverse cultures 16 like African Caribbean cultures, the particular 17 meaning of a child's death is -- it takes on 18 tremendous added proportions. And I think 19 sometimes those things are not given credence 20 within the documents that we have looked at, 21 because it's not been researched fully enough. 22 But I would just like to say, that's a really 23 important thing to say, that we, as a population 24 in the UK, are very diverse, and we should think 25 about those factors as well. And in my work,</p>

<p>53</p> <p>1 it's a really important element that comes 2 through.</p> <p>3 MS RICHARDS: And if we just turn to the next page 4 of this report, the observations you've made, 5 Professor Weinman, would bear on many of the 6 accounts that we've heard, not simply about the 7 death of a child, but about the deaths of 8 partners as well.</p> <p>9 PROFESSOR WEINMAN: Absolutely, yes.</p> <p>10 MS RICHARDS: Then there's some specific 11 observations here about some particular 12 additional components in relation to the 13 parental loss of a child. And so I'll just pick 14 it up in the first paragraph, four lines down: 15 "At various stages in the life-cycle, men 16 and women relate to child-conceiving and 17 child-rearing roles as central to their 18 existence." 19 And I think, Dr Thomas, that bears upon 20 a point you made before the break about those 21 who are -- do not have children, and the sense 22 of bereavement for the future you've described.</p> <p>23 DR THOMAS: Yes.</p> <p>24 MS RICHARDS: And then it continues: 25 "Within the bonds formed within the family,</p>	<p>54</p> <p>1 the parent-child bond is not only particularly 2 strong, it is also integral to the identity of 3 many parents and children."</p> <p>4 Then the next paragraph says: 5 "The parents of children and adolescents who 6 die are found to suffer a broad range of 7 difficult mental and physical symptoms. As with 8 many losses, depressed feelings are accompanied 9 by intense feelings of sadness, despair, 10 helplessness, loneliness, abandonment and a wish 11 to die."</p> <p>12 And of course, again, we've heard that from 13 people talking both about the deaths of children 14 and the deaths of partners and other loved ones.</p> <p>15 "Parents often experience physical symptoms 16 such as insomnia or loss of appetite as well as 17 confusion, inability to concentrate, obsessive 18 thinking, extreme feelings of vulnerability, 19 anxiety, panic and hyper-vigilance can also 20 accompany the sadness and despair."</p> <p>21 And then the passage goes on to talk in 22 particular about anger. Then the next 23 paragraph, please, Henry: 24 "Children take on great symbolic importance 25 in terms of parents' generativity and hope for</p>
<p>55</p> <p>1 the future. All parents have hopes and dreams 2 about their children's futures. When a child 3 dies, the dreams may die too. This death of 4 future seems integral to the intensity of many 5 parents' responses. Three central themes in 6 parents' experience when a child dies includes: 7 (1) the loss of sense of personal competence and 8 power, (2) the also of a part of the self, and 9 (3) the loss of a valued other person whose 10 unique characteristics were part of the family 11 system. While guilt and self-blame are common 12 in bereavement, they are especially pronounced 13 following the death of a child. The parent's 14 role competence as the child's care giver, 15 protector and mentor is severely threatened by 16 untimely death."</p> <p>17 PROFESSOR CHRISTIE: What I'd like to comment on is 18 this is not just an acute reaction. This is not 19 just something that happens when the child dies. 20 It's not just something that is around six 21 months afterwards. These feelings can last for 22 years and years and years and years, and I've 23 worked with parents who lost children 30 years 24 ago who still feel this way. So it's really 25 important to remember that this doesn't just go</p>	<p>56</p> <p>1 away. There's no, you know, neat psychological 2 theory that we all work through our grief and 3 bereavement, and suddenly we'll wake up and 4 we're not feeling that way anymore. Actually, 5 for many people, it changes subtly, it becomes 6 less immediate, but it's always there.</p> <p>7 DAME LESLEY: I wonder if we might also talk 8 a little bit about the impact on siblings. 9 Because in any chronic disease situation, where 10 the parents of course have got a major role in 11 caring for the sick child, siblings can respond 12 in a variety of ways, including a sort of 13 resentment towards the sick child that gets all 14 the attention, but then, perversely, when that 15 child dies, extreme guilt, because they almost, 16 like, wished it.</p> <p>17 Sometimes the parents, I think, and I know 18 this from work with cancer as well as other 19 chronic illnesses, the parents sometimes 20 hyper-invest in the remaining children, in 21 strange ways that puts huge pressure on them. 22 You know, "These are the ones that are left, 23 I've neglected them, perhaps to a certain 24 extent. I now have even greater expectations of 25 them", which is difficult for them sometimes to</p>

<p>57</p> <p>1 deliver on.</p> <p>2 And when we get on to talking about care and</p> <p>3 support services, I think that the grieving</p> <p>4 siblings, with their mass -- plethora of issues,</p> <p>5 really need help and support as well.</p> <p>6 MS RICHARDS: One of the other features you've</p> <p>7 alighted upon in your report in relation to the</p> <p>8 death of a child is in the context of those</p> <p>9 parents who were administering blood products to</p> <p>10 their haemophiliac children, the additional</p> <p>11 component of guilt, the guilt of "I have killed</p> <p>12 my child."</p> <p>13 In your report, at page 9 -- and again,</p> <p>14 perhaps we could have this up on screen, please,</p> <p>15 Henry, it's EXPG0000003.</p> <p>16 We can see at the top of the page the point</p> <p>17 I've just referenced. In the first paragraph,</p> <p>18 last sentence, having talked about the guilt</p> <p>19 that parents have experienced, you've observed</p> <p>20 that:</p> <p>21 "Guilt and self-blame are both potent</p> <p>22 precursors of depression and both almost</p> <p>23 certainly contributed to the considerable levels</p> <p>24 of negative mood and depression described in</p> <p>25 many witness statements."</p>	<p>58</p> <p>1 Then in the next paragraph, if we can just</p> <p>2 highlight the next paragraph, please, Henry, it</p> <p>3 says this:</p> <p>4 "The types of social impacts of HIV and/or</p> <p>5 hepatitis C on individuals and families were</p> <p>6 similar in many ways to those experienced with</p> <p>7 other chronic conditions where partners have to</p> <p>8 take on major new responsibilities for the</p> <p>9 family and the provision of care. However,</p> <p>10 there were aspects of the witnesses' situation</p> <p>11 that markedly increased the severity of the</p> <p>12 social impacts for both the affected individuals</p> <p>13 and family members."</p> <p>14 Then you've gone on to identify some of what</p> <p>15 you've observed as being particularly acute for</p> <p>16 the groups of individuals with which the Inquiry</p> <p>17 is concerned.</p> <p>18 "These included the relatively young age at</p> <p>19 which some individuals contracted these</p> <p>20 conditions, leading to particularly severe</p> <p>21 financial difficulties and related problems.</p> <p>22 There was limited availability of effective</p> <p>23 treatments for HIV or hepatitis C infections and</p> <p>24 newly researched drugs had many unwanted side</p> <p>25 effects."</p>
<p>59</p> <p>1 Then you refer to the virus not being</p> <p>2 cleared and risks of sexual transmission and</p> <p>3 vertical transmission.</p> <p>4 Is it also fair to say that when one is</p> <p>5 looking at the severity of social impacts for</p> <p>6 those with whom we're concerned, stigma,</p> <p>7 discrimination, and lack of support, all of</p> <p>8 which we're going to come on to shortly, are</p> <p>9 likely to have compounded and exacerbated the</p> <p>10 ordinarily severe impacts that flow from</p> <p>11 long-term chronic illness?</p> <p>12 PROFESSOR MORGAN: That's certainly the case. And</p> <p>13 I've felt in terms of the social impacts, we can</p> <p>14 see that many of the social impacts are similar</p> <p>15 for other chronic conditions, but given the</p> <p>16 number of conditions that people were coping</p> <p>17 with here, as well as the stigma, the impacts</p> <p>18 that these groups of people experienced were far</p> <p>19 more severe and they're more comprehensive. So</p> <p>20 they would experience nearly all those different</p> <p>21 types of social impacts that we've been</p> <p>22 referring to, and to a high degree.</p> <p>23 MS RICHARDS: Thank you.</p> <p>24 I'm going to come on to stigma next, but</p> <p>25 before I do so I just wanted to ask Ms Edwards</p>	<p>60</p> <p>1 just to tell us a little about the Haemophilia</p> <p>2 and HIV life history project in which you were</p> <p>3 involved.</p> <p>4 MS EDWARDS: So the Haemophilia and HIV life history</p> <p>5 project is an oral history project. Maybe</p> <p>6 I need to explain that a little.</p> <p>7 MS RICHARDS: Yes, please.</p> <p>8 MS EDWARDS: So an oral history project is the</p> <p>9 concept that you would record history by</p> <p>10 interviewing people who experienced that</p> <p>11 history. And often history is written by</p> <p>12 bureaucrats, politicians, historians, academics,</p> <p>13 but an oral history project would be</p> <p>14 a collection of memories, testimonies, from the</p> <p>15 people who experienced that. And certainly, in</p> <p>16 2003, a group of us realised -- I, having worked</p> <p>17 in the Haemophilia Unit as well as in HIV for a</p> <p>18 long time, realised that this story had not been</p> <p>19 told. It really hadn't. There was really very</p> <p>20 little. And we talked briefly yesterday about</p> <p>21 what research we had looked for around the</p> <p>22 psychological impacts of HIV, hepatitis C, and</p> <p>23 people with haemophilia. This was particularly</p> <p>24 the case for haemophilia, and we all agreed</p> <p>25 there was very little.</p>

<p style="text-align: right;">61</p> <p>1 This project is not the types of references 2 we're using here because these are peer-reviewed 3 journals by academics who have analysed, owned 4 this work. What we did was we were funded by 5 the Heritage Lottery to interview people 6 throughout the country who had -- firstly, who 7 had haemophilia and HIV. And it was in 2003, 8 and I don't really believe that we could have 9 done it earlier than that, because I think all 10 of the things that we've already been talking 11 about, the grief, the anger, the confusion, the 12 lack of certainty about what was happening in 13 people's lives, I don't think people were in 14 a position where they would have been very able 15 to be able to verbalise some of the things that 16 they were feeling.</p> <p>17 By 2003, that became a little easier, and 18 certainly that's what they told me. And so we 19 went around the country and we invited people to 20 talk about their experiences. And we did it in 21 what's called a life history method, which isn't 22 about asking questions about HIV and 23 haemophilia; it's asking questions about 24 everything, from grandparents to where you live 25 to where you went to school, who was your</p>	<p style="text-align: right;">62</p> <p>1 girlfriend, what did you play with, you know, 2 everything. So we have a whole life history. 3 So some of these interviews on the average were 4 about 4 hours of recording, and some many more. 5 Many more.</p> <p>6 Those interviews were archived in the 7 British Library. They don't belong to me or the 8 team. On the team there was an oral historian, 9 there was an archivist from the British Library, 10 there was myself, a counsellor, somebody with 11 haemophilia and HIV, Rob, who I think you know, 12 and between us this was the work we did for 13 those two years. And so those 30 interviews, 14 very extensive long life history interviews were 15 archived in the British Library.</p> <p>16 What of course we realised very soon while 17 we were doing this project was that many people 18 said to us when we asked them about what it was 19 like finding out that you were HIV positive, 20 they would say, "We don't know. Ask my mum, you 21 know, I was two."</p> <p>22 And of course the other big area that was 23 missing was the people who had died. We didn't 24 have those stories, and they are a huge story 25 that we were going to be missing out in 2003.</p>
<p style="text-align: right;">63</p> <p>1 And so we did a second project, for the next 2 two years, between 2005 and 2007, and that 3 project was called HIV in the Family, and that 4 project was interviewing the siblings, the 5 partners, the parents, the mothers, the children 6 of the people who had died over the previous 7 years. There were 35 -- 34 of those interviews, 8 so altogether we collected 64 life history 9 interviews.</p> <p>10 Like I said, they don't belong me, they 11 don't belong to anybody. They are in the 12 British Library. They have just gone online and 13 been digitised. They were on tapes, if people 14 remember tapes, C90s, and those tapes have been 15 digitised. There are a number of people in this 16 room who were interviewed for that project, and 17 who I've met over the last two days. And those 18 have gone online and can now be accessed from 19 your home computer. You can listen to the whole 20 recording. They are also summarised so that 21 areas can be found through the, sometimes four, 22 five, six-hour interviews.</p> <p>23 Can I just explain sort of an example of one 24 of these interviews? 25 MS RICHARDS: Yes.</p>	<p style="text-align: right;">64</p> <p>1 MS EDWARDS: For example I interviewed somebody who 2 had never ever spoken to a single person about 3 his HIV infection. He was infected as a young 4 man. He actually hadn't told his mother, and he 5 hadn't told his sister, who he was actually 6 very, very close to. But he never told them. 7 The only people who knew about his HIV and 8 hepatitis C diagnosis was his HIV doctor, his 9 haematologist, and myself. I happened to also 10 be his community nurse. And I asked him if he 11 wanted to do this interview and he agreed that 12 he would, but that he didn't want anybody to 13 hear it. And I ended up having to do four 14 interviews, four -- four sessions with him, 15 because he was very unwell.</p> <p>16 And the last session that I did, in this 17 interview, was in his hospital bed, a matter of 18 days before he died. And he finishes the 19 interview saying, "I know I'm going to die. I'm 20 really sorry that I was unable to share what 21 I've been through through my life with my sister 22 who I love and my mother who I love, but when 23 I die and at my funeral I want you to give these 24 tapes to my sister." And that was the first 25 time that she found out how he actually had</p>

<p>65</p> <p>1 died.</p> <p>2 So it was, you know -- that was one example.</p> <p>3 Some of the examples of the interviews that we</p> <p>4 did were full of laughter and full of</p> <p>5 resilience, as we talked about yesterday. You</p> <p>6 know, what comes out is that individuals are</p> <p>7 very, very diverse.</p> <p>8 But if anybody wants to hear these</p> <p>9 interviews, they are accessible. I may want to</p> <p>10 reiterate it's the British Library because one</p> <p>11 person that we interviewed was in an audience</p> <p>12 like this when I was talking about the project,</p> <p>13 and he said, "Where are they kept?" And I said,</p> <p>14 "The British Library, Mick", and he said, "Oh</p> <p>15 no, I've told everybody I'm in the Natural</p> <p>16 History Museum!"</p> <p>17 [Laughter]</p> <p>18 MS RICHARDS: I think it's right that there are</p> <p>19 a handful of the interviews that are not public</p> <p>20 in accordance with the wishes of those who gave</p> <p>21 the interviews.</p> <p>22 MS EDWARDS: Yes.</p> <p>23 MS RICHARDS: I should also say that the British</p> <p>24 Library has provided to the Inquiry all the</p> <p>25 materials that it can provide, and they are</p>	<p>66</p> <p>1 materials that have been read and listened to by</p> <p>2 the Inquiry, and members of the Inquiry team.</p> <p>3 MS EDWARDS: And I believe you have also got the</p> <p>4 closed interviews.</p> <p>5 MS RICHARDS: We do, yes.</p> <p>6 MS EDWARDS: Which is very, very, very unusual to</p> <p>7 have access to an oral history interview that</p> <p>8 has been closed.</p> <p>9 MS RICHARDS: That, I think, leads very naturally to</p> <p>10 the next theme I wanted to ask you about, which</p> <p>11 is the theme of stigma and discrimination.</p> <p>12 In your report, you say this, on page 20:</p> <p>13 "The impacts of medical conditions for</p> <p>14 individuals and families are profoundly affected</p> <p>15 by whether they are imbued by a stigma."</p> <p>16 I wanted to ask first about two aspects of</p> <p>17 stigma that are referred to in the report and in</p> <p>18 the literature: felt stigma and enacted stigma.</p> <p>19 Could you explain what those two concepts</p> <p>20 mean and what the difference is between them?</p> <p>21 PROFESSOR MORGAN: Yes, yes. Well first, just to</p> <p>22 say the stigma, so we're talking about</p> <p>23 a condition or behaviour which in the view of</p> <p>24 the wider society marks an individual as</p> <p>25 unacceptably different, and inferior. With felt</p>
<p>67</p> <p>1 stigma, people are aware of the social meanings</p> <p>2 of their condition. They're aware that they've</p> <p>3 got a condition that is regarded as unacceptable</p> <p>4 in the wider society. This influences their own</p> <p>5 self-identity.</p> <p>6 So felt stigma refers to this understanding</p> <p>7 of their own possession of the condition which</p> <p>8 is viewed so negatively and, obviously, it</p> <p>9 affects their identity and enacted stigma refers</p> <p>10 to the response of members of the society to</p> <p>11 people who are identified as possessing</p> <p>12 a stigmatising condition, and this can take</p> <p>13 various forms.</p> <p>14 It can take particularly avoidance of these</p> <p>15 people, avoidance in different circumstances,</p> <p>16 socially, at work, and in other settings, and</p> <p>17 avoidance and exclusion, and often bullying,</p> <p>18 children particularly can be subject to</p> <p>19 bullying. It's very, very painful and it was</p> <p>20 reported quite extensively by the witnesses.</p> <p>21 In addition, some people, even experienced</p> <p>22 property being vandalised and, you know, a very</p> <p>23 high level of enacted stigma. Fear of enacted</p> <p>24 stigma, even if you don't actually experience it</p> <p>25 the actual fear that you might is in itself</p>	<p>68</p> <p>1 very, very powerful and has a major influence on</p> <p>2 people's lives.</p> <p>3 MS RICHARDS: One of the consequences of stigma may</p> <p>4 be that individuals do not wish to disclose</p> <p>5 their condition, and many witnesses reported</p> <p>6 that, either contemporaneously or still today.</p> <p>7 PROFESSOR MORGAN: <i>(Witness nodded)</i></p> <p>8 MS RICHARDS: They didn't want to disclose their</p> <p>9 condition.</p> <p>10 That leads to two further concepts I wanted</p> <p>11 to ask you about and perhaps I can do this by</p> <p>12 reference to one of the papers in the bundle.</p> <p>13 Henry it's EXPG0000006, please.</p> <p>14 It's a paper by Beales and others. If you</p> <p>15 go to the next page please, sorry the next one.</p> <p>16 It's called "Stigma management and wellbeing".</p> <p>17 There are two parts I wanted to show you and ask</p> <p>18 you about. On that first page, right-hand</p> <p>19 column, please, picking it up four lines down,</p> <p>20 this particular paper it's focus was sexual</p> <p>21 orientation, but there are some general</p> <p>22 concepts. We see there reference to a process</p> <p>23 of stigma management, and it says this:</p> <p>24 "This process of stigma management is</p> <p>25 a major task for individuals with concealable</p>

<p>69</p> <p>1 stigmas who weigh the pros and cons of 2 disclosure versus concealment and make decisions 3 based on the circumstances." 4 Then it refers to another paper, Cain, 1991 5 "... observed that both options can be taxing 6 because disclosure often entails planning and 7 execution, and concealment requires individuals 8 to attend to many aspects of their social 9 presentation and lifestyle that would ordinarily 10 go unnoticed." 11 Then Henry, if we can turn on two pages. 12 Right-hand column under the heading, "The role 13 of suppression", we can see again in the first 14 paragraph, it talks about suppression: 15 "A feeling people may experience if they 16 conceal personal or emotional information they 17 would like to reveal." 18 Then it refers to another paper: 19 "Pennebaker and colleagues showed that 20 suppression can be detrimental to both 21 psychological and physical wellbeing." 22 We can leave that now Henry, thank you. 23 I want to ask you about these two concepts 24 of stigma management and suppression, please. 25 PROFESSOR CHRISTIE: I can speak from a child</p>	<p>70</p> <p>1 adolescent perspective, so a young person who 2 may have been aware of their condition. Even 3 with conditions which aren't, we don't think of 4 as being highly stigmatised, something like 5 diabetes, for example, there are many, many 6 adolescents who live with diabetes who don't 7 tell anybody at school. Who keep it an absolute 8 secret at the detriment of their wellbeing and 9 health, so they won't inject insulin, for 10 example, because they don't want their friends 11 to know. They don't want to feel different. 12 So if you multiply this by a million with 13 something like HIV, where there's masses of 14 ignorance and negative presentation, media 15 presentation, and we weren't in the middle of 16 the social media storm then, but even so on the 17 television, the dreadful adverts and the awful 18 newspaper reports that came out, it would have 19 been impossible for a young person living with 20 haemophilia and HIV to not be acutely aware of 21 the potential for stigma and to have to both 22 manage that but also suppress it, not to tell 23 people too -- and it's exhausting. 24 That's one of the things in that paper that 25 it doesn't say, it talks about the -- what you</p>
<p>71</p> <p>1 have to do in order to suppress but it 2 doesn't -- the end of the sentence should be, 3 "and it is exhausting", because it is exhausting 4 to constantly be trying to not let people know 5 through what you do, or how you do it, or what 6 you say, or where you go, or you know you don't 7 tell people about hospital appointments, you 8 don't tell people about medication that you're 9 taking, or the fact that you can't go out for an 10 evening because you're exhausted and feeling 11 dreadfully ill and you have to pretend that you 12 just don't want to go, so you get a reputation 13 as somebody who is not much fun rather than 14 people realising that you're actually very ill. 15 So I think that's -- so from an adolescent 16 perspective, again, that's really, really 17 difficult and challenging for a young person who 18 wants to be part of the world, but who has to 19 prevent themselves participating. 20 PROFESSOR WEINMAN: I'd like to say something about 21 suppression, really to follow on from what 22 Deborah said. The people who you cite there, 23 Pennebaker, Petrie and so on, are people we work 24 with, and a lot of their work has shown that if 25 you hold on to something, you don't disclose,</p>	<p>72</p> <p>1 you keep it inside you for long periods of time, 2 the costs not only emotionally, but the costs 3 physically can be huge. And there's very good 4 work now looking at people who have really 5 aversive memories or things they've never 6 disclosed to other people, trauma, you know, 7 a whole range of different experiences, 8 including illness-related experiences, and that 9 keeping sort of all those memories inside or 10 keeping those experiences inside comes at a big 11 cost. And what's very interesting about 12 James Pennebaker's work is that he many years 13 ago found that if he said to people, "What 14 I want you to do is write about something that 15 you've never told anybody about, and write your 16 innermost thoughts and feelings, try to contact 17 those", and typically he got people to write 18 over a number of days, and for a number of 19 people, the effects on them were profound. 20 Initially quite uncomfortable, but what happened 21 was that as they began to write and get 22 something out there, they started to make sense 23 of it a bit, understand it. Because when it's 24 all in your head and you haven't disclosed, you 25 haven't spoken to anybody, it's all at that very</p>

<p>73</p> <p>1 emotional, that very deep level, and you're not 2 really making sense of it. So again that, you 3 know, failure of disclosure or lack of 4 disclosure comes at that huge cost, and that we 5 know that disclosure, whether it's written 6 emotional disclosure or spoken disclosure, can 7 be very powerful, and some of Pennebaker's 8 studies and a whole lot of other people's have 9 shown that.</p> <p>10 MS RICHARDS: We certainly heard from witnesses who 11 have given evidence anonymously because they 12 still have not disclosed information about their 13 health to those who know them, and from 14 witnesses whose close relatives still do not 15 know that they are, for example, HIV positive. 16 And they talked to the Inquiry how they have 17 lived for decades living, in many respects, 18 a lie. The emotional burden of that must be 19 huge.</p> <p>20 DAME LESLEY: I think that emotional exhaustion is 21 really interesting because also as a coping 22 strategy, if you like, suppression and 23 concealment have this element of doomed to 24 failure about them, especially if somebody does 25 become progressively sicker, and externally,</p>	<p>74</p> <p>1 they can't disguise anymore what perhaps has 2 been happening.</p> <p>3 I think, you know, part of the emotional 4 exhaustion that people feel if they can't talk 5 about these things is due to this anxiety that 6 at any moment it could actually all be revealed, 7 and then the expectation is it's going to be 8 even worse.</p> <p>9 It's a terribly, terribly, if you like, 10 tenuous way to actually deal with things that 11 you're scared of.</p> <p>12 PROFESSOR CHRISTIE: But in some cases it is 13 actually worse, if -- in some cultures. I mean, 14 we're talking about stigma sort of at a broad 15 level, but I think, echoing what Dr Thomas has 16 said, in certain cultures, the idea -- I mean, 17 in certain cultures the idea of even admitting 18 that you are feeling a little bit low is not 19 appropriate. We have families who will 20 absolutely categorically not allow their 21 children to come and see a psychologist because 22 in that particular culture it's very -- it's 23 highly stigmatised. If you add on to that 24 cultures where things like HIV and even 25 haemophilia itself have -- or any haematological</p>
<p>75</p> <p>1 condition have negative conditions, the fear of 2 telling everybody something because you think 3 something bad is going to happen is actually 4 a true belief, because when you tell people you 5 will be excluded from society. So it's 6 a really, really difficult balance to get right, 7 in terms of disclose or not disclose. It's not 8 simple.</p> <p>9 PROFESSOR MORGAN: I think it's very much influenced 10 by the strength of the stigma, and so the likely 11 social reaction, when you do disclose. And 12 for -- our witnesses were describing situations 13 in which they -- some people disclosed to 14 trusted friends but in fact found that the 15 enacted stigma was so strong that they were 16 completely cut off and isolated.</p> <p>17 So I think there are different situations 18 according to the sort of strength of the stigma, 19 and so the strength of the social reaction, 20 because what we're hoping with disclosure is 21 these positive benefits for the individual and 22 some of these benefits come from greater social 23 support. But that can be limited.</p> <p>24 MS EDWARDS: Can I just add the fact that we talk 25 a lot about HIV stigma, I think further is</p>	<p>76</p> <p>1 evidence of the extraordinary stigma of 2 hepatitis C. And we tend to talk about HIV 3 stigma because it is very much in our lives and 4 because of the health promotion that went round 5 it, the fact that Freddie Mercury died, that 6 Princess Diana held people's hand, that actually 7 the stigma is something we verbalise and talk 8 about. There has been no such thing for 9 hepatitis, and I think the stigma of that today 10 is huge. And people find it very difficult to 11 verbalise and to talk about that because they 12 don't know what reactions people are going to 13 be, because it's not something that society 14 talks about very much.</p> <p>15 MS RICHARDS: Dr Thomas?</p> <p>16 DR THOMAS: Just picking up on that point around 17 psychological support, and for me coming out of 18 the documents that I've read was the lack of 19 support that was offered. People, some people 20 did get good support, and it was variable across 21 the country, but another barrier to people 22 accessing psychological support is a stigma 23 that's attached to psychological services. And, 24 you know, I remember just an anecdotal 25 conversation I've had with one of our</p>

<p style="text-align: right;">77</p> <p>1 consultants, and I sort of talked about, you</p> <p>2 know, the notion that I might sort of extend</p> <p>3 psychological support in an area, and he said,</p> <p>4 "Well, you know, Nicky, I don't really want you</p> <p>5 to do this touchy-feely nonsense with our</p> <p>6 patients", because actually it's still seen as</p> <p>7 a woolly concept, providing support for people.</p> <p>8 So if the establishments out there see it as</p> <p>9 not an acceptable form of support, it's also</p> <p>10 another barrier for people to overcome. And</p> <p>11 I just felt it important just to say that at</p> <p>12 this moment in time.</p> <p>13 MS EDWARDS: Can I add one thing to that, with</p> <p>14 regard to talking about the Life History</p> <p>15 Project, it's very interesting how many young</p> <p>16 men said to me it was an enormous step to access</p> <p>17 support when it was there. So I think it's an</p> <p>18 internal thing as well. And without making huge</p> <p>19 generalisations, these was young, male patients</p> <p>20 who'd had haemophilia, and now HIV and</p> <p>21 hepatitis C, and, you know, we talk a lot about</p> <p>22 did they access psychological support and</p> <p>23 counselling. For many people, that step was</p> <p>24 enormous, and we have some very amusing clips</p> <p>25 of -- on a website that we made about this,</p>	<p style="text-align: right;">78</p> <p>1 about people saying, "I wasn't going to go to</p> <p>2 Birchgrove and sit around with the chitty chatty</p> <p>3 stuff and start talking to people about my</p> <p>4 feelings."</p> <p>5 Of course he went and it was amazing, but</p> <p>6 verbalising that idea that it's not manly to</p> <p>7 access support. It's not only coming from</p> <p>8 institutional -- it's coming from within us, you</p> <p>9 know.</p> <p>10 MS RICHARDS: We're going to look at a couple of HIV</p> <p>11 and then hepatitis C-specific materials in</p> <p>12 relation to some of the particular aspects of</p> <p>13 stigma associated with those conditions, but</p> <p>14 just picking up on what you've said about</p> <p>15 Birchgrove, could we have up on screen, please,</p> <p>16 Henry, HSOC0005046.</p> <p>17 So this a report, "Keeping it in the family,</p> <p>18 access to information and service provision,</p> <p>19 findings from a study on behalf of the</p> <p>20 Birchgrove Group and The Haemophilia Society".</p> <p>21 For present passages there is one passage</p> <p>22 I'd like to ask you to note on the next page,</p> <p>23 please, Henry. It's halfway down the page</p> <p>24 beginning, "Then there is paradox", fifth</p> <p>25 paragraph down. If you could highlight that and</p>
<p style="text-align: right;">79</p> <p>1 the following paragraph. Could you highlight</p> <p>2 the second paragraph adds well, if possible,</p> <p>3 Henry, one after that. Thank you.</p> <p>4 So this really, in the words of those who</p> <p>5 are living with the condition and with the</p> <p>6 dilemmas, it encapsulates some of what you've</p> <p>7 described, I think.</p> <p>8 "Then there is paradox. In the first and</p> <p>9 probably second phase of the epidemic in the UK</p> <p>10 [this is talking about the HIV AIDS epidemic]</p> <p>11 raising the profile was seen to be the way to</p> <p>12 connect disease with human beings; to reduce the</p> <p>13 stigma and discrimination. People came out to</p> <p>14 raise the profile. If the stigma and</p> <p>15 discrimination associated with HIV are not</p> <p>16 challenged prevention won't work, people will</p> <p>17 not come forward for testing, and the move will</p> <p>18 be to drive it underground -- with all that that</p> <p>19 means.</p> <p>20 "So those living with HIV have had to manage</p> <p>21 something of a dilemma: to come out and perhaps</p> <p>22 experience profound discrimination or to remain</p> <p>23 closeted about their HIV status and thus</p> <p>24 perpetuate the view that 'It doesn't exist, it's</p> <p>25 the province of queers and junkies'; and if they</p>	<p style="text-align: right;">80</p> <p>1 do have it they should stay outside the norms of</p> <p>2 the rest of society, including the right to have</p> <p>3 children. Confidentiality or coming out,</p> <p>4 challenging social attitudes against the</p> <p>5 discrimination and stigma associate with HIV</p> <p>6 infection or protecting the individual's right</p> <p>7 to privacy."</p> <p>8 That captures the dilemma for many. In</p> <p>9 terms, specifically, first of all, of the stigma</p> <p>10 associated with HIV and AIDS, I just wanted to</p> <p>11 again put up one of the materials that you've</p> <p>12 referenced in your report on the screen, and</p> <p>13 just look briefly at the 1980s and then come</p> <p>14 forward to the present day. Henry, it's</p> <p>15 EXPG0000033, please. This is a paper about</p> <p>16 heroin, it says it in the title:</p> <p>17 "Heroin injecting and the introduction of</p> <p>18 HIV/AIDS into a Scottish city."</p> <p>19 Just one passage, page 3, please, Henry, at</p> <p>20 the bottom right-hand corner of the page. It's</p> <p>21 the last paragraph on the right-hand side,</p> <p>22 please. This refers to the advertising</p> <p>23 campaigns of the 1980s.</p> <p>24 "It was in 1987 that the famous UK campaigns</p> <p>25 were launched involving TV adverts which showed</p>

<p style="text-align: right;">81</p> <p>1 the tip of the iceberg and tomb stone images.</p> <p>2 Leaflets delivered to every household proclaimed</p> <p>3 'AIDS. Don't die of ignorance. Anyone can get</p> <p>4 it, gay or straight, male or female. Already</p> <p>5 30,000 people are infected'. The major</p> <p>6 influence on this was the fear that the</p> <p>7 infection would spread into the heterosexual</p> <p>8 community as a result of sexual contact with</p> <p>9 drug users. There was much less regard for the</p> <p>10 hapless human beings who were already infected.</p> <p>11 There was little information about what might</p> <p>12 happen to them, and estimates of illness and</p> <p>13 mortality were guesstimates based on widely</p> <p>14 differing reports from around the world."</p> <p>15 Do you know if there's been any research or</p> <p>16 study about the impact of those public health</p> <p>17 campaigns in the second half of the 1980s.</p> <p>18 PROFESSOR MORGAN: I don't know of any direct</p> <p>19 evidence of that but certainly witnesses</p> <p>20 referred to these campaigns as having the effect</p> <p>21 of increasing general fear and stigma. The</p> <p>22 campaigns were obviously trying to change</p> <p>23 behaviours, but by emphasising that HIV was</p> <p>24 something anybody could get, and so on, and</p> <p>25 knowing about the high death rates, this really</p>	<p style="text-align: right;">82</p> <p>1 increased the fear which stoked the stigma, so</p> <p>2 it was an unintended sort of consequence,</p> <p>3 really.</p> <p>4 DAME LESLEY: In fact much of the research that has</p> <p>5 been done, looking at public health campaigns,</p> <p>6 sort of does demonstrate that very often they</p> <p>7 are ill-informed, rarely actually do influence</p> <p>8 behaviour, because they don't come from, by and</p> <p>9 large, any theoretical underpinnings that we</p> <p>10 know about, and then they sort of die a natural</p> <p>11 death without people really looking and</p> <p>12 thinking: well how did smoking get reduced or</p> <p>13 have we actually tackled the obesity crisis in</p> <p>14 a sensible way?</p> <p>15 This campaign in particular, the only</p> <p>16 research I am aware of is the fact that it</p> <p>17 really portrayed exactly the wrong messages if</p> <p>18 you wanted to get behavioural change. Fear</p> <p>19 rarely works in terms of changing behaviours.</p> <p>20 MS RICHARDS: In your report at page 20, you've</p> <p>21 observed that the campaigns contributed to</p> <p>22 widespread public fear, and to the popular</p> <p>23 notion that HIV/AIDS could be caught through</p> <p>24 normal social interaction.</p> <p>25 Now, you've observed in your report from the</p>
<p style="text-align: right;">83</p> <p>1 statements and the evidence that the Inquiry has</p> <p>2 heard, number of examples of enacted stigma,</p> <p>3 really quite severe examples of enacted stigma.</p> <p>4 I don't know whether you can answer this,</p> <p>5 but are there any kind of steps or response that</p> <p>6 you think could or should have been taken in the</p> <p>7 1980s and 1990s, specifically dealing with this</p> <p>8 what's called the HIV or AIDS epidemic that</p> <p>9 might have reduced the stigma associated with</p> <p>10 the condition or mitigated its effects?</p> <p>11 PROFESSOR MORGAN: I don't know if my ...</p> <p>12 DAME LESLEY: I guess one of the problems was that</p> <p>13 people were starting from a rather uneducated</p> <p>14 basis anyway, in interpreting what was seen to</p> <p>15 be happening. So you had a dual problem,</p> <p>16 really, of the people who were trying to launch</p> <p>17 campaigns and provide information didn't</p> <p>18 actually always have it or did it in a rather</p> <p>19 cack-handed fashion, and that just created</p> <p>20 a sense of further panic amongst the sort of</p> <p>21 general population.</p> <p>22 PROFESSOR CHRISTIE: I also think that we didn't</p> <p>23 have the psychological knowledge that we have</p> <p>24 now about nudge and behaviour change. So the</p> <p>25 ideas that we have now about getting people to</p>	<p style="text-align: right;">84</p> <p>1 eat differently, shop differently, behave</p> <p>2 differently -- those campaigns are underpinned</p> <p>3 by very different psychological theories, and as</p> <p>4 Lesley said, fear was the -- you know, the</p> <p>5 anti-smoking -- I mean, the anti-smoking</p> <p>6 campaigns didn't work. They didn't reduce</p> <p>7 people smoking. A few people maybe. But the</p> <p>8 majority of people don't change their behaviour</p> <p>9 because you tell them not to. You know, if we</p> <p>10 yell at somebody and say, "Cut the grass", or</p> <p>11 "Paint the spare bedroom", or "Tidy your room",</p> <p>12 the response is "Not now, I'm busy", "I don't</p> <p>13 want to", "I'm not doing anything you tell me to</p> <p>14 do", and that whole governmental thing of "I'm</p> <p>15 going to wag my finger at you and tell you not</p> <p>16 to do it" was how we used to think that we could</p> <p>17 educate and control public behaviour, but we</p> <p>18 know that it doesn't work now. So, you know,</p> <p>19 educational campaigns now are much cleverer,</p> <p>20 they're about motivating people to feel that</p> <p>21 they have the capacity to change their</p> <p>22 behaviour, and the campaigns in the eighties and</p> <p>23 nineties just didn't do that. They just didn't</p> <p>24 have that ability. And as everybody has said</p> <p>25 here, what they did was they created more fear,</p>

<p>85</p> <p>1 you know, that people who did that were bad. 2 "I don't do it, I'm good, so those that do are 3 bad." And it created that polarity between good 4 people and bad people. 5 MS EDWARDS: I think the other thing with this 6 campaign, it did actually massively increase 7 people going for testing who were not at risk of 8 HIV at all. There was a huge, huge amount of 9 testing that was undertaken in the hospitals in 10 those early days, for people's fear who, despite 11 the fact that these leaflets -- if you remember, 12 the leaflet that went round everybody's house as 13 well as the television adverts actually did have 14 a lot of information on them. Whether people 15 read that and actually heard what they were 16 reading, is another matter. Because as said, 17 fear came up, and everybody rushed off to be 18 tested. 19 I think the thing that was particularly 20 difficult about this is watching these adverts 21 and reading these leaflets when you were already 22 infected. And I think, you know, what 23 Roy Robertson says then about the guys in 24 Edinburgh, and whether it was them or it was 25 here, it was gay men, it was people with</p>	<p>86</p> <p>1 haemophilia, if you had HIV, you were seeing 2 this: everybody's going to die, there is no 3 help. Which is such a distressing message to 4 have. 5 It was obviously to educate the public who 6 were uninfected but the impact it had on people 7 who were already infected and unwell was 8 enormous. 9 MS RICHARDS: Yes, Professor Morgan? 10 PROFESSOR MORGAN: I'd say that in some cases we 11 find that sort of media celebrities can be very 12 important in actually challenging the stigma. 13 And if you think about it, the late 14 Princess Diana actually shaking hands with 15 somebody with AIDS, I mean that seemed to be 16 more important to people in thinking about these 17 issues and recognising that you couldn't just 18 contract AIDS so easily, rather than just 19 endless sort of printed word and so on. So 20 I think that we have to think in different ways 21 of communicating to actually challenge the 22 stigma. 23 MS EDWARDS: Mark Fowler on Eastenders, remember? 24 Great job. 25 MS RICHARDS: Many of the most severe descriptions</p>
<p>87</p> <p>1 of enacted stigma in the witness statements 2 describe events in the 1980s and the 1990s, but 3 bringing matters forward to the 21st century, 4 you've referenced in your report some papers 5 which describe the ongoing stigma and 6 discrimination, first of all, in relation to 7 HIV. I'm not going to -- I'm going take you to 8 one of them but I'm going to ask you first to 9 note, you've referred to a paper which looked at 10 discrimination, HIV-related discrimination in 11 2004, 2005. But for anyone who wants -- sitting 12 behind me who wants a note of it, it's 13 EXPG0000014. 14 You don't need to put it up on the screen, 15 Henry. 16 But that was a survey in London -- and one 17 of the authors of it is Professor Anderson, who 18 will be coming on Thursday to talk about HIV, so 19 we may be able to ask her about it -- and nearly 20 a third respondents in 2004, 2005, reported 21 HIV-related discrimination. Almost half of 22 those reported some form of discrimination in 23 the healthcare sphere, and I'll come on to that 24 in a moment. But bringing it on, then, 10 years 25 further on, to 2015, you've referred in your</p>	<p>88</p> <p>1 report to the HIV Stigma Survey. 2 And we will put that onscreen, please. 3 Henry, it's EXPG0000027, please. 4 So we can see it's Stigma Survey UK 2015, 5 and it's titled "HIV in the UK: Changes and 6 Challenges; Actions and Answers The People 7 Living With HIV Stigma Survey". So this only 8 four or five years ago, and we only need to look 9 at couple of passages -- if we go to the next 10 page, please, Henry -- we can see it says this: 11 "The landscape for people living with HIV in 12 the United Kingdom is dramatically different 13 from what it was ten or twenty years ago. 14 Advances in treatment mean the life expectancy 15 of HIV positive people can be the same as that 16 of the general population. Living with HIV in 17 the age of undetectability and reduced risk of 18 transmission should mean a better quality of 19 life for people living with HIV. 20 "However, despite some shifts in public 21 attitudes a considerable number of people in 22 the UK still hold stigmatising attitudes towards 23 people living with HIV. Consequently, stigma 24 remains a significant obstacle for many people 25 living well with diagnosed HIV."</p>

<p style="text-align: right;">89</p> <p>1 Then if we just have the next page, please, 2 Henry, and we need look only at the summary of 3 the findings, I think, rather than the detail of 4 the report. 5 "In 2015 people living with HIV in the 6 United Kingdom continue to feel stigmatised and 7 experience HIV-related discrimination. 8 "The survey findings show that while 9 two-thirds of 1,576 participants felt overall 10 positive about their life and in control of 11 their health, in the past year around half 12 reported feeling shame, guilt or self-blame in 13 relation to their HIV status and one in five had 14 felt suicidal." 15 Then the report observes those feelings were 16 more likely to affect those who were recently 17 diagnosed. 18 Then two paragraphs further down: 19 "Experiences of stigma in the healthcare 20 setting were common and one in eight 21 participants had avoided seeking care in the 22 past year. Similarly, about one in eight people 23 had decided not to apply for, or turned down, 24 employment or a promotion due to their HIV 25 status."</p>	<p style="text-align: right;">90</p> <p>1 Then the last paragraph in that section: 2 "A considerable number of participants had 3 sought support in the last 12 months, including 4 from a local HIV support organisation. 5 Participants believe that education and 6 awareness campaigns are necessary to challenge 7 the stigma and discrimination experienced by 8 people living with HIV in the UK today." 9 So this not a phenomenon of the past. 10 Can I ask you in particular to comment upon 11 the suggestion there about the continuing need 12 for education and public awareness campaigns, 13 please. 14 PROFESSOR CHRISTIE: I mean, I'll start. I'm sure 15 other members of the panel will add on to this. 16 There is something about how conditions are 17 perceived as being your fault. So if, in the 18 world of eating disorders, for example, working 19 with people who are overweight, there's enormous 20 stigma, because generally people think that 21 people who are overweight are lazy and it's 22 their fault that they're fat. It's their fault, 23 they've done it to themselves, and that they 24 haven't tried to do anything to stop it. 25 Whereas at the other end, if you look at</p>
<p style="text-align: right;">91</p> <p>1 somebody who is living with anorexia nervosa, 2 there's this enormous outpouring of sorrow and 3 distress and feeling of sympathy for this person 4 who is ill and, therefore, it's not their fault 5 they're ill. It's because they have a mental 6 illness and eating disorder. 7 The same is true for HIV, this feeling of 8 blame that on the whole, the population, the 9 public, feel that it's something that you have 10 done to yourself, or somebody, you know, in the 11 case of sort of, if you're a child, and because 12 of the medication nowadays, children aren't born 13 with HIV, but when children were being born with 14 HIV it was their mother had done something and 15 so they came from a bad family and again there's 16 this use of the words "bad" and "good". 17 Nowadays I think we still have that concept 18 of blame. If you've got something that 19 everybody thinks is your fault because there's 20 not enough education to demonstrate that you 21 can't help it, it's nothing that you've done to 22 yourself, then people kind of disrespect you or 23 there's going to be that worry about stigma and 24 the impact of stigma, so that's how I would 25 start.</p>	<p style="text-align: right;">92</p> <p>1 DAME LESLEY: I think also we ought to mention 2 actually the role of religion here, and 3 different cultures, because for some it is seen 4 as divine retribution for your, you know, 5 misdemeanours and that, of course, in certain 6 parts of the world like South Africa, for 7 example, led to a huge explosion of HIV, even 8 when in fact most of the rest of the world were 9 able to contain it and treat it. Because of 10 a sort of perception by a lot of people over 11 there that either it didn't exist, which was 12 just plain ignorance, or that if people did get 13 it, it was due to their, you know, sort of 14 failure to follow the rules of the good book. 15 MS RICHARDS: Professor Morgan? 16 PROFESSOR MORGAN: I think you've not mentioned one 17 aspect underlying it, which is the blame, and I 18 think a second aspect is fear, and there is 19 still fear, and I think this is something that 20 needs to be addressed because the notion of fear 21 is sort of amplified and once you fear that HIV 22 could be more easily contracted than it is, and 23 so on, there is bound to be barriers and 24 discrimination. So I think it's both. It's the 25 issues of blame and the issue of fear.</p>

<p style="text-align: right;">93</p> <p>1 MS RICHARDS: Thank you. Sir, I note the time. I'm</p> <p>2 going move on to stigma and hepatitis C, but we</p> <p>3 can do that after lunch.</p> <p>4 SIR BRIAN LANGSTAFF: Well, let's do that after</p> <p>5 lunch. We'll take a break now until</p> <p>6 two o'clock. So two o'clock, please.</p> <p>7 (1.02 pm)</p> <p>8 (Luncheon adjournment)</p> <p>9 (2.03 pm)</p> <p>10 MS RICHARDS: I think we have one additional member</p> <p>11 of the panel to be sworn in.</p> <p>12 DAME THERESA MARTEAU (affirmed)</p> <p>13 Examination of Panel by MS RICHARDS (continued)</p> <p>14 MS RICHARDS: So we were looking before lunch at the</p> <p>15 question of stigma for those suffering from HIV.</p> <p>16 Before we leave the topic of stigma I wanted to</p> <p>17 look at one of the materials you've referred to</p> <p>18 in your report relating to stigma and</p> <p>19 hepatitis C.</p> <p>20 Henry, could we have up, please, onscreen</p> <p>21 EXPG0000028, please. This is a 2017 paper by</p> <p>22 Northrop, headed:</p> <p>23 "A dirty little secret: stigma, shame and</p> <p>24 hepatitis C in the health setting."</p> <p>25 If we just look down to the bottom of the</p>	<p style="text-align: right;">94</p> <p>1 left-hand column, please, on that page, under</p> <p>2 the heading "Introduction", four lines in:</p> <p>3 "Illnesses tainted by the stigma of</p> <p>4 questionable lifestyles present specific</p> <p>5 challenges particularly in health settings when</p> <p>6 treatments are sought. Hepatitis C provides one</p> <p>7 such example. Within the high-income world, the</p> <p>8 hepatitis C virus, replete with connotations of</p> <p>9 illicit behaviour and self-infliction, is most</p> <p>10 commonly associated with injecting drug use</p> <p>11 (IDU)."</p> <p>12 Then the paper goes on to talk about an</p> <p>13 Australian study with individuals, none of whom</p> <p>14 had engaged in injecting drug use, and it says</p> <p>15 this at the bottom of that column:</p> <p>16 "Despite this, the association between HCV</p> <p>17 and IDU was found to be highly problematic,</p> <p>18 impacting all aspects of life, personal</p> <p>19 relationships, employment opportunities and,</p> <p>20 significantly in this instance, access to health</p> <p>21 services. Because hepatitis C is often</p> <p>22 concealable, the decision to disclose one's</p> <p>23 blood status and to whom emerged as a centrally</p> <p>24 important consideration. Participant accounts</p> <p>25 underline shame, stigmatisation, fears of</p>
<p style="text-align: right;">95</p> <p>1 potential stigmatisation, and extreme caution</p> <p>2 around disclosure."</p> <p>3 Then it refers to:</p> <p>4 "In keeping with subsequent research health</p> <p>5 settings emerged as one of the most vulnerable</p> <p>6 sites for experiencing stigma."</p> <p>7 This paper goes on to narrate various</p> <p>8 experiences very similar to the experiences</p> <p>9 described by witnesses to the Inquiry. So</p> <p>10 I won't dwell upon the detail of the paper. But</p> <p>11 this exemplifies the continuing stigma</p> <p>12 associated to this day with hepatitis C; is that</p> <p>13 fair?</p> <p>14 Can I ask someone to answer because the</p> <p>15 transcribers wouldn't pick up a nod.</p> <p>16 PROFESSOR MORGAN: As we know, hepatitis C is more</p> <p>17 prevalent than HIV and it's still associated</p> <p>18 with some stigma, yes.</p> <p>19 MS RICHARDS: And it's very much -- for similar</p> <p>20 reasons to those you discussed before lunch,</p> <p>21 it's that question of seeing certain types of</p> <p>22 behaviour associated with it that are seen as</p> <p>23 bad by society and then the aspects of fear that</p> <p>24 you described earlier.</p> <p>25 PROFESSOR MORGAN: Yes, both, as you say, the shame</p>	<p style="text-align: right;">96</p> <p>1 from -- seen to be associated, the sort of</p> <p>2 stereotype of deviant behaviour, plus fear that</p> <p>3 you might contract it.</p> <p>4 MS RICHARDS: The way you put it in your report was</p> <p>5 to say that:</p> <p>6 "Hepatitis C is a stigmatised condition and</p> <p>7 shares some characteristics of HIV with its</p> <p>8 normal route of transmission thorough handling</p> <p>9 blood, particularly in the context of illicit</p> <p>10 drug use, linking it with publicly acceptable</p> <p>11 behaviour."</p> <p>12 Then you go on to say this:</p> <p>13 "The main difference was that no educational</p> <p>14 campaigns specifically targeted hepatitis C.</p> <p>15 The public therefore had very limited knowledge</p> <p>16 about hepatitis C and they therefore drew on</p> <p>17 their knowledge of HIV which they thought would</p> <p>18 be very similar and this frightened them."</p> <p>19 PROFESSOR MORGAN: Yes, several people said that</p> <p>20 explicitly, "I don't really know but I think</p> <p>21 it's a bit like HIV", and then had their image</p> <p>22 of HIV.</p> <p>23 MS EDWARDS: Can I say one thing: that underlying</p> <p>24 this of course is the society that we live in</p> <p>25 that has such a judgement, and I suppose from</p>

<p style="text-align: right;">97</p> <p>1 a nursing perspective -- you know, when you're</p> <p>2 a nurse, you don't make judgements about why</p> <p>3 people are sick. And I think we live in this</p> <p>4 society where we make judgments about people's</p> <p>5 behaviour with sometimes a very poor empathy and</p> <p>6 a poor understanding of what got them into that</p> <p>7 position, and whether that be drug users,</p> <p>8 whether that be anything else. And I think the</p> <p>9 stigma that we're talking about, you know, it</p> <p>10 hasn't just arrived. We make that stigma. You</p> <p>11 know, we've created this society.</p> <p>12 I think it is a really important thing, and</p> <p>13 especially with this article which talks about</p> <p>14 stigma within the healthcare service, and about</p> <p>15 whatever reason that you go into the healthcare</p> <p>16 service, you should be cared for as a human</p> <p>17 being and not be judged for whatever behaviour</p> <p>18 you're there for. But that comes from a very</p> <p>19 nursing perspective, which I think we need to</p> <p>20 have as nurses.</p> <p>21 MS RICHARDS: Witnesses have commented on, and</p> <p>22 relayed, and you've picked up on this in the</p> <p>23 report, a number of different ways in which they</p> <p>24 have experienced stigma, at least felt stigma,</p> <p>25 if not enacted stigma, within healthcare</p>	<p style="text-align: right;">98</p> <p>1 settings. And I just wanted to explore a little</p> <p>2 the potential consequences of that. That can be</p> <p>3 obviously distressing and upsetting for the</p> <p>4 patient, but it can presumably have a longer</p> <p>5 term impact in terms of engagement with</p> <p>6 clinicians, trusting clinicians and healthcare</p> <p>7 advisers, adherence to treatment and matters</p> <p>8 such as that.</p> <p>9 PROFESSOR WEINMAN: Yeah, very strikingly, I think</p> <p>10 we -- (a) we could see that, and that's</p> <p>11 consistent with research. I think when people</p> <p>12 lose faith in a system, lose that sense of</p> <p>13 trust, then (a) -- well, there are two things</p> <p>14 likely to happen: either they will try and avoid</p> <p>15 or work their way around different parts of the</p> <p>16 system, and there's a paper that we talked about</p> <p>17 following medical errors, how people tried to</p> <p>18 navigate their way around the bits of the system</p> <p>19 that they've been offended by.</p> <p>20 Or people go into slightly more passive,</p> <p>21 sort of resigned, "Well, there's nothing I can</p> <p>22 do", you know, and feel that somehow -- again,</p> <p>23 the blame gets internalised. You know, "Well,</p> <p>24 clearly I've got something that they really</p> <p>25 don't want to be bothering with."</p>
<p style="text-align: right;">99</p> <p>1 So I think, you know, there are a number of</p> <p>2 ways in which that can happen. And I think --</p> <p>3 it's interesting, before the break you talked</p> <p>4 about that was then, this is now, well, just</p> <p>5 a couple of weeks ago I read a study on looking</p> <p>6 at a large trial in America where they were</p> <p>7 offering PrEP, which is, you know, a treatment</p> <p>8 for prevention of HIV and AIDS to a large, you</p> <p>9 know, relatively socially excluded population,</p> <p>10 and it was a very large study from Chicago, and</p> <p>11 the study that the uptake of PrEP was low. And</p> <p>12 they started to look at it thinking it was going</p> <p>13 to be this excluded group and it wasn't. It was</p> <p>14 the failure of family doctors to really</p> <p>15 recommend it. And some actually said out loud</p> <p>16 things like, "Well, you know, I'm not sure, you</p> <p>17 know, whether it's right to encourage the sort</p> <p>18 of behaviour that this is going to allow people</p> <p>19 to have", ie, you know, more frequent sexual</p> <p>20 contact and so on.</p> <p>21 So, again -- and that's, you know, a 2019</p> <p>22 paper. So there's still a lot of big issues out</p> <p>23 there in terms of, you know, judgement that's</p> <p>24 being made by healthcare professionals, negative</p> <p>25 judgement.</p>	<p style="text-align: right;">100</p> <p>1 MS RICHARDS: Specifically within the healthcare</p> <p>2 setting, are there any suggestions that you can</p> <p>3 make, either now or, if not now, perhaps in the</p> <p>4 supplemental report that you're kindly</p> <p>5 undertaking to provide, about how stigma within</p> <p>6 a healthcare could be addressed? If it was</p> <p>7 something you would like to think about and</p> <p>8 reflect upon and put in the report, that's fine,</p> <p>9 but it's obviously an important</p> <p>10 -- (overspeaking) --</p> <p>11 PROFESSOR WEINMAN: Unless anybody has any</p> <p>12 immediate --</p> <p>13 DAME LESLEY: The only immediate thing that I can</p> <p>14 mention is the fact that if you actually</p> <p>15 associate different groups of people with</p> <p>16 things, prejudices, and what we're talking about</p> <p>17 here, they are so ingrained over years and</p> <p>18 years, and it doesn't matter which professional</p> <p>19 group you belong to, we all have different</p> <p>20 prejudices that sometimes are very overt, other</p> <p>21 times they're hidden and I think they're very</p> <p>22 difficult to change. They're very, very</p> <p>23 difficult to change. And you can do all sorts</p> <p>24 of online surveys to see how ageist you are, how</p> <p>25 racist you are, and even if we think, "Oh, I'm</p>

<p>101</p> <p>1 not ageist, I like old people as much as young 2 people", "I'm not racist, I like Asian people as 3 much as, you know, sort of Caucasian people", 4 you do some of these surveys and you see how 5 subliminally you've got a lot of these features 6 yourself. 7 So all I'm trying to say is that it's very 8 difficult to help people change behaviours that 9 they have developed over years or attitudes that 10 they have developed over years, belief systems 11 about certain groups, you know, being less 12 honourable or less reliable than others, all 13 these sorts of things. They're difficult to 14 shift. 15 PROFESSOR CHRISTIE: There is a move I think within, 16 well, perhaps the NHS but in other areas to 17 address racism with unconscious bias training, 18 where rather than sending people on a diversity 19 training which everybody hates to go on, and 20 doesn't think it applies to them, if people are 21 helped to understand their unconscious bias, 22 because we all have it. Every single person in 23 this room has it, towards the other. And it's 24 about recognising that when we see people as the 25 other, that we have that unconscious bias which</p>	<p>102</p> <p>1 then leads to stigma or discrimination. 2 And I think that that's, for me, that would 3 be one direction that we can think about in 4 relation to something like this, because I agree 5 with Sian that as healthcare professionals we 6 should behave in a certain way, and one thinks, 7 "Well, why did you go into the healthcare 8 profession and the helping profession if you're 9 going to behave in a way that isn't helpful", 10 but we also have other contexts in which we live 11 our lives. So we've already discussed the idea 12 of religion and faith, and there will be many 13 healthcare professionals who hold a very strong 14 position because of their faith. We have 15 positions according to our ethnicity, there's 16 many contexts, whether we're a mother, a father, 17 as to how we react to people. 18 If we didn't reflect on that then we never 19 change it. I would say that one of the things 20 that I think changes healthcare professionals 21 the most is the opportunity to have supervision, 22 good supervision, and right now, medical doctors 23 don't get supervision, and nurses very rarely 24 get supervision. The people who get the most 25 supervision are psychologists, who spend their</p>
<p>103</p> <p>1 whole life talking to people and then talking to 2 people about what they've talked to people 3 about. 4 DAME LESLEY: We like talking, yeah. 5 PROFESSOR CHRISTIE: As you can see, but that then 6 means that we then have an opportunity to 7 reflect on what we said, and was that hurtful, 8 was that the right thing to have said, and 9 should we do that the same way the next time 10 we're in an interaction with somebody? 11 So I think that would be a very good and 12 relatively -- well, not simple, but it would be 13 a good start to get people to have some greater 14 degree of reflective practice. 15 MS RICHARDS: And then Theresa, you ... 16 DAME THERESA: I was just going to add to what's 17 already been said, to say that people working in 18 a healthcare system are part of society, and so 19 our prejudices will be revealed through the 20 people working in the health service, so I think 21 it points to two targets for change. One is 22 society more broadly, and perhaps where there 23 would be faster change would be as has already 24 been said, unconscious bias training, which, as 25 a university teacher, I undergo. It's very</p>	<p>104</p> <p>1 important in terms of recruiting students to 2 university as well as in teaching, so it is 3 possible. 4 I don't know what is -- what happens in the 5 NHS, but I would have thought that this would be 6 an absolutely core part of effective and 7 sensitive communication training, which 8 I presume we will be coming on to. 9 MS RICHARDS: We will in just a moment. Doctor 10 Thomas, was there something you wanted to say? 11 DR THOMAS: Just to add to what everybody has just 12 said, that communication training is a really 13 important way of helping people, but involving 14 key participants who are, if you like, 15 hepatitis C sufferers, to be part of that 16 training programme, so that they are 17 communicating that experience at firsthand. 18 From my experience of working in another 19 area, it's a really powerful message that you're 20 sitting there and you're actually saying, "This 21 is how you make me feel", and those exchanges 22 are really helpful to get people to think about 23 their biases and to think about how they might 24 change. 25 SIR BRIAN LANGSTAFF: Before we just move on to what</p>

<p>105</p> <p>1 is going to be, I think, another topic, can 2 I ask you, when you do consider this question in 3 a supplementary report, you address a couple of 4 things. One is that it's been suggested 5 earlier, and has been suggested by a number of 6 people, that the answer to a lot of bias, a lot 7 of prejudice, a lot of stigma, is education. 8 That presumably is education about the disease, 9 it's natural progress, how you get it, what it 10 is, therefore replacing ignorance with 11 information. 12 That is particularly -- it is particularly, 13 therefore, worrying, perhaps, that some of those 14 who are currently in the health service are 15 suffering stigma when they ought to be the most 16 informed. Does that in any way invalidate or 17 cast any doubt upon education as such on its own 18 being an answer? 19 And secondly, if the NHS is a caring 20 profession, which ought to be fully educated, 21 how best do we prevent the societal -- it's not, 22 I think, an answer to say that society 23 stigmatises because it may be, might it, that 24 people in society have their attitudes affirmed 25 because they know somebody who works in</p>	<p>106</p> <p>1 a hospital who has exactly the same attitude. 2 [Witnesses all agree] 3 So there may be an element of 4 cross-affirmation going on but which affirms 5 prejudice or stigma as it's perceived and is 6 therefore unhelpful, and a way at least of 7 addressing society's stigmatising might be to 8 start with the health service. But it's 9 a suggestion which you might want to consider 10 and the pros and cons of it. It's just 11 a thought which has occurred to me as I've 12 listened to you. 13 MS RICHARDS: And we'll write to you and set that 14 out. You don't need to try to remember it. 15 I want to move to the question of 16 communication which a number of you have alluded 17 to in your answers already. In the report, you 18 say this: 19 "Good quality communication is an essential 20 element of healthcare practice." 21 And I wondered if you could just elaborate 22 upon why that is the case. 23 DAME LESLEY: Me? 24 MS RICHARDS: Yes, I'm looking at you. 25 DAME LESLEY: Yes, good quality communication is</p>
<p>107</p> <p>1 absolutely pivotal to everything that happens 2 within medicine, because if you are a poor 3 communicator, you're probably a poor listener as 4 well, so you don't hear what patients say, you 5 don't actually ask questions in ways that permit 6 them to be accurate givers of their history. 7 You probably don't communicate well with your 8 colleagues either. And all healthcare now is 9 a serious team business, the days of, you know, 10 a patient going and seeing one individual who 11 then offers a prescription and everything sort 12 of is all hunky dory are long over. 13 People are treated within teams, and so good 14 communication lies at the heart of absolutely 15 everything that is done within healthcare. And 16 sadly, it's one of the areas of health education 17 that probably receives scant training. In the 18 course of a clinical career spanning, if they're 19 lucky, about 40 years, the average consultant 20 within a hospital will have 240,000 interviews 21 at least with patients, which is more times than 22 they'll do anything else in their career. It's 23 more times than they'll wield a scalpel, take 24 a blood pressure, feel a pulse. Yet if you 25 contrast the amount of time that is given over</p>	<p>108</p> <p>1 to practical skills, in most of our medical 2 schools, with the amount of time given to 3 communication skills training, it's easy to see 4 why we have a major problem. 5 MS RICHARDS: We've obviously heard examples that go 6 back to the 1970s, through the 1980s, to the 7 present day, and from what you say, Dame Lesley, 8 it sounds as though, from your perspective, it 9 is still very much a present day problem. 10 DAME LESLEY: Yes, it is. Although certainly within 11 most of our medical schools there has been an 12 increase, and also schools of nursing, in 13 communication skills training, very often even 14 the format of the training is poor. You cannot 15 possibly -- rather as Nicky was just saying, you 16 can't possibly learn an experiential skill such 17 as communicating merely by reading a book about 18 it, or listening to a lecture. And yet that 19 still is how a lot of our communication skills 20 training is done. 21 You have to do it. You have to have 22 feedback from experienced facilitators, from 23 patients themselves, if you're going to actually 24 change the way you communicate in beneficial 25 ways.</p>

<p style="text-align: right;">109</p> <p>1 MS RICHARDS: One of the papers you'd referred to,</p> <p>2 I won't -- don't need to put it up onscreen but</p> <p>3 if anyone wants to know where to find it, it's</p> <p>4 EXPG0000016, and it's a paper by Elder 2017, and</p> <p>5 it talks about empathy and the importance of</p> <p>6 empathy in the clinician-patient relationship.</p> <p>7 Again, many of the statements that we have</p> <p>8 received describe a lack of empathy.</p> <p>9 DAME LESLEY: Yes.</p> <p>10 MS RICHARDS: What role does that play in modern</p> <p>11 medicine and is that something that can be</p> <p>12 taught or assisted?</p> <p>13 DAME LESLEY: That's a very interesting question</p> <p>14 because there are lots of debates that go on</p> <p>15 about whether or not you can actually teach</p> <p>16 people to feel, to care, to walk in the same</p> <p>17 shoes as the person in front of them. That's</p> <p>18 what empathy is about. And if you don't</p> <p>19 naturally possess those sorts of feelings as an</p> <p>20 individual, is it actually possible to teach it</p> <p>21 to people?</p> <p>22 I suspect it's difficult to teach empathy to</p> <p>23 people who are just -- you know, their</p> <p>24 personality disposition is that they are not</p> <p>25 empathic. However, one can teach them skills of</p>	<p style="text-align: right;">110</p> <p>1 conveying at least a sense of empathy when</p> <p>2 they're dealing with people. It's all in the</p> <p>3 nuance of the way you say things. You can</p> <p>4 always manage to say something that sounds</p> <p>5 callous and indifferent, or you can actually say</p> <p>6 precisely the same words but say them with</p> <p>7 a sort of empathy that is conveyed by either</p> <p>8 their non-verbal facial movements -- the fact</p> <p>9 that people even look at you when they're</p> <p>10 talking to you conveys "Hey, I'm listening to</p> <p>11 you. I feel what you're actually saying is</p> <p>12 really an important problem for you."</p> <p>13 And there's a very interesting paper</p> <p>14 that I read a few years ago that I give medical</p> <p>15 students and other healthcare professionals who</p> <p>16 come on training courses, and it's called "You</p> <p>17 me and the computer makes three". Because a lot</p> <p>18 of interaction now that takes place within our</p> <p>19 sort of, I don't know, GP surgeries as well as</p> <p>20 at hospitals, is with somebody in front of</p> <p>21 a computer typing things up, and that's when you</p> <p>22 also lose all the, you know, key non-verbals.</p> <p>23 You know -- and it looks as though somebody</p> <p>24 doesn't care if they're just looking at their</p> <p>25 computer.</p>
<p style="text-align: right;">111</p> <p>1 MS RICHARDS: Dr Thomas?</p> <p>2 DR THOMAS: Yes. And the flip side of empathy is</p> <p>3 compassion, and there's quite a lot of work</p> <p>4 being done at the moment within the NHS to try</p> <p>5 to instil more compassionate healthcare</p> <p>6 professionals, and an important element of that</p> <p>7 is enabling people to actually have feedback</p> <p>8 about their skills. And I think together,</p> <p>9 hopefully, those methods down the line will</p> <p>10 impact. But the transcripts were really clear</p> <p>11 that some of the experiences that people have</p> <p>12 had has been really unempathic and definitely</p> <p>13 without compassion.</p> <p>14 MS RICHARDS: Do you know, any of you --</p> <p>15 Dame Lesley, you may know the answer to this,</p> <p>16 I hope, but any others who may assist -- to what</p> <p>17 extent is any of this -- communication skills</p> <p>18 training, work on compassion and empathy -- part</p> <p>19 of any of the basic medical training that the</p> <p>20 medical schools deliver as part of a degree?</p> <p>21 DAME LESLEY: Most curricula do have some of that</p> <p>22 within it. As I've said before, though, I think</p> <p>23 very often the methods that are used are not</p> <p>24 always the most appropriate. And also the time</p> <p>25 that is devoted to it is just pathetic, really.</p>	<p style="text-align: right;">112</p> <p>1 And I -- you know, one of the things that</p> <p>2 I think is important is that -- and this</p> <p>3 actually, I think, is particularly pertinent as</p> <p>4 modern medicine becomes more and more complex --</p> <p>5 is that you can meet very good communicators who</p> <p>6 appear very empathic and, you know, sort of have</p> <p>7 the patient's needs right up front there, but</p> <p>8 they become so inured to the terminology that is</p> <p>9 used within the health service that they might</p> <p>10 just as well be talking Chinese to the person in</p> <p>11 front of them. And one of the other skills that</p> <p>12 I think we need to help people develop is how to</p> <p>13 put complex information into easy layman's</p> <p>14 terms, without being patronising, because people</p> <p>15 are not giving informed consent to tests or</p> <p>16 treatments if they haven't actually understood</p> <p>17 a word of what somebody has been saying, no</p> <p>18 matter how kind, compassionate or empathic they</p> <p>19 might appear.</p> <p>20 PROFESSOR CHRISTIE: I was going to say there's</p> <p>21 a very recent paper which has come out which has</p> <p>22 been very important in diabetes care, which is</p> <p>23 called Language Matters -- and those of you that</p> <p>24 are Twitter followers can read all about it on</p> <p>25 hashtag language matters, and it tells you --</p>

<p>113</p> <p>1 and it's really about the kind of words that you 2 use when you are thinking about somebody, when 3 you are communicating with somebody. It's 4 really powerful, powerful document, that the 5 diabetes world is trying to get everybody that's 6 providing care for the thousands and thousands 7 of people with diabetes to start using when they 8 talk to and about people.</p> <p>9 And it's not just about the talking to the 10 people that you work with, it's not your 11 clients, it's not just about that, it's to get 12 people to think differently, to stop thinking of 13 people as -- in some ways as patients, but 14 people that you owe a service to, and that it 15 should be a responsible, accountable service to.</p> <p>16 But it's also about thinking about how you 17 talk about people when they're not there, when 18 they're not in the room, because how we think 19 about people when they're not there, when we 20 then go out and communicate with them, it 21 communicates through our faces and through our 22 body language. If we think of somebody as 23 a nuisance and talk about them as a nuisance in 24 our little private consultations and then go and 25 speak to somebody, that comes across. People</p>	<p>114</p> <p>1 know if you don't like them. People know if you 2 have a judgemental attitude towards them. So 3 I think definitely the communication is really, 4 really important.</p> <p>5 And we looked at a -- we did a review 6 in 2017, so just two and a half years ago, which 7 looked at what communication training was 8 available to haematologists, and it was 9 non-existent. It's -- there's guidelines, there 10 are loads of guidelines, but guidelines aren't 11 mandatory, guidelines are just suggestions. And 12 there's no consistency. So one medical school 13 may do more than another one, and one will do 14 hardly any at all. And as already has been 15 said, there's no real pedagogy attached to these 16 trainings, there's no real thought about the 17 education. And how you educate people, you have 18 to train people properly in order to do it. And 19 you have to keep monitoring them. Once you've 20 done it -- you might do as a key medical 21 student, but once you become a consultant, 22 nobody ever checks your communication skills. 23 Medical students get monitored but nobody ever 24 sits in and says to a consultant, "You know that 25 last conversation you had with somebody was</p>
<p>115</p> <p>1 really very poor." That doesn't happen. And 2 that's another thing that needs to happen, is 3 that senior doctors who think they know how to 4 do it, they need to be held to account as well 5 as training up the junior ones.</p> <p>6 PROFESSOR WEINMAN: Yes.</p> <p>7 MS RICHARDS: Dr Thomas?</p> <p>8 DR THOMAS: We're going to talk about that later on, 9 I know, about embedding psychological services, 10 and an important role that psychologists have 11 when they're part of a medical team, you see the 12 doctor, you see the nurse, you see the 13 psychologist, is normalising psychology, but 14 it's also about having those conversations which 15 challenges those negative views of patients in 16 a closed room. So, "When you say that, what 17 exactly are you meaning about that individual?"</p> <p>18 So those conversations, we call them 19 cross-fertilisation of ideas, because -- the 20 doctor's conversation -- we learn from them and 21 they learn from us. And I think that's a really 22 important way -- that psychology service, 23 embedding them. It's not only a benefit to the 24 patient when they have therapy, but for the 25 wider team as well in learning how to put those</p>	<p>116</p> <p>1 prejudices aside.</p> <p>2 MS RICHARDS: I'm going ask about some of the 3 potential psychosocial consequences of poor 4 communication in a number of different respects. 5 Taking, first of all, consent, and I'm not 6 asking about the legal requirements for informed 7 consent, but can you just perhaps assist us with 8 the importance, in psychosocial terms, of 9 informed consent, and conversely, the impact of 10 being treated or tested or entered into research 11 or clinical trials without informed consent. 12 Whoever wants to answer?</p> <p>13 DAME LESLEY: Well, informed consent, I mean 14 obviously again, it's a sort of pivotal thing 15 within the practice of medicine generally, 16 because any procedure, any test, at least the 17 patient has got to have given tacit consent to, 18 if not written consent to. So if you hear that 19 a healthcare professional has done something to 20 you that you were unaware of ever having an 21 option at least to express whether or not you 22 wanted this done or not, you're going to feel 23 deeply mistrustful of absolutely everything else 24 that follows.</p> <p>25 And I think certainly my readings of many of</p>

<p>117</p> <p>1 the transcripts, when I attended some of the</p> <p>2 hearings as well, it made my hair stand on end</p> <p>3 actually seeing how often people reported that</p> <p>4 they never even knew that they had been tested</p> <p>5 for something, so obviously hadn't given any</p> <p>6 overt consent to it, let alone sort of some of</p> <p>7 the treatments, particularly when we came to</p> <p>8 clinical trials. And that's probably another</p> <p>9 topic you might want to move on to.</p> <p>10 So I think if somebody does something to</p> <p>11 you, because that's what was happening. People</p> <p>12 were doing stuff to patients, and they had no</p> <p>13 knowledge of having given at least some verbal</p> <p>14 consent to it, no understanding of why something</p> <p>15 was being done, or had an opportunity to express</p> <p>16 whether or not their preferences would be for</p> <p>17 one treatment or one procedure rather than</p> <p>18 another, if they had different burdens and</p> <p>19 consequences associated with them, then that is</p> <p>20 deeply, deeply troubling for the rest of the</p> <p>21 relationship that that individual will have, not</p> <p>22 only with the healthcare professional that they</p> <p>23 were initially treated by, but everybody else in</p> <p>24 the system as well.</p> <p>25 MS RICHARDS: Dame Theresa.</p>	<p>118</p> <p>1 DAME THERESA: If I could just add to that, Lesley</p> <p>2 has described how this could erode/undermine</p> <p>3 trust. The other thing that consent does is it</p> <p>4 provides what we could think of as psychological</p> <p>5 preparation for a test result, so some of the</p> <p>6 harrowing evidence that people describe that</p> <p>7 they'd undergone testing for HIV, they had no</p> <p>8 idea that they had, and then suddenly learnt</p> <p>9 that they were infected. So with appropriate</p> <p>10 consent comes talking through not only the</p> <p>11 nature of the test, but the potential results</p> <p>12 giving people the opportunity to think through</p> <p>13 and prepare, and have support at the time of</p> <p>14 testing for the different outcomes, so all of</p> <p>15 that is lost through not having appropriate</p> <p>16 consent procedures.</p> <p>17 MS RICHARDS: Then you've addressed in the report</p> <p>18 the consequences potentially and the importance</p> <p>19 of adequate information and accurate information</p> <p>20 being provided. If insufficient information is</p> <p>21 provided about whether it's a test result or</p> <p>22 a condition or treatment or side effects, is it</p> <p>23 fair to assume that patients may then have to</p> <p>24 take on the burden of researching themselves</p> <p>25 what the condition means, and we heard lots of</p>
<p>119</p> <p>1 testimony about that, and they may find</p> <p>2 information alarmist or inaccurate or not</p> <p>3 relevant to them and they have no means of</p> <p>4 knowing what the correct position is as regards</p> <p>5 to their own health.</p> <p>6 DAME LESLEY: Absolutely, and I think that leads to</p> <p>7 even deeper anxiety amongst patients. Dr Google</p> <p>8 has a lot to answer for. We're talking about</p> <p>9 some doctors that you've all actually had</p> <p>10 indifferent experiences with, but Dr Google is</p> <p>11 universally I think responsible for causing</p> <p>12 a great deal of anxiety and confusion.</p> <p>13 Patients who have not been adequately</p> <p>14 informed about the consequences of things, the</p> <p>15 need for different treatments, the, you know,</p> <p>16 side effects and, as I said, different burdens</p> <p>17 associated with different types of treatment, if</p> <p>18 they then go online, they fall prey to all</p> <p>19 manner of purveyors of snake venom and whatever</p> <p>20 else.</p> <p>21 That I think in itself just exacerbates the</p> <p>22 confusion that they're already sort of</p> <p>23 experiencing. Guiding somebody through the</p> <p>24 tranche of information they need to make truly,</p> <p>25 not just informed -- I don't like the informed</p>	<p>120</p> <p>1 consent. I think it's educated consent that</p> <p>2 allows a patient to pull in their own lifestyle</p> <p>3 preferences and choices and so forth. That</p> <p>4 actually takes time, and some online stuff is</p> <p>5 quite good, but it still needs somebody to</p> <p>6 direct the patient towards, and I think it was</p> <p>7 very alarming, again, in many of the</p> <p>8 transcripts, to read how people were just so</p> <p>9 desperate to try and find out things that they</p> <p>10 went online and, of course, we are dealing with</p> <p>11 a time when knowledge in itself about</p> <p>12 particularly HIV/AIDS was a little scanty.</p> <p>13 MS RICHARDS: Doctor Thomas, was there something you</p> <p>14 want to say?</p> <p>15 DR THOMAS: Just to say that in addition to what</p> <p>16 Professor Fallowfield has said, is really that</p> <p>17 if you have got poor information or scant</p> <p>18 information, then how -- you're not supported to</p> <p>19 go forward to take on board what are very</p> <p>20 complex healthcare treatments, and we know they</p> <p>21 also have some difficult and unwanted side</p> <p>22 effects. So if you've got poor information to</p> <p>23 start with, you're not going to be supported to</p> <p>24 actually adhere to medicines comfortably.</p> <p>25 PROFESSOR WEINMAN: I think there's an additional</p>

<p>121</p> <p>1 element to this, which is again something we saw</p> <p>2 in the witness reports, is that information was</p> <p>3 actually withheld on the grounds, apparently, at</p> <p>4 the time, that people didn't want to know. And</p> <p>5 that was a view -- and I know when I started</p> <p>6 teaching medical students, there was a strong</p> <p>7 belief out there that people didn't really want</p> <p>8 to know the bad stuff. And I can remember</p> <p>9 seeing a really good paper very early on with</p> <p>10 a title "No news is not good news, it's an</p> <p>11 invitation to fear". So if you don't get</p> <p>12 adequately prepared or you don't have that</p> <p>13 information and you're feeling bad, you fear the</p> <p>14 worst. All sorts of, you know, perceptions and</p> <p>15 interpretations go on inside people's heads.</p> <p>16 So again, you know, I think going back --</p> <p>17 it's still an issue now, but I think back in the</p> <p>18 old days information was withheld because people</p> <p>19 really genuinely believed -- I think out of</p> <p>20 complete ignorance -- that somehow it was not</p> <p>21 helpful for people to receive information.</p> <p>22 Which is worrying, you know.</p> <p>23 PROFESSOR CHRISTIE: Just one small thing I think</p> <p>24 also, that there's often an idea that</p> <p>25 communication is like the doctor holds all the</p>	<p>122</p> <p>1 knowledge, and the patient is a sort of</p> <p>2 receiver, and the doctor transmits information</p> <p>3 and the patient receives it, and so therefore</p> <p>4 communication must have taken place. And</p> <p>5 I think it was George Bernard Shaw said</p> <p>6 something about the greatest illusion in life is</p> <p>7 that communication has taken place. We'll</p> <p>8 correct it if I've misquoted it slightly. But</p> <p>9 the -- but actually, you can't just communicate</p> <p>10 something like that in one go. You have to come</p> <p>11 back and say: what did you understand? What do</p> <p>12 you need me to go over again?</p> <p>13 And it's an organic ongoing process with</p> <p>14 giving anybody bad news, or any news, actually,</p> <p>15 about your medical condition, because you hear</p> <p>16 the first two minutes and if it's devastating or</p> <p>17 difficult, you don't hear the rest of the</p> <p>18 15-minute consultation. You don't remember</p> <p>19 anything. You walk out there, and it's all gone</p> <p>20 apart from the big words that were in capital</p> <p>21 letters. And then you go in again and it's</p> <p>22 almost like, "Well, I can't ask again because</p> <p>23 they've told me everything, so I'll just -- I'll</p> <p>24 go and look for myself." So there's got to be</p> <p>25 an understanding that communication isn't</p>
<p>123</p> <p>1 a one-off, it's an ongoing process of you</p> <p>2 checking and checking again.</p> <p>3 And I think that's where nurses serve such</p> <p>4 an amazingly valuable purpose because they're</p> <p>5 often the ones who pick up the pieces, who sit</p> <p>6 down and say, "What did the doctor tell you?"</p> <p>7 Most of the young people I work with will</p> <p>8 say, "The doctor said, 'Blah, blah, blah, blah,</p> <p>9 blah, blah, blah', because I have no idea what</p> <p>10 they just said to me", and then somebody will</p> <p>11 have to go through it again, and use different</p> <p>12 words and visual images, or -- you know, and</p> <p>13 different materials and different media. So</p> <p>14 it's a really interactive process. It's not</p> <p>15 just "I'm going to say something and you're</p> <p>16 going to understand it."</p> <p>17 MS RICHARDS: You've set out very helpfully in your</p> <p>18 report good principles or good practice of how</p> <p>19 to communicate bad news.</p> <p>20 PROFESSOR CHRISTIE: Yes.</p> <p>21 MS RICHARDS: I'm not going to take time going to</p> <p>22 that because we've got it in the report, but</p> <p>23 you've also drawn attention to a particular</p> <p>24 paper, Bernacki, which we've also got, and some</p> <p>25 elements of best practice when discussing a</p>	<p>124</p> <p>1 diagnosis of serious illness.</p> <p>2 Can I then come on to about candour,</p> <p>3 openness, about when things have gone wrong,</p> <p>4 where there has been -- whether you call it</p> <p>5 medical error or an adverse incident, whatever</p> <p>6 terminology you want to use.</p> <p>7 Again, you've set out some principles in</p> <p>8 your report, on page 11 in section 13.4.2. I'm</p> <p>9 not going to, again, take time to just repeat</p> <p>10 what you've set out, but I wanted to ask you if</p> <p>11 you can, please, help us with, again, the</p> <p>12 psychosocial impact upon patients of not being</p> <p>13 told that something serious has happened to them</p> <p>14 as a result of the care or treatment that they</p> <p>15 have been given or not been given. How does</p> <p>16 that impact upon a patient's experience?</p> <p>17 PROFESSOR WEINMAN: Well, you cited the Elder paper</p> <p>18 earlier, which actually was exactly about that.</p> <p>19 It was on primary care and it was looking at</p> <p>20 when things have gone wrong from a patient's</p> <p>21 point of view, from sometimes quite minor</p> <p>22 things, like being treated badly, to, you know,</p> <p>23 treatments going wrong, adverse drug reactions.</p> <p>24 There, they showed very clearly that, first of</p> <p>25 all, there were big emotional impacts. People</p>

<p>125</p> <p>1 felt angry, they felt resentful. They felt --</p> <p>2 the thing that really bugged them, and this</p> <p>3 comes out in the other paper that we've cited,</p> <p>4 the Southwick paper, that lack of</p> <p>5 accountability. That, you know, that people (a)</p> <p>6 were not saying what had happened, they weren't</p> <p>7 even acknowledging that actually, you know, "It</p> <p>8 was us, we did this. We had a role in this, or</p> <p>9 the healthcare system in some way."</p> <p>10 So there are very clear emotional reactions</p> <p>11 there. And that was -- the Elder paper was</p> <p>12 relatively minor errors, problems. The</p> <p>13 Southwick paper, which I think is a really</p> <p>14 informative one, was about a survey of something</p> <p>15 like 700 people where there had been serious</p> <p>16 medical error, and then looking at two things,</p> <p>17 really. First of all, people's emotions. And</p> <p>18 people's emotions were really, you know, very</p> <p>19 highly affected. They were things like, you</p> <p>20 know, surgery that had gone wrong, adverse drug</p> <p>21 reactions, treatments that had failed and so on.</p> <p>22 Again, lack of accountability, a lack of</p> <p>23 explanation, lack of apology, all those sorts of</p> <p>24 things really emerged in that. And the effects</p> <p>25 on people were 90% of people talked about</p>	<p>126</p> <p>1 serious emotional consequences and major</p> <p>2 financial impacts, as a result of all of that</p> <p>3 happening. And so the impacts there were huge.</p> <p>4 Absolutely huge.</p> <p>5 You know, it was in the US where the</p> <p>6 financial aspects of health are fortunately,</p> <p>7 from our point of view, a little bit different</p> <p>8 to they are here, but even so, the impacts are</p> <p>9 huge. I mean that review, or that survey</p> <p>10 I think is a very powerful one, a very powerful</p> <p>11 indictment.</p> <p>12 MS EDWARDS: Can I add something to that?</p> <p>13 MS RICHARDS: Yes.</p> <p>14 MS EDWARDS: I think that -- moving on from what</p> <p>15 John is saying is that also -- that was the</p> <p>16 emotional impact but the paper also goes on as</p> <p>17 well to discuss the behavioural impact, and the</p> <p>18 behavioural impact where somebody feels that</p> <p>19 they -- the acknowledgment of error at whatever</p> <p>20 level is not being made, that people stop going</p> <p>21 to the doctor.</p> <p>22 PROFESSOR WEINMAN: Yes.</p> <p>23 MS EDWARDS: And they do things like go -- not them,</p> <p>24 but on Google, you know, you do search for your</p> <p>25 answers elsewhere, and you avoid going back to</p>
<p>127</p> <p>1 that doctor, and often you avoid going back to</p> <p>2 the whole system. So the healthcare system</p> <p>3 becomes something very negative in one's life,</p> <p>4 and whether that be the nurses, the hospital</p> <p>5 itself, whatever. And so your healthcare is</p> <p>6 therefore going to be compromised because you're</p> <p>7 no longer going to get the care and help that</p> <p>8 you need and you deserve because of your</p> <p>9 behavioural anger towards that doctor, nurse,</p> <p>10 you know, whoever.</p> <p>11 DR THOMAS: Just to add that justifiable anger,</p> <p>12 which the paper actually speaks about quite</p> <p>13 well, it comes through very clearly from the</p> <p>14 transcripts. And if you are stuck with that</p> <p>15 anger, you're sort of -- you can't move on with</p> <p>16 some aspects of your life, really, because</p> <p>17 nobody has acknowledged or taken responsibility</p> <p>18 for what has happened to you. So I think that</p> <p>19 just adds to -- goes on top of all this, all the</p> <p>20 psychological distress and psychosocial concerns</p> <p>21 that our population have gone through.</p> <p>22 MS RICHARDS: Dame Lesley?</p> <p>23 DAME LESLEY: I was actually going to say something</p> <p>24 rather similar. I mean when I did quite a bit</p> <p>25 of work with what was then called the National</p>	<p>128</p> <p>1 Patient Safety Agency, when we were trying to</p> <p>2 encourage more open disclosure -- in fact the</p> <p>3 programme ended up being called at the time</p> <p>4 Being Open -- we were very struck when we spoke</p> <p>5 to patients who had been the victims of</p> <p>6 sometimes some very serious medical errors,</p> <p>7 including sort of infected blood, but there were</p> <p>8 many other sorts of things, operations that had</p> <p>9 gone wrong, wrong drugs being administered and</p> <p>10 so forth, we were very struck with how those who</p> <p>11 were stuck with the anger. They were so</p> <p>12 incensed that people had never just 'fessed up</p> <p>13 and said right at the outset, "This was our</p> <p>14 error. We apologise wholeheartedly. We are</p> <p>15 going to investigate exactly what went wrong</p> <p>16 here. In the meantime we're going to do</p> <p>17 everything possible to try to help you," and</p> <p>18 furthermore -- and this becomes the important</p> <p>19 thing for many of the people that we spoke to --</p> <p>20 they wanted to know that something would be done</p> <p>21 to stop it happening to others.</p> <p>22 And it was the failure, I think, for people</p> <p>23 to first of all acknowledge the problem, but</p> <p>24 then not actually try and put in place measures</p> <p>25 that would ensure it would never happen to</p>

<p>129</p> <p>1 another person. And look at the hundreds of 2 you, who I'm quite sure actually also 3 experienced exactly the same feelings: anger not 4 just for what had happened to you, but anger 5 that it continued to go on.</p> <p>6 That's one of the reasons that the National 7 Patient Safety Agency actually sort of changed 8 their name to the National Reporting and 9 Learning System, because at the very least, 10 apart from personal acknowledgment and 11 recompense for what had happened, people so 12 wanted the system to learn so it wouldn't keep 13 on happening to others.</p> <p>14 MS RICHARDS: Just in relation to that guidance 15 being open, which was 2009 guidance, I should 16 say it's guidance that relates now to England, 17 but there is guideline in Wales, Scotland and 18 Northern Ireland, and we will obtain those and 19 provide them to core participants. You talked 20 also about the Australian study and about the 21 legal duties of candour, and again, we'll 22 provide information to core participants about 23 the duties as they apply in different parts of 24 the United Kingdom, but I understand that duty 25 of candour worldwide is not necessarily a new</p>	<p>130</p> <p>1 thing, and that there's at least one country 2 that recognised it in legal form decades ago.</p> <p>3 Could you tell us about that, Dame Lesley?</p> <p>4 DAME LESLEY: Absolutely. I mean in New Zealand 5 40 years ago there was a duty of candour that at 6 the moment an error was spotted, there was 7 a legal responsibility, a mandatory 8 responsibility, to report it, and set in process 9 not only treatment for the individuals affected, 10 but also the, you know, legal means to get some 11 recompense for this.</p> <p>12 I think Australia and New Zealand actually 13 were probably ahead of us, but New Zealand it 14 was 40 years ago they first published their work 15 on a duty of candour to investigate, learn, and 16 recompense the people that had actually been 17 affected in whatever way it was.</p> <p>18 MS RICHARDS: Dame Theresa, was there something you 19 were going to add?</p> <p>20 DAME THERESA: I was just going to mention that 21 really in this context, and some of the witness 22 statements emphasised this, that insult was 23 added to injury where sometimes people were 24 encouraged in a hostile way to take blood 25 products and were falsely reassured that they</p>
<p>131</p> <p>1 would not be infected. So not only was there, 2 if you like, an error in terms of an adverse 3 medical outcome, but they were falsely reassured 4 that what they were being given was completely 5 safe and that they should not be making such 6 a fuss.</p> <p>7 So I don't doubt that that would further 8 contribute to the psychological toll on those 9 individuals.</p> <p>10 MS RICHARDS: Then can I just ask you a little 11 about -- apologies -- what they mean, who they 12 might need to come from, how they might need to 13 be expressed.</p> <p>14 First of all, an acceptance of 15 responsibility or some kind of comprehensive 16 apology, if made promptly, is presumably likely 17 to be of greater benefit than if it's made 18 begrudgingly or many years after the event.</p> <p>19 DAME LESLEY: Absolutely. I mean there is so much 20 evidence that really what people require is an 21 immediate hands up, something went wrong here, 22 rather than, "Well what's going on here?" 23 I don't think this is right. Why isn't anybody 24 actually talking this through with me?"</p> <p>25 There are several things about apologies,</p>	<p>132</p> <p>1 though, that are quite interesting to look at.</p> <p>2 First of all, a formulaic, "The hospital are all 3 extremely sorry that this has happened to you" 4 in a letter, that does not work. That really 5 does not cut it. The apology has to be 6 personal. It has to be face-to-face. It's not 7 necessarily the doctor/nurse that was 8 responsible for administering the drug or 9 cutting the wrong arm or leg off, or whatever it 10 was, who has to be there. It should be, though, 11 somebody who is experienced in some way. They 12 have as many facts as they -- as are available, 13 in front of them, but they can personalise the 14 apology.</p> <p>15 Because too many people report that it's 16 just a sort of cut and paste letter, and that is 17 not an apology. Even with the apology, "We are 18 so, so sorry that this has happened to you", 19 there has to be a, "Look, we still don't know 20 all the facts", because you can't always 21 identify exactly what went on, "but we will put 22 in place now an investigation. We will keep you 23 appraised of how that goes as more facts emerge, 24 but, first of all, I want to know how you at the 25 moment are actually feeling, what we can do, how</p>

<p>133</p> <p>1 we can best support you and, by the way, this is</p> <p>2 the treatment that you're now going to actually</p> <p>3 really need."</p> <p>4 Now, that sounds a lot to do, but it can be</p> <p>5 handled well, and one of the things that again</p> <p>6 the National Patient Safety Agency "being open</p> <p>7 programme" started, it wasn't just that we wrote</p> <p>8 a big report; we actually did develop some</p> <p>9 training modules that were meant to be used by</p> <p>10 all hospitals, where individuals would take</p> <p>11 responsibility for, you know, sort of dealing</p> <p>12 with medical errors of different sorts of</p> <p>13 severity. They'd come to the training</p> <p>14 programmes, we'd train them, and part of that,</p> <p>15 the most important part of it, was how to do the</p> <p>16 apology.</p> <p>17 The other thing is that when you're dealing</p> <p>18 with a family, of course they're likely to want</p> <p>19 very different types of apology. And so that's</p> <p>20 what I meant by the personalising it, rather</p> <p>21 than just a formulaic, "I'm sorry this happened</p> <p>22 to you, it wouldn't happen again."</p> <p>23 MS RICHARDS: Your report and your evidence</p> <p>24 obviously focuses upon apologies, candour within</p> <p>25 the healthcare setting for obvious reasons. But</p>	<p>134</p> <p>1 would the basic principles that you describe, of</p> <p>2 the importance of there being acceptances of</p> <p>3 responsibility, candour about mistakes,</p> <p>4 potentially also apply to Government, to other</p> <p>5 public bodies and institutions, and politicians</p> <p>6 and individuals?</p> <p>7 DAME LESLEY: You're getting into very sort of</p> <p>8 touchy sort of ground here, because obviously</p> <p>9 there are levels at which the buck should stop.</p> <p>10 And sometimes the people that actually really</p> <p>11 have to be made the sacrificial lambs are not</p> <p>12 really the people who were responsible. And</p> <p>13 I guess, with certain sorts of -- I mean, I use</p> <p>14 this term -- well, I don't think you can</p> <p>15 describe it as anything other than scandals --</p> <p>16 one of the problems with scandals such as this</p> <p>17 is that there were probably people who knew</p> <p>18 a long time ahead, for a long time, what was</p> <p>19 happening, and yet for whatever reason, this was</p> <p>20 concealed.</p> <p>21 And I think that there does need to be</p> <p>22 a very public apology at the highest level, but</p> <p>23 meant. But meant sincerely.</p> <p>24 MS RICHARDS: Just one further aspect of candour and</p> <p>25 communication, but a slightly different one.</p>
<p>135</p> <p>1 Significant numbers of witnesses to the Inquiry</p> <p>2 have reported either lost or missing medical</p> <p>3 records, incomplete records, destroyed records,</p> <p>4 or they've reported difficulties in accessing</p> <p>5 records, either their own records or the records</p> <p>6 of deceased relatives.</p> <p>7 Some might view it as deliberate. That may</p> <p>8 be their view. Some may see it as evidence that</p> <p>9 they are unimportant, that what's happened to</p> <p>10 them doesn't matter to the organisations that</p> <p>11 they're asking for this information from. How</p> <p>12 might that again impact upon the psychosocial</p> <p>13 experiences of the individuals?</p> <p>14 DAME LESLEY: I think that's likely to have</p> <p>15 a serious sort of impact on them in terms of</p> <p>16 trust and confidence. Even something such as</p> <p>17 this Inquiry, sadly.</p> <p>18 You know, if things go missing and it was</p> <p>19 the people, you know, who call all the shots,</p> <p>20 people in power who actually allowed this to</p> <p>21 happen, I mean it's funny how similar sorts of</p> <p>22 documentation appear to have all gone missing at</p> <p>23 the same time in wildly different hospital</p> <p>24 situations, schools and whatever, isn't it?</p> <p>25 But if people feel there has been an</p>	<p>136</p> <p>1 institutional concealment or cover-up of things,</p> <p>2 it's going to make them -- really, really</p> <p>3 difficult for them to trust even, I guess, what</p> <p>4 we're saying.</p> <p>5 MS RICHARDS: I'm going to move on to the -- my</p> <p>6 penultimate topic is difficulties in accessing</p> <p>7 treatment, which I can take shortly, and then</p> <p>8 there's a slightly longer topic in relation to</p> <p>9 care and support, which is an important one and</p> <p>10 we'll need some time. So if I may, I'll just</p> <p>11 trespass into the break for two or three minutes</p> <p>12 to deal with the penultimate topic.</p> <p>13 The question of difficulties in accessing</p> <p>14 treatments, for example, drug treatments for</p> <p>15 hepatitis C, is a theme of many statements. Now</p> <p>16 I'm not going to ask you to comment upon what</p> <p>17 the reasons for that might have been. We know</p> <p>18 there are issues about rationalisation, funding,</p> <p>19 and the like. There may have been all sorts of</p> <p>20 other impediments to giving people treatment.</p> <p>21 I wanted to ask you what -- again, the</p> <p>22 psychosocial consequences for individuals,</p> <p>23 particularly individuals who have been infected</p> <p>24 as a result of NHS treatment, then being denied</p> <p>25 the treatment or having that treatment deferred</p>

<p style="text-align: right;">137</p> <p>1 that might address the consequences of that, how</p> <p>2 might that affect them?</p> <p>3 DAME LESLEY: You'd feel victimised, wouldn't you?</p> <p>4 Doubly victimised, I think.</p> <p>5 PROFESSOR WEINMAN: I think the whole issue of</p> <p>6 access to treatment is quite a complicated one</p> <p>7 because there are lots of reasons or lots of</p> <p>8 different sorts of access problems, as you've</p> <p>9 alluded to, and some involve, you know, just the</p> <p>10 fact that the centre was some way away, people</p> <p>11 had distances to travel when they were feeling</p> <p>12 fatigued, nauseous, whatever. So I think some</p> <p>13 of those impacts were horrendous, in -- just the</p> <p>14 toil that that took -- the toll, rather, that it</p> <p>15 took on people.</p> <p>16 I think where you're looking at sort of</p> <p>17 other -- what I would call more pernicious</p> <p>18 aspects of access, difficulty, I think where the</p> <p>19 problems really compound. So where people</p> <p>20 talked about feeling that they were not</p> <p>21 prioritised, feeling that they were being</p> <p>22 discriminated against, maybe there was</p> <p>23 rationing. You know, they weren't -- or even</p> <p>24 when there are sort of perhaps cost-related</p> <p>25 issues, that, you know, there, I think, what</p>	<p style="text-align: right;">138</p> <p>1 that really added to was -- a little bit like</p> <p>2 what Lesley was saying -- a real sense of</p> <p>3 discrimination and stigma. You know, you are</p> <p>4 part of a group who actually somehow were not</p> <p>5 worthy of the sort of healthcare you should be</p> <p>6 getting.</p> <p>7 And I think those two very -- there were two</p> <p>8 very different -- you know, there are access</p> <p>9 issues which the individual experiences, and</p> <p>10 then the ones which are the more practical ones.</p> <p>11 And I think that's the secondary of that more</p> <p>12 pernicious group, where people felt that they</p> <p>13 were not getting the sort of -- you know, they</p> <p>14 were being blocked off, in various ways, from</p> <p>15 the sort of treatment they should be getting,</p> <p>16 could be getting. I think the impacts there are</p> <p>17 huge. You know, the negative mood, distrust,</p> <p>18 dissatisfaction -- you know, a large amount of</p> <p>19 work looking at patient satisfaction with</p> <p>20 healthcare. Huge dissatisfaction there. Lack</p> <p>21 of confidence in the whole healthcare system,</p> <p>22 reluctance to follow advice and treatment.</p> <p>23 I think, you know, all sorts of behavioural,</p> <p>24 psychological impacts of being blocked off in</p> <p>25 that way, or finding it difficult to access --</p>
<p style="text-align: right;">139</p> <p>1 and again, it's consistent with literature.</p> <p>2 There's a big literature on HIV, again, which</p> <p>3 are very parallel to that -- just HIV on its own</p> <p>4 or in the context of, you know, infected blood.</p> <p>5 MS RICHARDS: Thank you.</p> <p>6 Sir, the final topic, which I'll deal with</p> <p>7 after the break, is about psychosocial care and</p> <p>8 support, and also picking up on some issues in</p> <p>9 relation to vCJD notification. I would ask any</p> <p>10 core participants, through their recognised</p> <p>11 legal representatives or otherwise, if they have</p> <p>12 additional questions arising out of what they've</p> <p>13 heard so far that they would like to have put,</p> <p>14 to raise those with their recognised legal</p> <p>15 representatives who will raise them with</p> <p>16 Ms Scott during the course of the break, and, to</p> <p>17 the extent that time permits, we may be able to</p> <p>18 ask some additional questions.</p> <p>19 SIR BRIAN LANGSTAFF: I would ask, in that case, to</p> <p>20 make sure that you know in good time in order to</p> <p>21 work out what you're going to ask in what</p> <p>22 remains of today's hearing time.</p> <p>23 MS RICHARDS: Yes. Ultimately it means that the</p> <p>24 lawyers behind me will have to miss their break,</p> <p>25 but so will we.</p>	<p style="text-align: right;">140</p> <p>1 SIR BRIAN LANGSTAFF: Well, everyone else won't, and</p> <p>2 if you can be back, please, by 3.30, so slightly</p> <p>3 shorter break, 25 minutes.</p> <p>4 (3.05 pm)</p> <p>5 (A short break)</p> <p>6 (3.35 pm)</p> <p>7 SIR BRIAN LANGSTAFF: Yes.</p> <p>8 MS RICHARDS: I want to ask you now about the</p> <p>9 question of psychological and social care and</p> <p>10 support. Starting with psychological support</p> <p>11 and counselling.</p> <p>12 First of all, do you consider that the</p> <p>13 provision of counselling and psychological</p> <p>14 support would have been of benefit to patients</p> <p>15 infected with hepatitis and HIV in the way that</p> <p>16 we've heard?</p> <p>17 PROFESSOR CHRISTIE: Yes, absolutely. Absolutely.</p> <p>18 Without question. Without question.</p> <p>19 There's very good evidence that when</p> <p>20 somebody receives a diagnosis that is</p> <p>21 challenging and distressing, that proper,</p> <p>22 adequate psychological counselling and support</p> <p>23 can make a significant difference to their</p> <p>24 ability to develop coping strategies, to the</p> <p>25 family's ability to manage. So there's</p>

<p>1 absolutely no question.</p> <p>2 MS RICHARDS: And family support, informal support</p> <p>3 networks, through groups such as a number of the</p> <p>4 groups that we've heard described, are clearly</p> <p>5 very, very important, but they are important in</p> <p>6 their own right rather than as a substitute for</p> <p>7 psychological and professional assistance?</p> <p>8 PROFESSOR CHRISTIE: Yes, there's a difference</p> <p>9 between a support group, which is there to,</p> <p>10 like, activate political support in some ways,</p> <p>11 to have the condition recognised -- what I would</p> <p>12 say is that what's needed is a number of</p> <p>13 different therapeutic kinds of support groups.</p> <p>14 So there are therapeutic groups where there's --</p> <p>15 are facilitated and supported using</p> <p>16 psychological theory and psychological therapy</p> <p>17 techniques to help people share. It's really</p> <p>18 important not to re-traumatise people. We know</p> <p>19 that just getting people to tell their story,</p> <p>20 again and again and again and again, just</p> <p>21 creates a re-traumatising situation and is not</p> <p>22 helpful.</p> <p>23 There's got to be a way of people working</p> <p>24 that through, of transforming a distressing</p> <p>25 emotion, recognising their own resilience.</p>	<p>141</p> <p>1 There are lots of different ways that people can</p> <p>2 be supported, and people can and deserve to</p> <p>3 choose the kind of therapeutic support that</p> <p>4 works for them, and when it's the right time for</p> <p>5 them. So at the immediate point of diagnosis it</p> <p>6 can be too raw, too painful, and too difficult</p> <p>7 to sit down and talk with the psychologist, but</p> <p>8 there will be a point at which -- they should</p> <p>9 continually be asked, "How are you doing right</p> <p>10 now? How are you dealing with it right now?</p> <p>11 Would you like to talk things through and work</p> <p>12 out what would work for you?"</p> <p>13 And that might be individual work or it</p> <p>14 might be family work, it might be couples work.</p> <p>15 There are a vast range of psychological</p> <p>16 approaches and psychological therapies that will</p> <p>17 fit different people in different ways and have</p> <p>18 good outcomes.</p> <p>19 MS RICHARDS: And in the absence of formal</p> <p>20 psychological support, is there a risk that</p> <p>21 patients may develop their own coping and</p> <p>22 adjustment strategies? And that might include</p> <p>23 strategies that are damaging or harmful. We've</p> <p>24 had some accounts for example of people turning</p> <p>25 to alcohol and drugs [all witnesses nod] as</p> <p>142</p>
<p>143</p> <p>1 a means of coping in the absence of any other</p> <p>2 form of support?</p> <p>3 DR THOMAS: That's absolutely right. They can</p> <p>4 utilise unhelpful coping strategies which</p> <p>5 undermine their own physiological health systems</p> <p>6 and mental health systems, but I think it's</p> <p>7 really important that for us, as a group of</p> <p>8 psychosocial experts, what's come out again, is</p> <p>9 that individuals have found important ways of</p> <p>10 transforming that experience, and making that</p> <p>11 experience a positive one, and so resilience has</p> <p>12 been a really important thing that's come out,</p> <p>13 that they have found ways, individual ways,</p> <p>14 of -- without support, of becoming resilient.</p> <p>15 That's not to say support isn't important, but</p> <p>16 we must acknowledge that they've found ways of</p> <p>17 doing that.</p> <p>18 Just to add to what my colleague was saying</p> <p>19 here about there's quite a lot of research that</p> <p>20 shows with adding psychological care in the</p> <p>21 context of the medical setting, that you can</p> <p>22 reduce psychological distress, you can reduce --</p> <p>23 improve the coping mechanism, and the frequency</p> <p>24 people are hospitalised and how long they're</p> <p>25 staying in hospital are enormously benefited</p>	<p>144</p> <p>1 from having -- adding psychology to the team.</p> <p>2 I think it's absolutely right what you were</p> <p>3 saying about how -- what kind of psychology</p> <p>4 services are available, and in my experience and</p> <p>5 certainly when I was doing the work, trying to</p> <p>6 do the literature search around this, we found</p> <p>7 very little evidence for hepatitis C patients</p> <p>8 who had been infected or haemophilia patients,</p> <p>9 and the large support literature has come from</p> <p>10 the HIV literature, which -- you know, people</p> <p>11 were infected -- and MSM literature, which in</p> <p>12 some ways, although they had support structures</p> <p>13 there, people with haemophilia didn't</p> <p>14 necessarily feel that they could access those.</p> <p>15 And I think that's -- that was also an added</p> <p>16 problem, and I don't know whether you want to</p> <p>17 say something about that, Sian, because you've</p> <p>18 got more direct experience of that.</p> <p>19 MS EDWARDS: It's interesting because we cannot</p> <p>20 pretend in this era that HIV psychological</p> <p>21 support was absent. In many areas, there was</p> <p>22 enormous support. There was fabulous</p> <p>23 communication, things that we have talked about</p> <p>24 and that witnesses have expressed. In some</p> <p>25 areas, in the HIV specialist areas, there was</p>

<p>145</p> <p>1 a lot of resources. There was a lot of money 2 being put into this area. You know, when we 3 think about healthcare services, we think 4 about -- when you want a good healthcare system 5 to work for you, you need somebody who has 6 in-depth knowledge, who has expertise, and who 7 has experience. And in the early days of the 8 eighties, nobody had any of that. And so what 9 happened in many of the HIV specialist centres, 10 where people were coming into the service 11 because they wanted to be there as healthcare 12 professionals, the question was: tell me, as 13 a patient, how you want to be nursed and how you 14 want me to care for you. And actually, that was 15 very transformative in the HIV specialist 16 services. And in that area, there was huge 17 psychological support.</p> <p>18 On our discussion earlier all about 19 communication, communication -- on one level 20 it's about patient and doctor; on another level 21 it's between healthcare professionals. I think 22 in some ways we didn't access some of the 23 support that was around for all sorts of 24 reasons. Because much of the support was seen 25 as HIV specialist care, that was seen as</p>	<p>146</p> <p>1 something that was focused on gay men who were 2 infected with HIV, and therefore inappropriate 3 or not targeted, not sympathetic. The 4 Birchgrove report that we mentioned earlier on 5 talks about this a lot.</p> <p>6 And in retrospect, did we do -- you know, 7 did we do something wrong? Did the healthcare 8 workers -- we talked about prejudice within the 9 healthcare working -- workers' areas, there were 10 many doctors who would not refer to specialist 11 areas of HIV, and I think -- we can't pretend it 12 wasn't there. I think what we do know, that it 13 wasn't accessed, and often referrals weren't 14 appropriately made, and it may be that it was 15 not appropriate.</p> <p>16 MS RICHARDS: Is there still the potential for 17 benefit for patients to access psychological 18 support services now, so many years after some 19 of the initial events?</p> <p>20 DR THOMAS: Absolutely.</p> <p>21 MS EDWARDS: Absolutely.</p> <p>22 DAME LESLEY: Absolutely.</p> <p>23 DR THOMAS: I mean, it's -- in the break I was 24 speaking to a hepatitis C sufferer and who was 25 talking to me about how she had managed to hold</p>
<p>147</p> <p>1 on to a lot of her information and the secret 2 around carrying hepatitis C, managing herself 3 and also her daughter and her family, and how 4 this has been -- on one hand, she sees herself 5 as being quite strong and has brought out her 6 resilience, but actually, you know, that's sort 7 of -- a loneliness of carrying that has actually 8 meant that she hasn't had a space where she's 9 given permission to kind of debrief and look at, 10 you know, all of this, the stress that she's 11 had.</p> <p>12 So I think it's immensely important going 13 forward.</p> <p>14 PROFESSOR CHRISTIE: I mean, every single transcript 15 that I read, and I can't remember how many 16 I went through, but I went through a lot of the 17 transcripts, and every single one that I read 18 I could see the potential for support and help 19 from psychological therapy. In every single 20 transcript. For some people, I felt that there 21 was the opportunity to work with an individual 22 to help them with some of the guilt that they'd 23 experienced. There was opportunities for 24 families, to support the family and help the 25 family see what an amazing job they had done.</p>	<p>148</p> <p>1 There was the opportunity for parents to help 2 them think about how they'd managed to parent 3 despite the difficulties that they'd had. For 4 young people to realise that despite having 5 lived with this really awful challenging, 6 challenging condition, throughout their teenage 7 years, how they had turned into amazing 8 individuals.</p> <p>9 And therapy can be about good stuff too. 10 Therapy doesn't have to be -- you don't have to 11 be sad, bad or mad to see a psychologist. You 12 can just be living with stuff that you'd like to 13 work through, and the service that I work in, we 14 see people to celebrate. We see people to 15 celebrate and witness their triumphs, not just 16 to talk about the miserable stuff.</p> <p>17 And there's some very good work in the 18 narrative field which is around people who have 19 lived -- a lot of it actually, interestingly, 20 coming from New Zealand -- with people who have 21 lived with trauma and lived with abuse, which is 22 what a lot of people effectively have 23 experienced, they've experienced abuse, 24 iatrogenic abuse, abuse by the medical system, 25 for them to actually come together to witness</p>

<p>149</p> <p>1 and to celebrate the fact that they have 2 survived, and that they are survivors and should 3 be really proud of being a survivor. 4 DAME LESLEY: I think Professor Christie has made 5 some good points there, but one of the things 6 that I'm mulling over is just that there isn't 7 a generic form of support that would be 8 appropriate for everybody, it's got to again be 9 very individualised and personalised. And 10 sometimes it might be groups, and sometimes it 11 might just be one person. 12 But I feel from all the sorts of things I've 13 read and the spontaneous conversations I've had 14 with some of the affected and infected, that 15 until particularly this Inquiry comes to some 16 conclusion, the reconciliation process that will 17 bring a great deal of comfort and support to 18 people can't be achieved. 19 You can talk and talk and talk about how you 20 feel, you can talk about methods to, you know, 21 manage your anger, your resentment, your 22 feelings of guilt, you can do all that, but 23 I think the greatest form of support for a large 24 number of people is going to be achieved by 25 a successful outcome from this Inquiry, and</p>	<p>150</p> <p>1 reconciliation. 2 MS RICHARDS: One issue that has -- or one concern 3 that's been expressed by a number of people is 4 about the variability amongst different parts of 5 the United Kingdom and the different schemes 6 within the United Kingdom, different elements of 7 both psychological and social support being 8 available, and that's engendered in some further 9 sense of discrimination or stigmatisation. Is 10 it fair that they understand it in that way or 11 experience it in that way? 12 PROFESSOR CHRISTIE: It's absolutely accurate. 13 There is a postcode lottery for mental health 14 care across the whole of the UK, and depending 15 where you live will determine whether or not you 16 have quick or, indeed, any access to child and 17 adolescent mental health service or an adult 18 mental health service, whether or not you have 19 access to increased psychological therapy, 20 access via your GP. Some GPs will pay for 21 a counsellor, others won't. 22 There is a -- it's appalling that there is, 23 but there is a really significant postcode 24 lottery in relation to support for emotional 25 wellbeing.</p>
<p>151</p> <p>1 MS RICHARDS: A common theme -- I'm sorry, 2 Dr Thomas? 3 DR THOMAS: Just that where there are psychologists 4 within haemophilia or hepatitis C services, 5 their access is very, very variable as well, so 6 you may have, say -- I can speak for my 7 centre -- you know, psychologists providing 8 three or four days to Haemophilia Centre, and 9 then you go to Ireland or Scotland and find that 10 you've got one psychologist doing half a day. 11 So how does it possibly meet the need? And 12 I think it's disingenuous sometimes of 13 healthcare providers to say that they've got 14 access when the calibre of access or the 15 quantity that they've got is extremely limited. 16 And it's those things, I think, that need 17 challenging. 18 MS RICHARDS: One of the common concerns expressed 19 by witnesses has been where they've attempted 20 some form of psychological support -- accessing 21 some form of psychological support, it's been at 22 a level of general mental health services, and 23 they have found themselves having to explain the 24 history of infection through blood and blood 25 products, and so a number of witnesses have said</p>	<p>152</p> <p>1 what they would want is a service which is 2 sufficiently specialist and focused that those 3 who are delivering the service understand and 4 have a good knowledge of the history as well as 5 of the particular conditions of HIV and 6 hepatitis C and its consequences. Would you 7 agree with that? 8 DR THOMAS: Absolutely. And again, I draw on my 9 experience, and certainly some of my patients 10 who are in the audience here, where we provide 11 what we call a dedicated service for people with 12 haemophilia. So you have an expert knowledge of 13 haemophilia, as well as hepatitis C and HIV. 14 And there are joint clinics that are run within 15 the Haemophilia Centre with all these 16 professionals who come to the department, and 17 that involves a psychologist as well. So I do 18 think, if you -- if the psychologist -- the 19 psychologist needs to have that history of 20 infected blood disorder as well, infected blood 21 products, and -- so that the individual feels 22 that they can go and they're in a safe pair of 23 hands, they don't have to start explaining 24 themselves all over again. Which is very, very 25 distressing and wearing, you know, takes its</p>

<p>153</p> <p>1 toll. So I do think embedding a psychology 2 service within the medical team, so the doctor, 3 the nurse, the psychologist is there, normalises 4 psychology, so there isn't a sense of, oh -- you 5 know, you see the psychologist and you can have 6 informal conversations, and when individuals are 7 ready to have that referral and see 8 a psychologist for one-to-one and detailed 9 psychological support, they've already sort of 10 bridged some of those initial conversations, and 11 then it doesn't feel like it's something that's 12 foreign and unusual.</p> <p>13 I think the other thing to say about that is 14 just that we have spent a lot of time 15 demystifying what psychology is. You bring to 16 us -- you are the experts with your health 17 problem and we're learning from you as 18 psychologists. We're novices. So they may 19 initially feel like there are power dynamics in 20 the room where we, the psychologists, are 21 powerful, but the important role is to educate 22 the individual patient to say, "Actually, you 23 know more about this than I do, what is it you 24 want from this therapy? It's not what I'm going 25 tell you you need; it's about what you feel you</p>	<p>154</p> <p>1 want to get."</p> <p>2 And that's a really important way, I think, 3 services should be structured.</p> <p>4 MS RICHARDS: You've referred in the report to UK 5 quality standards for haemophilia and for 6 haemoglobin disorders. Now obviously at the 7 risk of perhaps stating the obvious, that's only 8 going to be available for individuals who are 9 accessing those centres, and because they have 10 either a bleeding disorder or a haemoglobin 11 disorder. So that's not a service that's open 12 to those, for example, infected through 13 transfusion.</p> <p>14 You've also, I think, alluded to the fact 15 that there is very different availability in 16 different centres across the country in relation 17 to that.</p> <p>18 For some -- and some witnesses, not all, 19 have said this -- for some, receiving 20 psychological support at the centre where they 21 were infected, albeit involving treatment from 22 different individuals a number of years before, 23 is itself problematic.</p> <p>24 DR THOMAS: Yes. And an important dimension in 25 terms of how a haemophiliac -- and I can only</p>
<p>155</p> <p>1 speak for haemophilia obviously, and it is 2 absolutely right that other people who are 3 infected also need support, and that sort of 4 specialist focus work in an area that is 5 non-stigmatising is very important. That in 6 a way it's important that, going forward, we are 7 actually taking account of what people are 8 bringing to sessions, and -- I've lost my thread 9 of what the question is now. Can you repeat 10 that last question for me?</p> <p>11 MS RICHARDS: I'm going to have to check. No, 12 I can't even see it on the transcript. I was 13 asking, I think, about the -- people having to 14 go back to the same centre where they had been 15 infected.</p> <p>16 DR THOMAS: Yeah, so Haemophilia Centres have 17 actually then provided kind of outreach work, 18 and certainly one recommendation would be, and 19 within our centre, we would go out to centres to 20 see patients there. And of course this is not 21 always possible because it comes back to 22 resources again, if you don't have adequate 23 psychology resources you can't provide that. 24 But that would be an ideal way of meeting people 25 within the community or linking them up with</p>	<p>156</p> <p>1 appropriate people in the community to get that 2 support.</p> <p>3 MS RICHARDS: Dame Lesley?</p> <p>4 DAME LESLEY: I wonder if I could slightly disagree 5 in the sense that it for many people, what has 6 happened is they've lost trust and if you're 7 going to re-establish trust you can't actually 8 do that by sending them somewhere else. And 9 also some people live, certainly parts of the 10 devolved nations, Scotland, you're miles and 11 miles away from specialist centres, you're 12 likely to actually experience other sorts of 13 illnesses and ailments or your family will, 14 where you'll have to be treated in your local 15 centre. And so I guess I'm sort of thinking 16 about a little more widely as we're talking 17 about this, that perhaps also there are some 18 support services that are required for the 19 healthcare professionals who inadvertently have 20 been actually involved in these errors. It's 21 not been their fault, not their responsibility. 22 It might have happened years before they ever 23 even joined the service and unless we -- again 24 I'm coming back to this reconciliation -- it 25 works both ways. There are some probably quite</p>

<p>157</p> <p>1 damaged healthcare professionals out there who 2 feel desperate about the situation of the 3 families, and also have a sort of corporate 4 guilt themselves, that their institution or 5 hospital did this to people, wittingly or 6 unwittingly.</p> <p>7 And I think, unless we can try and 8 re-establish the trust factor, it doesn't matter 9 if you're sending somebody a million miles away, 10 they might still feel mistrustful of healthcare 11 professionals there.</p> <p>12 MS RICHARDS: Professor Christie? 13 PROFESSOR CHRISTIE: I suppose I wanted to suggest 14 something slightly in the middle because I think 15 I agree absolutely with both positions. As 16 a psychologist, you don't have to have diabetes 17 in order to work with a young person with 18 diabetes. You don't have to have a particular 19 condition. You don't also -- what you have to 20 have is an understanding of the impact of 21 illness.</p> <p>22 Now, I think one of the things that's really 23 striking for me was, when I started to read, to 24 start to get a sense of understanding how many 25 other people there are out there who have</p>	<p>158</p> <p>1 developed these infections as a result of having 2 something other than haemophilia, so the people 3 you are referring to who aren't going to 4 a Haemophilia Centre because they became 5 infected through a pregnancy transfusion or an 6 accident or something like that.</p> <p>7 So I think it is possible to think more 8 widely. I think it's possible to have a trained 9 workforce, and I think you would need to think 10 about how people are trained in order to start 11 to help people think about these really 12 unusual -- this is not usual. You don't come 13 across people who have been infected by 14 a healthcare service in your everyday work, but 15 it is possible for psychologists to work, if 16 they have an overall understanding, and 17 I think -- and Lesley has also said this -- that 18 actually it's not going to be possible to have 19 "The Infected Psychology Service". It's just 20 not going to work, because everybody here in 21 this room is different, and everybody here in 22 this room will have a different thing that they 23 need to think about or work through.</p> <p>24 So, again, the workforce has got to be of an 25 adequate calibre -- and Nicky used that word,</p>
<p>159</p> <p>1 "calibre", it's so important -- it's got to be 2 people who can work with difference, with 3 diversity, with uncertainty, and not quite know 4 where they're going to go, but be able to be 5 driven by what the person coming to them is -- 6 needed. So I'm not entirely sure that it does 7 need to just be in Haemophilia Centres. I do 8 think there needs to be some embedding within 9 a medical service. I think psychology for 10 chronic illness and emotional distress is very 11 different to just mental health. You know, 12 that's why we don't have good evidence for what 13 kind of treatments are needed. We know what 14 works for people who just have depression but we 15 don't know what works for people who have 16 diabetes and depression or HIV and depression. 17 We don't have the clinical trials to tell us. 18 But we have the clinical skills to know what 19 might work.</p> <p>20 We need to be flexible and we need to be 21 adequately resourced, because without adequate 22 resourcing what we will get is an unqualified 23 workforce that will provide unhelpful, 24 low-quality services, and people will say, 25 "Well, we're doing something", and that's not</p>	<p>160</p> <p>1 good enough.</p> <p>2 MS RICHARDS: Dame Theresa, was there something you 3 want to add? 4 DAME THERESA: Yes, just to say it's not my area of 5 expertise so I defer to what I'm hearing here, 6 but I'd just like to add that I would want to 7 think about this not just in terms of 8 psychologists, there are other healthcare 9 professionals who can provide expert 10 counselling, and I think we also need to look at 11 this in the context of the lack of parity 12 between mental and physical health, and 13 Sir Simon Wessely, who produced a report for the 14 Government before last, I think it was under the 15 Prime Minister Theresa May, he wanted to see 16 a levelling up, if you like, of resource for 17 mental health services. So I would see this as 18 part of that, as well as having the particular 19 colour that it has here.</p> <p>20 And we've talked about medical errors, and 21 I don't know what provision there is within the 22 NHS for managing that. So there are going to be 23 very, very expert services, such as the kind 24 that Nicky is providing, but I would want to see 25 a response that goes across the piste for all</p>

<p>161</p> <p>1 the reasons that we've discussed.</p> <p>2 MS RICHARDS: Would you also expect psychological</p> <p>3 care and support to be available to affected</p> <p>4 individuals, in the sense that the Inquiry has</p> <p>5 used that term: family members, partners,</p> <p>6 children, et cetera?</p> <p>7 PROFESSOR CHRISTIE: We opened this morning by</p> <p>8 stating very, very clearly that nobody lives on</p> <p>9 their own with this, that the illness, the</p> <p>10 condition, the infection, is in the family. One</p> <p>11 person may carry it, sometimes more than one</p> <p>12 person may carry it, but everyone in that family</p> <p>13 lives with it, and you cannot provide good</p> <p>14 psychological care by just focusing on that one</p> <p>15 person. You have to think about their wider</p> <p>16 system. You have to think about whether there's</p> <p>17 siblings, friends, aunties, uncles. You have to</p> <p>18 think about everybody, parents, grandparents,</p> <p>19 everybody needs to be considered and included,</p> <p>20 because one person may be infected but everybody</p> <p>21 is affected.</p> <p>22 MS RICHARDS: Dame Theresa?</p> <p>23 DAME THERESA: Just to add: infected; affected; and</p> <p>24 a very important point not to lose sight of that</p> <p>25 Lesley has already mentioned, the healthcare</p>	<p>162</p> <p>1 providers. I think it's absolutely key that any</p> <p>2 kind of training that we talk about continues</p> <p>3 through in terms of providing support for those</p> <p>4 individuals to be able to manage the situations</p> <p>5 that they have found themselves in.</p> <p>6 MS RICHARDS: A number of those that have given</p> <p>7 evidence about bereavement have pointed to an</p> <p>8 absence of psychological support for them,</p> <p>9 either in the weeks or months preceding death or</p> <p>10 in the weeks, months and years after death.</p> <p>11 Would that be another important part of any</p> <p>12 service offered?</p> <p>13 DAME LESLEY: Yes, and actually some of those things</p> <p>14 exist. Certainly when I worked at the London</p> <p>15 Hospital, we had a bereavement service that was</p> <p>16 actually run not by specialist psychologists,</p> <p>17 myself and a psychiatrist called</p> <p>18 Colin Murray Parkes used to train up very good</p> <p>19 counsellors, because we just didn't have funding</p> <p>20 or enough personnel to offer the service, but</p> <p>21 they were very good at actually visiting people,</p> <p>22 compassionate friends. There are quite a few</p> <p>23 bereavement services that I think, with a little</p> <p>24 extra support and training, you could</p> <p>25 realistically help to do this job.</p>
<p>163</p> <p>1 MS RICHARDS: Can I ask, if an individual is</p> <p>2 reluctant to access psychological support -- and</p> <p>3 there may be all sorts of reasons, many of which</p> <p>4 you'd discussed why that might be the case --</p> <p>5 how active should healthcare professionals be in</p> <p>6 trying to encourage that individual to access</p> <p>7 support services?</p> <p>8 DR THOMAS: I think everybody has to get to that</p> <p>9 place where they feel ready and able to take</p> <p>10 that kind of support, but if you don't know that</p> <p>11 that support exists within your vicinity of</p> <p>12 where you're getting the care, then that's just</p> <p>13 such a travesty, you know, that we healthcare</p> <p>14 professionals are not doing a duty to our</p> <p>15 population of patients. So educating our</p> <p>16 patients about what the service entails is</p> <p>17 a really, really important thing to do. And</p> <p>18 what it means. So normalising it, again.</p> <p>19 I remember when I started working in sickle cell</p> <p>20 all those years ago, this -- psychology was seen</p> <p>21 as such a stigmatising area, and one of the</p> <p>22 biggest advocates for it, and enabling patients</p> <p>23 to access it, were the clinical nurse</p> <p>24 specialists. They would talk about it in a way</p> <p>25 that was useful and helpful, that the patients</p>	<p>164</p> <p>1 could access, about all kinds of things that</p> <p>2 they found that -- that they would find it</p> <p>3 useful for. So there's a role for the</p> <p>4 healthcare professional to sell it, if you like,</p> <p>5 in a way, so that they know it's there, it's</p> <p>6 part of the service they can access, but if you</p> <p>7 don't know it's there, you won't -- it's another</p> <p>8 barrier, and you struggle for years. And then</p> <p>9 you suddenly discover, oh, yes, it's there. So</p> <p>10 I think that's an important role.</p> <p>11 PROFESSOR CHRISTIE: You should just never stop</p> <p>12 asking because you just never know when people</p> <p>13 are going to be ready. So some people will want</p> <p>14 support immediately when something traumatic</p> <p>15 happens. Other people will be ready in</p> <p>16 six months. Other people, six years. And some</p> <p>17 people maybe 20 years. So, you know, there will</p> <p>18 be young people I'll see who will categorically</p> <p>19 refuse to see me, and will -- I know, can you</p> <p>20 believe that -- and they will say, you know,</p> <p>21 "I can't see the point of this, there's no point</p> <p>22 in talking", and we'll say, "That's fine, let's</p> <p>23 try this again in six months' time", and we</p> <p>24 start at 12, and when they're 18, just before</p> <p>25 they're about to be transferred to adult</p>

<p>165</p> <p>1 services, they go, "Oh, I've changed my mind, 2 I'd like some psychology now." But there are 3 equally people who get in touch with me six, 4 seven years later after I saw them in their 5 early twenties, and say, "I just wanted you to 6 know I finally did what you suggested and I went 7 and saw a psychologist. I wish I'd done it 8 earlier." 9 So it's never ever, ever too late, if you 10 feel that you -- that there's something that's 11 not quite right. If you feel that you need help 12 and support, then go and ask, and keep asking. 13 Keep asking, because you will get it eventually, 14 but you just have to persevere, just persevere. 15 MS RICHARDS: If we just broaden out the discussion 16 from psychological support to other forms of 17 support more broadly, social support, what other 18 kinds of support might alleviate some of the 19 kinds of psychosocial impacts that you've 20 identified? 21 PROFESSOR CHRISTIE: Decent financial support, yes. 22 PROFESSOR WEINMAN: Definitely. 23 PROFESSOR CHRISTIE: Decent financial support so 24 people aren't -- we heard this morning and 25 earlier this afternoon about the massive impact</p>	<p>166</p> <p>1 socioeconomic financial hardship has on people, 2 on their physical wellbeing and on their mental 3 wellbeing, so appropriate and adequate financial 4 support can make such a difference to people. 5 It can help a family go on holiday, something as 6 simple as that, but that could make such 7 a difference to people's wellbeing, so I think 8 financial support, very, very important. 9 And social support is a major mediator of 10 physical wellbeing, so creating good social 11 support systems and, again, asking people. It 12 is absolutely essential for healthcare 13 professionals to keep asking the people that 14 they're working with, "How are you doing? How 15 are you doing? What can I do to help you?" 16 Not, "Tell me what your blood levels are". 17 That's not the question. "What can I do to help 18 you today? What is it that will make your life 19 better?" 20 The question that needs to be asked, and 21 when somebody tells you, it's your job then to 22 do it. Often it's not psychology. We will get 23 families we see where actually what they need is 24 a decent house to live in, decent accommodation, 25 a decent school. They don't need a psychologist</p>
<p>167</p> <p>1 to fix. They're not depressed. They're living 2 in squalor and a psychologist can't fix that, so 3 good social care, decent social care. 4 DAME LESLEY: There is one other thing of course 5 that we are slightly forgetting, and that is 6 that not everybody lives in a warm family 7 environment. There are lots of people who 8 anyway contracted all these awful sort of 9 diseases who are already socially quite isolated 10 anyway, and I have a slight concern that the 11 only people who usually knock on doors asking 12 for help are those who are already actually in 13 receipt of some of it. 14 I think it would be quite useful to be a bit 15 more proactive in seeking out those who had lost 16 loved ones when they were already socially quite 17 isolated and who don't have any existing 18 supports. If we have to focus our efforts on 19 individuals because of a lack of different sorts 20 of resources, manpower, money and everything 21 else, I think there's a very needy group who 22 don't have a voice at all. They don't have 23 a friend. They don't have a family who will 24 shout and beat the drum for them. 25 MS RICHARDS: Dame Theresa, can I ask you now</p>	<p>168</p> <p>1 a slightly different topic about the 2 consequences of vCJD notification. Your report 3 very properly draws attention to what I think is 4 the only study that has looked at the 5 psychological or emotional consequences of being 6 told about the possibility of exposure to vCJD. 7 That study, which was a small one of 11 8 individuals, found in those 11 individuals, no 9 evidence of particular long-term emotional 10 psychological disturbance. 11 As the panel know, the evidence that the 12 Inquiry has received from in excess now of 2,000 13 statements paints a different picture. Not 14 everybody obviously responds in a different way, 15 each -- people respond in their own way, but we 16 know from what we've been told that it is 17 something that has weighed very heavily on 18 a number of individuals, and has been a cause of 19 considerable fear, anxiety, psychological 20 distress. 21 Dame Theresa, I think you have some 22 observations about why the study which you spoke 23 about wouldn't be representative of the broader 24 group with whom we're concerned. 25 DAME THERESA: That's absolutely right, and thank</p>

<p>169</p> <p>1 you for giving me the opportunity to expand on</p> <p>2 that. So the only study that has been conducted</p> <p>3 looking at people who have been notified that</p> <p>4 they have a risk of about 1% of having become</p> <p>5 infected with variant CJD, so there's a very low</p> <p>6 risk, so the only resource that was available</p> <p>7 was to interview 11 people, and those</p> <p>8 individuals, as far as I know, had not already</p> <p>9 had experience of being infected through</p> <p>10 healthcare.</p> <p>11 So these were individuals who were being</p> <p>12 informed of a real but theoretical -- you know,</p> <p>13 a low risk -- for a condition for which there</p> <p>14 was no test and no treatment. And what we know</p> <p>15 from those individuals -- so they're selected --</p> <p>16 they're self-selecting, so they were approached,</p> <p>17 but if you were feeling pretty ropey about that</p> <p>18 notification, you would be unlikely to come</p> <p>19 forward to be interviewed. We know from other</p> <p>20 research that those who respond to life-changing</p> <p>21 risk information, how they respond is very much</p> <p>22 predicted by their psychological and emotional</p> <p>23 resources before being notified.</p> <p>24 So the main study in this area which we cite</p> <p>25 in the report was a study which might feel very</p>	<p>170</p> <p>1 removed from your experiences, of those who were</p> <p>2 found to be at risk of an inherited condition of</p> <p>3 Huntington's disease, and undergoing testing.</p> <p>4 And the thought always was that if you were</p> <p>5 found to have inherited the gene, and you would</p> <p>6 go on to develop this condition for which there</p> <p>7 was no treatment, you would be understandably</p> <p>8 depressed and anxious. And if you found you</p> <p>9 hadn't inherited the gene, you would be not</p> <p>10 anxious and depressed.</p> <p>11 Whereas what the evidence told us was that</p> <p>12 how you felt before the testing predicted how</p> <p>13 you felt afterwards. So if you were depressed</p> <p>14 and anxious before, regardless of your test</p> <p>15 results, you felt like that afterwards. So</p> <p>16 that's a long way of saying that initial</p> <p>17 vulnerability is extremely important in</p> <p>18 affecting how people respond to being given risk</p> <p>19 information about their health. So for those</p> <p>20 who had already been informed that they were</p> <p>21 infected, through treatment that they'd been</p> <p>22 receiving, whether it's HIV or hep C, to then</p> <p>23 learn that they had a chance that they had been</p> <p>24 exposed to another infection, that would lead</p> <p>25 me to predict, on the basis of what we know, the</p>
<p>171</p> <p>1 impact would be very, very different.</p> <p>2 MS RICHARDS: Then going back to questions of</p> <p>3 communication, how does what you told us earlier</p> <p>4 about good communication inform what should be</p> <p>5 the right approach to this situation, where</p> <p>6 you're not telling somebody that they have been</p> <p>7 diagnosed with a condition; you're telling them</p> <p>8 that they may have been exposed to something</p> <p>9 that cannot be tested? Are there any</p> <p>10 recommendations or observations that any of you</p> <p>11 have about how that should be approached?</p> <p>12 DAME THERESA: I think, again, it would depend on</p> <p>13 the individuals. So for those such as the</p> <p>14 infected and the affected that are the focus of</p> <p>15 this Inquiry, so already within a healthcare</p> <p>16 system where people are dealing with the</p> <p>17 damaging consequences of having already received</p> <p>18 blood or products or undergone surgery where</p> <p>19 they have been exposed to infection, I think, as</p> <p>20 Lesley has already outlined, face-to-face</p> <p>21 communication, explaining. And as Deborah has</p> <p>22 already stated, it's not sort of one-way. So</p> <p>23 there's an interaction with an individual, with</p> <p>24 a healthcare professional, who has all the</p> <p>25 information at their hands, being able to</p>	<p>172</p> <p>1 explain in a way that is effective and</p> <p>2 sensitive. So checking that people have</p> <p>3 understood what this information means, and</p> <p>4 providing them with the support that they need</p> <p>5 to adjust, to yet more information about</p> <p>6 a potential infection.</p> <p>7 MS RICHARDS: Dame Lesley.</p> <p>8 DAME LESLEY: I'm always very interested in</p> <p>9 individual differences and how different people</p> <p>10 respond in ways that you think, you know: this</p> <p>11 is really strange. Why is one person devastated</p> <p>12 by the news? Why is another entirely, you know,</p> <p>13 sort of cool about it?</p> <p>14 And there's a very interesting test you can</p> <p>15 give people, quite a quick one, called the</p> <p>16 intolerance of uncertainty test, and it's quite</p> <p>17 robust. And it really is highly predictive as</p> <p>18 to how well people are going to cope with</p> <p>19 different sorts of risky information that</p> <p>20 involves uncertainty. So if you have a high</p> <p>21 intolerance to uncertainty, you are likely to</p> <p>22 find it very, very difficult to live with that,</p> <p>23 and will need a lot of really quite intensive</p> <p>24 support services to help you through it. But if</p> <p>25 you're someone who actually has a high tolerance</p>

<p>173</p> <p>1 to uncertainty, then living with this</p> <p>2 information is probably not, in the order of</p> <p>3 things, as difficult as, you know, thinking</p> <p>4 about whether or not your football team will win</p> <p>5 on Saturday or not.</p> <p>6 DAME THERESA: But critically, it will -- to add to</p> <p>7 that -- depend on your pre-existing -- how you</p> <p>8 are feeling, what your emotional resources are.</p> <p>9 So added on to that.</p> <p>10 DAME LESLEY: Added to it, yes.</p> <p>11 DAME THERESA: So not everybody, but many of those,</p> <p>12 as we've read from the accounts of the witnesses</p> <p>13 in this Inquiry, these were individuals who had</p> <p>14 already had to deal with errors that were being</p> <p>15 made. So to add to that with something else</p> <p>16 that, for those who haven't previously had that</p> <p>17 experience, actually in the ordinary course of</p> <p>18 events, they could deal with it. But actually</p> <p>19 it's like the final straw for many people.</p> <p>20 DAME LESLEY: There is also, when you're looking at</p> <p>21 people communicating about risk and uncertainty</p> <p>22 to patients, something that's quite interesting:</p> <p>23 the same words can be received very differently</p> <p>24 by patients because of the nuance, the way that</p> <p>25 people actually express themselves.</p>	<p>174</p> <p>1 And I think that's another reason why we</p> <p>2 feel quite often, in certain situations about --</p> <p>3 when an error has occurred, when an adverse</p> <p>4 event has occurred, you should actually have</p> <p>5 somebody talking through the implications of</p> <p>6 this with a patient who has actually had some</p> <p>7 specific training, and will recognise when they</p> <p>8 are offering that information in a way that</p> <p>9 actually biases, if you like, things to</p> <p>10 over-optimism or over-pessimism. Being</p> <p>11 objective about the information you're giving</p> <p>12 can sometimes sound quite cold, but you really</p> <p>13 don't need somebody to either over or under-egg</p> <p>14 it. And again, healthcare professionals have</p> <p>15 different tolerances to uncertainty and risk as</p> <p>16 well.</p> <p>17 DAME THERESA: Can I also add that, having sat on</p> <p>18 one of the many panels that were set up by</p> <p>19 Government to deal with variant CJD and the</p> <p>20 implications of it, it was very much informed by</p> <p>21 what was considered to be -- and I would have to</p> <p>22 choose my words advisedly, so not a scandal, but</p> <p>23 a recognition that what has happened to many</p> <p>24 people in this room should not be repeated.</p> <p>25 So you could tell by the communications that</p>
<p>175</p> <p>1 were happening with people who were at risk of</p> <p>2 variant CJD, there was going to be no sitting on</p> <p>3 hands. People were going to be giving the</p> <p>4 information. And a lot of care went into the</p> <p>5 communication of that.</p> <p>6 So little comfort, I suspect, to many in</p> <p>7 this room, but already there was some learning</p> <p>8 that was happening as a result of the</p> <p>9 experiences of you in this room.</p> <p>10 MS RICHARDS: We have heard from one witness whose</p> <p>11 son died in consequence of vCJD. His son's</p> <p>12 experience of the care and support that was</p> <p>13 available, and your report alludes to the</p> <p>14 specialist provision that was made for people</p> <p>15 diagnosed with a prion disease, his experience</p> <p>16 was very different from the experience that the</p> <p>17 majority of infected individuals and their</p> <p>18 families have described of their own experiences</p> <p>19 of the trusts and schemes set up to support</p> <p>20 them. I think you've drawn attention in your</p> <p>21 report to that specialist service, the</p> <p>22 specialist guidance for social workers dealing</p> <p>23 with vCJD and a national service that has been</p> <p>24 established.</p> <p>25 I've one further question and then a handful</p>	<p>176</p> <p>1 of questions that others have asked to be put to</p> <p>2 you. You will have heard from what you've read</p> <p>3 and those of you who heard the evidence</p> <p>4 yesterday from intermediaries, that there are</p> <p>5 a number of individuals who, in giving their</p> <p>6 witness statements, giving their oral testimony,</p> <p>7 if they've done that, or speaking to</p> <p>8 intermediaries, are speaking for the very first</p> <p>9 time about deeply personal and deeply traumatic</p> <p>10 experiences.</p> <p>11 Some have reported that that has in some</p> <p>12 respects felt cathartic but is it fair to say</p> <p>13 that for some that very experience may also be</p> <p>14 traumatic? And, if so, what kind of care or</p> <p>15 support should potentially be being made</p> <p>16 available for people who are reliving</p> <p>17 distressing events?</p> <p>18 PROFESSOR CHRISTIE: I mean I would say that the</p> <p>19 research does say that asking victims of trauma</p> <p>20 to recount their experience creates</p> <p>21 a re-traumatising situation and one where you</p> <p>22 could re-experience the distress that you went</p> <p>23 through the first time, so just as you asked the</p> <p>24 question about what we should do, we should</p> <p>25 offer what we can. So we need to make sure that</p>

<p>177</p> <p>1 anybody who has been brave enough to stand up 2 and tell their story needs to know that help and 3 support is available, and it should be offered. 4 It may not be taken up, but that's somebody's 5 preference. But it should be. It should be 6 offered.</p> <p>7 MS RICHARDS: Again this is, as I say, a handful of 8 questions from various core participants and 9 their various legal representatives. One is 10 question for clarification of something 11 Dame Lesley said when we were talking about 12 consent earlier, and you used a phrase "tacit 13 consent", and I wondered if you could explain 14 what you meant by that phrase.</p> <p>15 DAME LESLEY: Ah, well, we have written consent, for 16 example if you're going to go into a clinical 17 trial or you're about to have a knee replacement 18 or an operation. But for certain sorts of 19 treatments or procedures, the doctor will just 20 say, "I think we should just run a few blood 21 tests", and the patient nods, and that's taken 22 as tacit consent, which I think has been 23 potentially a big issue here in this particular 24 problem that patients have had. 25 A lot of the people who actually claim --</p>	<p>178</p> <p>1 and I don't doubt them for a second -- that 2 tests were done without their knowledge, I bet 3 you'd find most of the healthcare professionals 4 would argue that you had provided at some stage 5 some tacit content. I can see somebody shaking 6 their head, and that's exactly it. They would 7 have picked up, or thought that they had 8 actually got your approval. Some of them would 9 have done. And that's what I mean by tacit 10 consent. If somebody doesn't actually put their 11 hand up and say, "Excuse me, but what exactly 12 are you doing here? What does this involve?", 13 and they just nod, they've given tacit consent 14 sometimes, some healthcare professionals would 15 say. I don't agree with the practice, but 16 that's what I meant by it.</p> <p>17 MS RICHARDS: And that reinforces the importance, 18 perhaps, of two things. One is the provision of 19 full information by the healthcare clinician as 20 to what they are doing, or what they are asking 21 the patient to agree to. And the second is the 22 importance of written consent, of recording 23 that.</p> <p>24 DAME LESLEY: Yes, absolutely. 25 PROFESSOR CHRISTIE: Yes.</p>
<p>179</p> <p>1 DAME LESLEY: And checking that people have 2 understood what they've just signed. Because 3 that's another thing. Many consent forms are 4 actually written demanding a health literacy 5 skill that most of the population don't have. 6 The health literacy in the UK is probably about 7 that of -- 25% of the population have health 8 literacy skills of a 10-year old. And if you 9 look at most informed consent forms that people 10 sign, they are way beyond that. They're 11 graduate level reading skills required. 12 I don't think it's just that we need written 13 consent from people, somebody should go through 14 the form with them and say, "Have you got any 15 further questions? What does this mean to you?" 16 Those sorts of open questions.</p> <p>17 MS RICHARDS: Then the next question is about care 18 plans for treatment. What are the benefits, the 19 psychological benefits, of having an agreed care 20 plan and of having input into that care plan as 21 an individual?</p> <p>22 DR THOMAS: So an important benefit from that is 23 that the care plan is individualised to that 24 patient's needs, and if it's been drawn up as an 25 effective care plan, the patient or, you know,</p>	<p>180</p> <p>1 the impacted or infected person would be party 2 to that, so they would be collaborating in 3 developing that care plan and identifying their 4 needs. Because as we said before, they are the 5 expert in terms of their physiological and 6 psychological needs. So it's important that 7 they are saying to us what it is. And of 8 course, added to that is a medical and nursing 9 dimension that goes into that, as well. But 10 a care plan is useless if you don't have signed 11 and -- sort of collaboration from the person who 12 is going to be impacted on.</p> <p>13 PROFESSOR CHRISTIE: I was just going to say very 14 quickly, in terms of adherence or concordance, 15 which is a phrase that we prefer, where people 16 are part of their medical treatment, you're much 17 more likely to get people to take their 18 medication more regularly, you're more likely to 19 get people to follow recommendations for 20 physiotherapy or any -- anything that you ask 21 somebody to do, if they have created 22 a co-created care plan, then the chances of that 23 happening then are much, much higher than if you 24 don't have one.</p> <p>25 MS RICHARDS: The next question is about</p>

<p>1 psychological impact again. And it's this: 2 would you expect there to be an additional 3 adverse psychological impact for someone who has 4 been infected as a result of treatment that 5 wasn't for a life-saving event, but may have 6 been treatment that wasn't essential or even 7 appropriate because they'd been misdiagnosed or 8 because they were, for example, a mild 9 haemophiliac for whom other treatment methods 10 were well established. Is an additional sense 11 of injustice or harm that people in those 12 situations might experience? 13 PROFESSOR WEINMAN: I don't think there's any direct 14 evidence on that, because that was something 15 I was interested in. It was brought up by one of 16 the questions you gave us. 17 Off the top of my head one would say yes, it 18 is most likely. But as we said yesterday, you 19 know, with additional problems, you don't 20 necessarily get additional or some sort of 21 linear psychological impact. So terribly 22 difficult to answer. And my sort of gut, you 23 know, from what I read and what I've read around 24 it is yes, you would expect that, because of the 25 sort of shock and all those other issues that</p>	<p>181</p> <p>1 came out of something that was possibly 2 unnecessary. 3 MS RICHARDS: Then again we explored yesterday 4 a number of different psychological and indeed 5 psychiatric impacts arising from illness and 6 treatment and so on. Does the risk of those 7 impacts also include the risk of other harmful 8 behaviours such as addictions or behavioural 9 issues? 10 PROFESSOR WEINMAN: We certainly heard that from 11 some of the witnesses. You know, because 12 it's -- we talked about illness having an impact 13 on, you know, one's sense of oneself and so on 14 and how one deals with that. And the ways in 15 which one deals with the sort of demands that 16 are on you now can vary hugely, and this sort of 17 heading of what we call coping. So, you know, 18 a large amount of coping is attempting to deal 19 with things directly, but a lot of coping is 20 around dealing with things that actually you 21 can't change, or you can't prepare yourself, or 22 whatever. It's out there, it's some enduring 23 problem. 24 And I think a lot of people go for a sort of 25 an avoidant type of coping which might involve</p> <p>182</p>
<p>1 blanking oneself off, you know, turning towards 2 alcohol, turning towards comfort eating, turning 3 to whatever it is to, you know, avoid that 4 awfulness that's in you. And it's all part of 5 that avoidant type of coping that we talked 6 about that can be very harmful in the long run. 7 MS RICHARDS: Dr Thomas, yes. 8 DR THOMAS: There is this existing literature in 9 NICE guidance suggesting that people with 10 physiological long-term health problems, so 11 chronic health problems that a haemophiliac or 12 hepatitis C or HIV already have, what we call -- 13 they are twice if not three times more likely to 14 be psychologically depressed. So this is the -- 15 again, it's a background. And many people are 16 not necessarily aware that they're depressed, 17 but there's a low level of depression that's 18 there. And some people are really quite 19 severely depressed, which then interferes with 20 people's motivation, ability to live life, then 21 they might turn to other means of coping, like 22 drugs and alcohol and so on and -- as a way of 23 coping. But I think it's something that -- when 24 I was doing this work, I was thinking really, 25 that we already -- people are already</p> <p>183</p>	<p>1 compromised because of having to cope with two 2 long-term conditions. 3 MS RICHARDS: Ms Edwards. 4 MS EDWARDS: We mustn't forget as well that the 5 things that we're dealing with are also 6 extraordinarily painful, so we're dealing with 7 haemophilia, which can be very painful, for men, 8 for women with von Willebrand, we know there are 9 people with haemophilia who are women as well, 10 these are very, very, very painful situations. 11 HIV also can be a very painful debilitating 12 illness, the treatments that go with that. Then 13 you've got your hepatitis C treatments that come 14 in on top of that. There's an enormous amount 15 of treatments. Drugs and alcohol take some of 16 that pain away, as well as the psychological 17 pain. It would be very unsurprising in many 18 ways that people don't turn to those methods of 19 relief. 20 MS RICHARDS: Then moving on to the theme of 21 communication, some of the evidence we've heard 22 suggests that people were given their diagnosis 23 or information about their diagnosis either in 24 a group setting or in a non-confidential setting 25 of some other kind, being -- something being</p> <p>184</p>

<p>185</p> <p>1 called out across a corridor or a clinic. Is</p> <p>2 that appropriate, and what are the psychological</p> <p>3 consequences of it?</p> <p>4 DAME LESLEY: I don't think any of us even need to</p> <p>5 answer that directly, but just -- I mean, I was</p> <p>6 totally shocked at the number of reports that we</p> <p>7 read where people had been told what had to be</p> <p>8 life-shattering information in the most callous,</p> <p>9 insensitive manner, with a total lack of</p> <p>10 privacy. I mean, to be told the sorts of</p> <p>11 information -- particularly as we also have the</p> <p>12 backdrop of, you know, the stigmatisation, the</p> <p>13 lack of knowledge about things such as HIV/AIDS</p> <p>14 and Hep C at the time -- to be told that in</p> <p>15 a corridor, to be told it on the telephone by</p> <p>16 a receptionist in a GP surgery, that just</p> <p>17 violates every principle of common decency, let</p> <p>18 alone sort of how medical professionals should</p> <p>19 behave.</p> <p>20 [Applause]</p> <p>21 This is starting to feel like Question Time!</p> <p>22 The other thing, actually, on a serious note</p> <p>23 that I feel sort of is really important to sort</p> <p>24 of say here, and that is that we've already</p> <p>25 mentioned that part of the process of coping</p>	<p>186</p> <p>1 with a serious diagnosis that's got prognostic</p> <p>2 sort of implications, lifestyle implications for</p> <p>3 you, part of the, you know, thing that we should</p> <p>4 always do to help people is give them some</p> <p>5 warning. Fire a warning shot. The realisation</p> <p>6 that you have a life-changing diagnosis, that</p> <p>7 you're going to have expectations, sort of no</p> <p>8 longer -- realise that you're going to need</p> <p>9 lengthy treatments, and a lot of this might</p> <p>10 never get better. That's a process, and it</p> <p>11 needs to be done over time with the right</p> <p>12 pacing, with the right sort of information, at</p> <p>13 the right level of complexity for the person in</p> <p>14 front of you. And no one should ever be told</p> <p>15 a serious diagnosis like this by somebody just</p> <p>16 who happenstance to come across the information.</p> <p>17 People lying on trolleys in an A&E department</p> <p>18 being told, "Oh, I think we're dealing with</p> <p>19 full-blown AIDS here", I think I remember</p> <p>20 reading one transcript. That is just utterly</p> <p>21 totally unacceptable. I'm sure that no one</p> <p>22 could ever forgive somebody who did that to</p> <p>23 them.</p> <p>24 And you will find, certainly in the world of</p> <p>25 cancer, which is primarily my area, people will</p>
<p>187</p> <p>1 recall verbatim the words that somebody used</p> <p>2 when it was done insensitively. Bad news is</p> <p>3 always bad news. You can't make it good news if</p> <p>4 it's bad, but the way in which people receive it</p> <p>5 is totally dependent on the person who's</p> <p>6 actually giving it.</p> <p>7 MS RICHARDS: Sir, I'm going turn my back and see</p> <p>8 whether there are any other pressing matters</p> <p>9 which legal representatives would wish to have</p> <p>10 raised.</p> <p>11 No one, I'm happy to report, is popping</p> <p>12 their hand up, so those are the questions I had,</p> <p>13 sir.</p> <p>14 SIR BRIAN LANGSTAFF: I have one, but it's</p> <p>15 a question which is addressed -- although I'm</p> <p>16 putting it to all of you, it's one which you may</p> <p>17 prefer, in due course, to answer individually.</p> <p>18 I'm not asking you to answer it now, for reasons</p> <p>19 which I shall explain.</p> <p>20 You've given a lot of thought and a lot of</p> <p>21 suggestions, and you've demonstrated a number of</p> <p>22 important changes that there might be, which</p> <p>23 would make matters -- would improve the health</p> <p>24 service, would help to make sure that something</p> <p>25 like this never happens again. Could you please</p>	<p>188</p> <p>1 just think of the single biggest improvement you</p> <p>2 think could be made to stop this happening</p> <p>3 again.</p> <p>4 Secondly, the second part to the same</p> <p>5 question is I've asked what could be made,</p> <p>6 should be made. There may be a difference</p> <p>7 between those two. But it may be very much an</p> <p>8 individual reaction to that. If it's</p> <p>9 a collective reaction, that's fine. But it is</p> <p>10 your expert views which I'm looking for.</p> <p>11 PROFESSOR WEINMAN: Now?</p> <p>12 SIR BRIAN LANGSTAFF: I'm going leave that with you</p> <p>13 and it can be answered with the supplementary</p> <p>14 questions.</p> <p>15 PROFESSOR WEINMAN: Okay.</p> <p>16 SIR BRIAN LANGSTAFF: But can I now let you into</p> <p>17 a bit of a secret. When we were planning, we</p> <p>18 thought that the evidence overall that you would</p> <p>19 give would last a little bit into this</p> <p>20 afternoon, and we're very glad that it did</p> <p>21 because we were worried that we might not get</p> <p>22 full value from Dame Theresa and her</p> <p>23 availability. I'm very glad to say we have</p> <p>24 done. But the reason it's gone on beyond the</p> <p>25 16.30 -- I'd better not make it too late, but</p>

<p>189</p> <p>1 we've had, is because it has been so valuable, 2 and indeed, leading counsel said to me at the 3 last break that she might go on, but I'm very 4 happy that that should be the case, because 5 I don't think there's -- I think it's unlikely 6 to be any one of us who has not found your 7 evidence riveting, not found it resonant with 8 many people who are here.</p> <p>9 It has certainly added a dimension to the 10 evidence that we've heard over weeks from and 11 about those who have been infected or affected 12 by the infection of others, and when it comes to 13 communication, you have demonstrated how it 14 should be done, in your own way.</p> <p>15 So can I thank you very much for that. 16 You've shown us as well, I think, the proper 17 place of your expertise. It isn't an add-on, it 18 certainly isn't airy fairy, as one of you put it 19 earlier, but it seems to me that you've made the 20 most powerful case there could be for it being 21 an integral part of care. Because it meets 22 a need. Not just the -- well, a need for just 23 that sort of care. For those -- and you've 24 emphasised this too -- for those who want to 25 take advantage of it, because you've emphasised</p>	<p>190</p> <p>1 the importance of choice.</p> <p>2 Can I thank you enormously for that, and all 3 the more so because I know that you have busy 4 lives. I know that for instance -- and I'm 5 singling out one only, the same probably applies 6 to all of you -- but Professor Christie, this is 7 her day off, would you believe? And this is how 8 she spends it, instead of with her 2-year old 9 grandchild. So that is a sacrifice, I can tell 10 you.</p> <p>11 PROFESSOR CHRISTIE: Am I allowed to say that for me 12 personally it's been an enormous privilege to 13 have been part of this process, and I would like 14 to thank everybody for allowing me to have taken 15 part in this. I've been really, really moved, 16 and it has been a tremendous privilege, and 17 I feel very inspired.</p> <p>18 SIR BRIAN LANGSTAFF: Well, the privilege is ours. 19 Thank you.</p> <p>20 Well, Ms Richards. Tomorrow?</p> <p>21 MS RICHARDS: Hepatitis, sir.</p> <p>22 SIR BRIAN LANGSTAFF: And 10.30. 23 (4.43 pm) 24 (Adjourned until 10.30 am the following day) 25</p>

<p>DAME LESLEY: [35] 38/24 42/12 56/6 73/19 82/3 83/11 91/25 100/12 103/3 106/22 106/24 108/9 109/8 109/12 111/20 116/12 119/5 127/22 130/3 131/18 134/6 135/13 137/2 146/21 149/3 156/3 162/12 167/3 172/7 173/9 173/19 177/14 178/23 178/25 185/3 DAME THERESA: [10] 103/15 117/25 130/19 160/3 161/22 168/24 171/11 173/5 173/10 174/16 DR THOMAS: [21] 4/10 41/14 45/2 52/4 53/22 76/15 104/10 111/1 115/7 120/14 127/10 143/2 146/19 146/22 151/2 152/7 154/23 155/15 163/7 179/21 183/7 MS EDWARDS: [21] 15/17 19/11 19/14 43/11 60/3 60/7 63/25 65/21 66/2 66/5 75/23 77/12 85/4 86/22 96/22 126/11 126/13 126/22 144/18 146/20 184/3 MS RICHARDS: [116] 2/7 3/5 6/11 8/13 9/15 16/6 20/3 21/2 21/17 22/11 27/4 27/11 28/12 29/14 29/18 30/21 31/8 32/22 33/1 33/21 35/1 35/13 36/2 38/11 38/15 40/7 41/25 44/2 44/23 45/22 46/2 46/8 53/2 53/9 53/23 57/5 59/22 60/6 63/24 65/17 65/22 66/4 66/8 68/2 68/7 73/9 76/14 78/9 82/19 86/8 86/24 92/14 92/25 93/9 93/13 95/18 96/3 97/20 99/25 103/14 104/8 106/12 106/23 108/4 108/25 109/9 110/25 111/13 115/6 116/1 117/24 118/16 120/12 123/16 123/20 126/12 127/21 129/13 130/17 131/9 133/22 134/23 136/4 139/4 139/22 140/7 141/1 142/18 146/15 150/1</p>	<p>150/25 151/17 154/3 155/10 156/2 157/11 160/1 161/1 161/21 162/5 162/25 165/14 167/24 171/1 172/6 175/9 177/6 178/16 179/16 180/24 182/2 183/6 184/2 184/19 187/6 190/20 PROFESSOR CHRISTIE: [40] 2/20 3/17 6/21 8/19 21/11 21/14 22/25 27/10 27/14 28/15 29/17 29/20 31/7 31/10 32/25 33/2 45/10 55/16 69/24 74/11 83/21 90/13 101/14 103/4 112/19 121/22 123/19 140/16 141/7 147/13 150/11 157/12 161/6 164/10 165/20 165/22 176/17 178/24 180/12 190/10 PROFESSOR MORGAN: [19] 19/13 19/15 34/9 35/8 35/22 41/2 43/2 44/15 59/11 66/20 68/6 75/8 81/17 83/10 86/9 92/15 95/15 95/24 96/18 PROFESSOR WEINMAN: [23] 2/16 4/24 14/15 20/21 21/21 37/18 38/14 38/23 49/22 53/8 71/19 98/8 100/10 115/5 120/24 124/16 126/21 137/4 165/21 181/12 182/9 188/10 188/14 SIR BRIAN LANGSTAFF: [17] 1/2 20/22 21/3 21/13 21/15 45/25 46/3 93/3 104/24 139/18 139/25 140/6 187/13 188/11 188/15 190/17 190/21 'AIDS [1] 81/3 'Blah [1] 123/8 'fessed [1] 128/12 'It [1] 79/24 'patients [1] 14/8 'ripple [1] 14/6 - -- well [1] 98/13 ... 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