Wednesday, 30 October 2024

(10.00 am)

LADY HALLETT: Mr Fireman.

MR FIREMAN: Good morning, my Lady. Can I please call Lesley Moore, who will affirm. Hopefully she can hear us.

MS LESLEY JEAN MOORE (affirmed)

Questions from COUNSEL TO THE INQUIRY

MR FIREMAN: Can you provide your full name, please, Ms Moore.

A. Lesley Jean Moore.

Q. Ms Moore, you have given a witness statement to the Inquiry dated 13 June 2024. That's INQ000485656. I hope you're familiar with this and have a copy available to you.

Ms Moore, thank you very much for giving evidence today. You're here to provide evidence of your experience of shielding and your experience of your son shielding, who is clinically extremely vulnerable; that's right, isn't it?

A. Indeed.

Q. To start, can you please tell the Inquiry a little bit about your son and his needs.

A. I adopted my son when he was three years of age, however.

Q. Sorry, could you just slow down a little.

LADY HALLETT: We're having difficulty hearing you. I don't know if it's something to do with the audio but if you could start again. I'm really sorry.

A. I adopted my son when he was three years of age. I have known him since he was 18 months of age as I was his senior portage worker which is a home school teacher for children with complex and difficulties, special needs.

I had originally had him on respite care at weekends and then he came home to me when he was three and a half. He had very complex cerebral palsy, made more complex by the fact that he has dystonic cerebral palsy on his left-hand side, which means he has lots of involuntary movements going on, and he has spastic cerebral palsy on his right-hand side, which means that he had very tight movements, which means his body is pulled all over.

When I first had my son he was screaming a lot and wasn't sitting in any seating of any sort and was a very disabled little boy, and it took a number of years for us to get him to sit in any sort of equipment, and now he is sitting in a wheelchair, with lots of physical support. He can't lie on a bed unsupported, he needs positioning equipment on either side, and overnight he lies on a specially made sleep system and he lies on his

stomach, which allows for his movements and enables him to wear a CPAP mask overnight of the ventilator machine due to his obstructed breathing overnight.

He has very complex, severe learning difficulties and he is gastrostomy fed, nil by mouth, and this has been since he was about 12.

In 2015 he went down drastically and was likely to end up with a tracheotomy, but at the time his quality of life was so poor that that was decided not to be the answer, so he came home literally in 2015 to die. However, now he is a very different young man. Although he still has all his very complex needs he has been much healthier, apart from the last year where his health has taken a dip again with chest infections and increased epilepsy.

When he is ill, all of his movements, all of his vulnerable movements, all of his involuntary movements, everything increases and he gets into dystonic sort of spasms which become very, very painful and he's very difficult to physically manage when he is ill.

One of his major issues is his suctioning needs and he has two types of suctioning needs. One would be maintenance suction, where you're just taking out little bits of pieces with a suction machine, any secretions, or we have what we call "blue light" suctioning, which

is where you don't know what the outcome will be, during the suction you don't know whether he will still be alive at the end of the suctioning. But he has very complex needs.

MR FIREMAN: Thank you for summarising that so eloquently. In addition, it's right, isn't it, that your son is non-verbal?

A. Yes, non-verbal. He takes at least nine months to a year to understand his movements and his noises. He can communicate. He can choose from, sort of, objects. If you were to give him a pair of swimming trunks and car keys, he would more or less know that he was going out in the van or he was going -- well, actually he wouldn't know he was going swimming but he would when you were by the pool. He has very complex learning difficulties. And it takes a good nine months to a year for any member of staff to have any real understanding of what he's telling him, what he's trying to portray.

Q. You've just mentioned how long it takes for a member of staff to understand his movements and his communication style. In pre-pandemic times what were the specific care arrangements which were in place?

A. I have -- or my son had a personal health budget and there were two members of staff at that time who were employed who came in and did a number of day shifts,

which would be putting him to bed, getting him up and working with him during the day, and I think they were working about two evenings, overnights, a week.

Q. In your statement I think you make clear that he needs two care staff with him at all times except for if it's you who is looking after him?

A. Yes, when he's at home and it's just me then he -- it's one to one. Because of the 22 years of having him, I know if he's smiling in another room just by the sound of his breathing, whereas if he's at day centre, respite at home, he's on 2:1 support. And that's mainly for his suctioning needs and his moving and handling needs.

Q. Taking you back, Ms Moore, to the start of the pandemic in March 2020, you make clear in your statement that you became very concerned about the risk to your son, and you decided on 11 March 2020 to take him out of school; is that right?

A. He was at college at the time. It is. Because of his very, very complex needs, when my son is poorly he goes into all this dystonic panic, which very painful, it increases his suction needs and puts him at great risk. I was very aware, especially as Covid was coming as a coughing disease, that my son would be exceedingly difficult to manage because of this. And on 11 February I had close contact with another parent of a young man

with special needs and we were starting to contact each other as news was coming through, because her son also has respiratory issues, and on 11 February we'd seen somebody talking about a pandemic coming.

By 29 February 2020 we were talking about whether we should send our sons to college.

On 3 March I was really, really stressed about it, what was going to happen.

On 11 March I was sat in the college car park after just dropping my son off at college and I heard Michael Rosen, the poet, talking on the radio about how the elderly were going to be left to get on with it and that they were like lambs to the slaughter, that they wouldn't be being looked after, they would just be seen as of no concern. And as I was sat in the college car park I was just thinking: this is exactly what's going to be for my son. His needs pre-pandemic aren't even taken into account on many occasions, and he's not valued by many in society, I really felt that he would not be valued during the pandemic.

So on 11 March I made that decision to lock him down ourselves. And I'd already been out and shopped and did things that I needed to do to keep him at home from that point.

I did contact the GP surgery and asked for advice

and the advice was: just follow government advice. I then said there was no respiratory advice, and she just said, "Wash hands and wait and see."

On 13 March I then rang and asked the ventilation team at the local hospital what I should do and I got an email back saying: follow online National Health Service advice. Again, there was no respiratory advice specifically for those with respiratory issues.

Q. Thank you, Ms Moore. If you could just try to keep your answers a little bit shorter, we may be able to get through all of the information we need to.

So just in terms of the timeline, we were talking about March 2020, and you spoke about how you decided to take your son out of college. What did you decide to do with respect to the care staff who were attending your house ordinarily to look after him?

A. Because I knew that they were -- one member of staff had a young son who was going around family members for childcare and the other member of staff was still attending social events and still shopping, I decided that with -- also discussing it with his disability social worker, that I would stop the staff members coming into the house. So I then did my son by myself for four months.

Q. Am I right that, given your son's complex needs, you

expected that he would be designated by the government as clinically extremely vulnerable?

A. I did.

Q. Did you in fact receive a letter from the government indicating --

A. I did eventually. I registered him myself on the government clinically vulnerable website page on 23 March and it was only six weeks after I'd locked down on 23 April that I got a clinically vulnerable letter.

Q. You then began to shield, I understand it?

A. I did.

Q. And can you tell us a little bit about your experience just you and your son shielding for a number of months initially until --

A. Luckily because I come from the profession and have worked alongside physios and occupational therapists and speech language therapists that I was able to continue many of my son's college activities and postural needs at home.

Really it was just surviving, day-to-day surviving. It's very hard being in a house by yourself with your son 24 hours a day.

Q. Just take a moment.

What was the impact on you then of that additional care and responsibility?

A. It's the total responsibility that you are responsible for your son and your son's needs and the fact that at the time I really did not think the government cared about my son's needs.

Q. In June 2020 were you able to re-introduce the personal support workers to support you and your son?

A. I did but very, very slowly and carefully because it was better weather, and then they came back and they worked in the garden and they were masked up and were trying to stay within 2 metres of him but doing singing and dancing activities and throwing balls and things, not that he can catch a ball but helping him and things, to try and keep him as Covid safe as possible so that I could have 2 hours to myself at a time.

It took quite a long time before they were back in doing care. That would probably be a lot longer later on that they were actually back in doing personal care.

And I used to write Covid guidelines every week that I had made for myself to keep him safe which was all doors and windows open, they had overalls that they put on so that they weren't coming in in their outdoor clothes or if I knew they had been anywhere else I had asked them to bring a change of clothes so they weren't bringing it in with them.

Q. When you say they were masked up, is it right that you

requested that they wear the FFP3 respiratory masks?

A. They were provided FFP3 masks but I very quickly, after researching the FFP3 masks that we were given, realised that they had valves and the valves allowed the staff to breath out their air which meant that my son wasn't being kept safe. My son was going nowhere, we were going nowhere, my son was the one that would have no Covid and so he could not possibly give Covid to anybody whereas the staff were coming in from elsewhere but were given masks, they went off to have them fitted, that had valves which meant that the air would be or any Covid that they had would travel through the valve to my son.

Q. During the periods of time where you were shielding, did you and your son leave the house at all?

A. Not for the first 40 days and 40 nights. I have a horse, or had a horse at that time, and I had put her on full livery because she's 7 miles away and it's not -- with my son it's not just the fact that you're catching Covid, it's what happens if your car breaks down 7 miles away, how on earth do you get him back because there aren't sort of adapted taxis that are easily available or if you were getting in an adapted taxi you were still putting him at Covid risk, so it was a lot more than just catching Covid that somebody with my son's level of special needs we had to take into

account.

I had made -- he had a special off-road buggy but he can't -- couldn't sit in it very well but I was trying very hard to make it very safe for him to sit in so that if I did go for a walk and anything happened that I could physically put him back but, in the end, he had a suctioning episode sat in the buggy in the back garden and it became obvious that I wouldn't be able to physically manage him so that was put on hold. I didn't do it.

Q. Ordinarily, is it right that you would have had quite a lot of interaction with healthcare services prior to the pandemic?

A. I wouldn't say a lot of interaction but then you would never have known -- just like now we're having quite a lot of interaction with healthcare services, but we would now avoid going to healthcare services wherever possible because of the nosocomial risk of Covid.

Q. And during the relevant period is it right that you did everything you could to also avoid going to healthcare services or hospital?

A. We wouldn't be going anywhere because the risk was just too great. My son cannot mask because of his involuntary movements so it's very hard to manage him anywhere because he cannot mask.

Q. You describe in your statement a particular occasion where you received correspondence from a hospital requesting the return of any spare ventilation machines or CPAP machines or feed pumps. Can you describe this interaction for us and the impact it had on you?

A. I cannot remember whether it was a letter or a phone call, but we were all asked to return any spare ventilating machines or feed pumps.

At the time my son had two ventilator machines, one that he was using and one as a spare. Because of all the things that had been happening in the background that we'd heard of that various factories were being asked to make ventilating machines, that we weren't procuring them from Europe, ventilating machines, that I really felt that if I sent the spare ventilating machine back and then the one that he was using broke down I truly felt that he would not get a ventilating machine back because they wouldn't have any spare, so I kept hold of them both.

It was a major, major concern in all the special needs groups that I'm in online about the fact we were being asked to return equipment and we all really felt or a number of parents and myself felt that if my son was to turn up at hospital requiring a ventilating machine that if there were three other people and him

that he probably would not be the person that got the ventilating machine.

Q. Can I ask you about --

A. [Unclear: multiple speakers].

Q. Sorry. Can I ask you about another experience that you had interacting with the healthcare system, something that you describe in your statement as particularly harrowing, and this is in relation to receiving a letter which suggested that a DNACPR be put in place for your son. Is it right you received this letter in around July 2020?

A. As far as I can recollect it was around 19 July. I believe it was then -- I don't have the letter still -- but I believe it was around then because again I have close contact with a number of other special needs parents and we were discussing our feelings and views around this and were absolutely horrified.

Q. Can you remember in general terms, I appreciate you don't have the letter in your possession anymore, in general terms, can you remember what the letter said?

A. I cannot remember in general terms, all I can remember and all I remember discussing was that what we would do about the do not resuscitate and we all felt that what that letter was saying was that we're not going to take care of your young person's medical needs if they needed

to be.

Q. From what you're saying, is it right that a DNACPR is not something you would have wanted to have in place for your son?

A. That gets much more complex because if my son had got to the level of needing to not be resuscitated I felt he would have been so poorly anyway. Our discussion and our beliefs were that we wanted our sons and daughters to be treated far earlier so they did not get to that level of needing do not resuscitate CPR.

Q. Did you ever have any further conversations with the healthcare services about the potential for a DNACPR or anything around --

A. I can't remember. However, I did definitely get a letter on 16 May where I was asked to write down all of his needs so that he could go to hospital without me. There was no way, knowing how my son is and the fact it takes nine months to a year for my son to go anywhere without me, that he could have gone into hospital without me. He's had two recent admissions to hospital this year and on both occasions it has shown that if he did not have the one-to-one person that knows him really, really well, that his life would be put at greater risk by being in hospital, due to the lack of equipment to meet his needs. And I'm talking about his

physical needs that he usually has at home, like his sleep system, a high enough overhead hoist to get him onto the sleep system, and all the equipment that we have at home to manage his needs.

Q. How did receiving this correspondence impact your confidence in the healthcare system?

A. There was no confidence in the healthcare system at that time. I had many conversations about the fact that I would be keeping him at home because I did not feel that he would be treated safely in hospital because of his complex needs.

Q. Separately, you discuss in your witness statement a more positive experience that you had with the healthcare services in relation to your son's wheelchair breaking down. Are you able to elaborate a bit on this?

A. They were very quick to come and fix it and they were very happy, we have an outdoor balcony that has a lift at the back and they were very happy to fix the wheelchair on the back, on the outdoor balcony. They were masked up and they disinfected it and I was able to leave the wheelchair outside for 30 minutes until we brought it back in because he was able to be able to be lying on his bed and I was able to watch him whilst they were repairing the wheelchair.

Q. Overall, how long were you shielding for?

A. Because of his very complex needs he's one-to-one or actually two-to-one in a room at college, he didn't eventually go back for 18 months. We were fully shielding for the first four months, then staff came back, then the December in 2020 the staff went off again for three months. We were vaccinated in February '21, first vaccine', and then he eventually got back to college in September 2021. And although it's not health, the local authority were trying to take off his educational and health and care plan whilst he was away from college, they were trying to cease his educational, health and care plan which also added increased stress.

Q. Longer term, I appreciate you've described earlier on the extent of your son's complex needs and what they were like prior to the pandemic. Have you been able to identify any significant changes in him as a result of shielding or as a result of the time that's passed since the beginning of the pandemic?

A. He would have been greatly helped by having physio throughout the pandemic and when we were shielding at home. I did the best that I could. He managed well but he's delighted to be back into his routines, he's very keen on seeing his carers and people at his present day centre and he thoroughly enjoys going out. There were moments in the pandemic or the pandemic when we were

locking down where he would start to cry uncontrollably for no apparent reason and that doesn't happen anymore.

Q. Is it possible to say then that this period had an impact on his mental health as well as potentially his physical health?

A. It's very hard with my son to say how much it impacted him but he was definitely -- he was very excited -- if I put his coat on to go outside in the garden and we went near the car he would be very, very excited thinking he was going out in the car out and about and then would get very upset, distressed if we then didn't get in the car. He couldn't understand why we weren't going anywhere, seeing anybody or doing anything.

Q. From your perspective as a carer for someone with such complex needs, what has the long-term effect been on you?

A. For me physically I have a very sore hip now, very sore wrists, and back issues that I did not have before the lockdown and dealing with my son daily. For me the mental health came from the fact that I felt very, very let down by not having a competent government at the time. I felt very unsafe and I did not feel that there was anybody really looking out for our needs as clinically vulnerable people and I still feel that to some extent.

Q. As someone who has had the experiences you've described are there any particular recommendations which you have from your perspective that you'd like to raise with the Inquiry?

A. For me the main thing is that we still are clinically vulnerable, my son and I are still shielding to some extent. We aren't going anywhere indoors that isn't at home or his day centre. I will go in shops but I'm masking in shops and also I still feel he's being put at great risk by having to go into hospital for treatment for things because I really don't think that we're fully understanding what clinically vulnerable is and nor are we making allowances for clinically vulnerable people.

MR FIREMAN: My Lady, those are all my questions for Ms Moore.

Thank you very much, Ms Moore, for attending.

I don't know whether you have any questions, my Lady.

LADY HALLETT: No, I have no questions.

Ms Moore, thank you very much indeed for your help with the Inquiry. I can't imagine what your life is like on a normal basis let alone during lockdown on your own.

THE WITNESS: It's been an absolute pleasure.

LADY HALLETT: Well, you've done an extraordinary job

looking after your son who is lucky to have found you and by the sounds of things you're lucky to have found him. Thank you very much indeed.

(The witness withdrew)

MS CAREY: My Lady, the next witness is going to be Ms Natalie Rogers.

MS NATALIE ROGERS (affirmed)

Questions from LEAD COUNSEL TO THE INQUIRY for MODULE 3

MS CAREY: Ms Rogers, your full name, please.

A. Natalie Rogers.

Q. Mrs Rogers, I think you've come to give evidence today as a founding trustee of Long Covid Support; is that right?

A. That's correct, yes.

Q. And Long Covid Support is one of four organisations that collectively make up the Long Covid core participant group?

A. That's correct, yes.

Q. The other organisations in the group are Long Covid Kids; is that correct?

A. Yes.

Q. Long COVID Physio?

A. Yes.

Q. And Long Covid SOS?

A. That's correct, yes.

Q. And I'll just, if I may, at the beginning give a little background to those four organisations. Obviously you can speak to Long Covid Support but, where you feel able, please tell us about the concerns of the group as a whole, as we go through your evidence.

A. I will do.

Q. I think you have in front of you your statement ending 370954, and we may call that up on screen if we need to look at various parts of it.

A. Okay.

Q. The four organisations I think together represent tens of thousands of adults and children who have suffered life-changing illness or disability following infection with Covid; is that correct?

A. That is correct, yes.

Q. And Long Covid Kids was established in September 2020, and supports over 11,000 families, with advocating for those families and the children and young people with Long Covid?

A. They do, yes, although there's probably more children affected than that.

Q. Understood. And I think, in fact, Long Covid helps those anywhere in the world, not just the UK?

A. Long Covid Support, you mean?

Q. Long Covid Kids?

A. And Long Covid Kids, yes.
Q. Long COVID Physio was formed in November 2020 to connect physiotherapists and allied healthcare professionals who are living with Long Covid.
A. That's correct, yes.
Q. And Long COVID Physio has over 25,000 Twitter followers alone, and the statement sets out the number of times that the Facebook group and online videos have been watched. I think there's been more than 1 million online videos watched by people suffering with Long Covid and wanting to understand more about Long COVID Physio?
A. Yeah. And if I could just say, the numbers in the statement referred to, in terms of the membership and following of all the groups, were correct at the time but continue to increase.
Q. Yes, you are quite right, Mrs Rogers, the statement was dated 28 November 2023, so 11 months ago now?
A. The numbers have increased substantially since then.
Q. Understood. Long Covid SOS was established in June 2020 as a volunteer-run patient advocacy and campaign group, and advocates for recognition, research and rehabilitation for people affected by Long Covid.
A. It does, yes. And those are the kind of core principles of what the Long Covid groups were advocating for

throughout the pandemic for people affected.
Q. And then Long Covid Support began as a peer support Facebook group in May 2020 and in fact now is a registered charity, as of May 2021, and Long Covid Support has 62,500 members globally?
A. Again, that was correct at time of writing.
Q. As at November 2023.
A. Yes.
Q. Right.
A. Long Covid Kids and Long Covid SOS are also registered charities.
Q. Thank you. And I think you make the point in your statement that those four organisations are mostly led by people that have Long Covid or are caring for those with Long Covid?
A. That's true. There are also people involved in the organisation who are interested in either, you know, furthering research or clinical care for people with Long Covid.
Q. Can I ask, please, that we call up on screen INQ000370954_5, please, and paragraph 1.14.

Ms Rogers, if it's easier for you to look on the screen rather than put your head down into the statement, all well and good. But I just want at the outset if I may, through you -- sorry, shall I give the

number again?

INQ000370954_5. Thank you very much. And if we could highlight paragraph 1.14. Thank you.

I think just at the outset of the statement you very helpfully set out overarching concerns of the core participant group and you say this:

"From our first-hand experience and the experience of our members, those who were suffering from Long Covid struggled for recognition; they struggled to access appropriate care, diagnosis, and treatment during the relevant period. Many people report that their physiological symptoms were routine disbelieved and disregarded by healthcare professionals and instead, often attributed to a psychological cause. In our view, there was a damaging delay in the UK's healthcare system recognising and responding to Long Covid."

And although this was written back in November 2023, do they remain the concerns of the Long Covid core participant group today?
A. That remains part of our concern, yes.
Q. Right. Now, we have heard from experts about what is Long Covid so I'm not going to ask you about that, please, Mrs Rogers, but I'd like to start, really, with the recognition and diagnosis of Long Covid as

a condition.
A. Okay.
Q. And I think you say in your statement that there was a significant delay in the UK's healthcare sector recognising and responding to Long Covid.

Can you give us an indication of how long the delay was and the kind of impact that delay had.
A. Okay. So our experience and the experience of our members and, you know, other people that we hear about through, you know, social media, et cetera, was very much that it just wasn't recognised, at all, that there was any possibility of ongoing symptoms as a result of Covid-19 infection.

So, from the very early days there was this very pervasive and damaging misconception that, particularly if you were a non-hospitalised patient, Covid was going to be a very short, mild, flu-like illness. There was absolutely no mention of the possibility of there being any long-term illness at any stage throughout the pandemic in the daily briefings that people were watching on the television. So, you know, for us, as people that did not recover within that expected two-week time frame, we wanted to raise the alarm that you weren't necessarily going to recover.

There was no recognition of the fact that if you

were previously fit and healthy or if you were a child or a young person there was any chance that you were going to develop serious health issues. Which, you know, to me, seemed very counterintuitive. There's been a long history of post-viral illness. It's not a new concept. We've had Spanish flu, we've had SARS, we've had MERS. Yet the experience of people seeking healthcare, particularly in the early days, was that you couldn't possibly have ongoing symptoms as a result of a Covid-19 infection. You were met with, you know, "Well, it's -- two weeks has passed, it should be better", was kind of the response that you got.

Q. I think you say in your statement that your organisations received many reports of patients' physiological symptoms being disbelieved and minimised by healthcare providers, and I'd like to ask you, please, about one of the surveys that was conducted, I think by Long Covid SOS.

But could we have up on screen page 14 of INQ000370954.

This was a survey Mrs Rogers conducted in September 2020, so about six months in from the start, and if we look at paragraph 3.5 we can see there some of the difficulties encountered by adult patients when contacting their GPs, reporting the symptoms. And it

included 33% --

"33.3% of respondents stated that their GP was willing to accept long-term symptoms were a feature of Covid-19 but was unaware of any steps that could be taken to alleviate them."

A. Yes, so it was certainly my experience. I met with a number of different GPs in my attempt to access healthcare, and I went through quite a few before meeting with one that was actually willing to accept that the ongoing symptoms that I was experiencing could be due to an acute infection with Covid.

Q. This was a UK-wide survey, I think with 271 respondents to it, most of whom were for England but there were respondents from Scotland, Wales and Northern Ireland as well, and most of the respondents were females --

A. Yes.

Q. -- to this survey?

A. Possibly because females are more likely to respond, in terms of wanting to get that information out there to share their experience and protect others.

Q. I think we heard from the experts yesterday that women are actually more likely to suffer with the symptoms of Long Covid as well, so that may also feed into why more women responded to this.

A. But that, again, could be due to different

health-seeking behaviours.

Q. If we look further down at some of the responses to the survey:

"10.7% of respondents reported [having] their GP suggested they may be suffering from anxiety due to having had Covid-19 or experiencing lockdown."

A. Yeah, a lot of people did have that suggested to them. This is possibly due to the fact that Covid seems to have a significant impact on the autonomic nervous system, so you kind of completely lost control of your blood pressure, heart rate. You know, people had very high, racing heart rates when they were presenting to healthcare professionals. That was my own experience. But it wasn't down to anxiety.

Q. If I just finally, while looking at the survey, 3.55:

"More than two thirds of GP ... did not follow up this initial contact by phone or other means."

And:

"37.0% of respondents reported that their GP did not discuss referral to any specialist services."

Now, by September they may not have -- we're going to hear about the plans that were put in place by various governments. In reality, in September 2020 there wasn't very much, was there, Mrs Rogers, by way of referral services at that stage?

A. There wasn't very much in terms of services to refer to but there was also a distinct lack of understanding of the possibility of ongoing illness. You know, it was, as I said before, so widely publicised that, particularly for community patients, it would be a short illness of two-week duration. You know, many patients were met with complete disbelief that they could possibly still be suffering the ongoing effects of the virus. If they were believed, as you said, there weren't any known services to refer in to, there was a lack of knowledge and understanding of the symptoms that patients were experiencing amongst GPs. So, you know, they may have their symptoms acknowledged but then there wasn't anything that could be done about them.

Q. If I understand it correctly, two problems here: those that were disbelieved or had their symptoms minimised by a GP; but where there is a GP that was a more understanding and sympathetic, nowhere for the patient to be referred to or help to be -- or support given? All right, understood.

Can I ask you, from your own experience, did you have difficulty with being disbelieved or diagnosed at the beginning?

A. So, I mean, I had difficulty from the outset, from when I first became ill. So I was severely acutely unwell at

home. I tried phoning NHS 111, both the Covid and non-Covid lines. It was very difficult getting through to either. The whole kind of act of seeking healthcare was exhausting at a point that you were sort of suffering from crippling fatigue, intense headaches, all sorts of, you know, difficulties just being, really. Breathing itself was difficult. So having to constantly try to get through to seek healthcare during the acute phase was a challenge. And when you did get through, you may not be believed, because initially there were, sort of, three cardinal symptoms: cough, fever, lack of -- sorry, loss of sense of smell. If you didn't have those cardinal symptoms it was often questioned did you have Covid. That was the first thing that happened with me.

My most intense initial symptom was the inability to draw breath, intense crushing chest pain. But I was told that for as long as, you know, I could actually breath, speak, then I didn't need to be hospitalised and I should manage the condition at home. My difficulty breathing was so intense that I actually researched online myself what I could do to try to manage that, and I found a YouTube clip from a doctor that advised lying on your front so that you would take the pressure off your lungs.

And I just kind of, like, lay there, you know, sort of listening to my own laboured breathing and counting the days, because I'd also read somewhere that if I got to day 8 and I was still breathing I was going to continue doing so.

So, that initial acute phase was really, really quite harrowing. But I did survive. And then I kind of assumed that I would have that sort of typical linear recovery that you expect to get after most illnesses, and that didn't really happen. And then I had this sort of whole-system crash, really, and then I just had this whole raft of debilitating symptoms on top of those that I was already experiencing.

So I had -- as I said, my heart rate, blood pressure sort of went out of control. I had vertigo. You know, I couldn't walk. I just felt like I was going to fall over. Just getting to my own bathroom was a challenge.

The only way -- I found it really, really difficult, and this was one of the problems when you were seeking healthcare, was articulating the symptoms that you were having. It was really difficult to describe. I felt like I had radiation poisoning. But, you know, to go and say that to your GP, they're just going to think "What's she talking about?" kind of

thing. So I kept phoning up and I did eventually get triaged in May.

Q. 2020?

A. In May of 2020, having become ill in March of 2020. I got triaged in -- it was like a Covid hub, sort of outdoor medical tent, if you will.

And I hadn't received a test until that point because testing wasn't available in the community. So I did get a PCR test at that point. But of course by this point I think I'd been ill for about 37 days. So it unsurprisingly came back negative. So I didn't have a positive test result and I also had medical professions sort of saying: well, you didn't have the typical initial symptoms and you should be better by now. And I remember saying, "Look, we are in the middle of a pandemic with a novel virus that is impacting thousands of people, it's highly likely that that's the root cause of the symptoms that I'm experiencing."

Q. Now, much of what you said will resonance with evidence her Ladyship heard yesterday and through other witnesses, but is your experience common amongst the Long Covid group core participants?

A. Yeah, so because of that experience, I found myself, you know, questioning: do I have Covid? And I just kept coming back to the answer: it's got to be. You know,

mainly because of the difficulty that I had with breathing was so intense and the fevers that I had, it was unlike anything else that I had experienced.

So I was looking online to try to find any information I could.

Q. That's what I wanted to ask you about, Ms Rogers, because I think you say in your statement that although you've just told us that you were diagnosed in May 2020, it wasn't really until the early summer of 2020 that medical and scientific advisers began to recognise the long-term effects of Covid. Is that roughly right in the chronology of --

A. That's roughly right, but obviously, you know, the people experiencing it, they already had, kind of, all of the information about what symptoms they were experiencing, so when I went online I stumbled across the Facebook group, that has later become the charity, Long Covid Support, and that was kind of a sort of moment of enlightenment, if you will, because there was just story after story of people going through similar experiences to mine.

Q. Can I ask you about that, because you've obviously alighted upon a large number of people experiencing the same thing as you and I think in your statement you make the point that between April and August 2020 there were

various documents, including those with -- at SAGE level beginning to talk about the long-term consequences of Covid. But between April and 2020 where there was emerging understanding of the consequences, did you ever see anything from the Department of Health that was warning people or alerting them to the fact that there may be long-term consequences of Covid?

A. No. No, I didn't. I have, you know, since become aware of the video that was produced.

Q. The video came out I think in October?

A. Right.

Q. So here we are in the summer.

A. Yeah.

Q. It's beginning to be recognised at government/organisational level, it's obviously being recognised on social media amongst all the people that are experiencing these things but do I take it that nothing really was coming out warning the public in messaging that there was --

A. Nothing. Nothing in the public domain.

Q. You will probably be aware, Mrs Rogers, that we have heard evidence that long-term consequences are not new but certainty Professor Whitty told us, for example, that precisely what those consequences are, are not necessarily known at the beginning of a pandemic.

Bearing that in mind, what do you think could have been done in terms of public messaging to help alert people to the fact there may be the consequences when the consequences aren't in fact known at that stage?

A. I think sufficient was known about the fact that there were ongoing consequences and that they were potentially very debilitating to make people aware of that possibility. There were enough -- there was kind of a sufficient critical mass of people presenting to healthcare, raising the alarm on social media, for it to be known that there was potentially going to be a significant ongoing problem here if we didn't make people aware of the possibility of ongoing symptoms. And that at least should have happened.

Q. Can you help, what do you think they should have said?

A. Like I said, the video that was produced that went out in October, the messaging on that was actually quite good but I didn't see it at the time. Nobody else I knew saw it at the time and it's a shame that that message didn't get out there.

Q. We'll come to the video in a moment, but I think in your statement there was a number of attempts by members of the Long Covid core participant group to try to raise awareness. I'm not going to go through all of them, you set them out in your statement, but I would like to ask

you about a letter that was sent to the Prime Minister, Mr Hancock, Professor Whitty, the chief executive of NHS England.

And could we call up on screen INQ000238582. Thank you very much.

This is July 2020. It's from Long Covid SOS. It was signed by over a thousand members of the group and we can see there that you're writing to a significant number of people in senior positions "on behalf of thousands of forgotten victims". Why was it described in that way?

A. Well, you just felt like you were invisible because there was no public health messaging. When you were seeking healthcare you were met with disbelief. So -- you know, the messaging was that if you weren't hospitalised or if you didn't, sadly, lose your life to this virus then it was going to be a short two-week illness and you were going to be fine.

So we were suffering, you know -- we were going through a horrendous experience. I mean, in fact I'm incredibly grateful to the people that wrote this letter in July raising the alarm because I myself at this point was in bed in a dark room with intense pain, searing pain in my head like nothing else I've ever experienced, so I wasn't at that point in a position to be able to

advocate. And in that respect there were many other people like me who were alone, you know, in their room trying to make sense of the experience that they were having, trying to get validation for the experience that they were having, but it was a real challenge to do so because the symptoms that you were experiencing at the time made it impossible for you to advocate for yourself because just the process of breathing was exhausting.

Q. Well, if we just go down in the letter slightly, to the paragraph beginning "Throughout this period", having set out the statistics about infection rates:

"Throughout this period the general public have been assured by government and public health sources that most 'mild' or 'moderate' cases not requiring hospital admission, resolve within two weeks. However, it is becoming increasingly clear that for many this far from the case."

Then reference there to a study that suggests as many as one in ten people with Covid are sick for three weeks or more and reports in the press are starting to emerge describing a pattern of illness experienced by many which is completely at odds with the prevailing view about the virus.

So setting out in terms there --

A. Yes.

Q. -- that the messaging that it was just mild or moderate and you'll recover was not according with what a number of people were feeling and experiencing on the ground.
A. That's correct, and members of the Long Covid groups were desperately just trying to get that message out there by whatever channel they could. So in parallel to raising concerns with government officials, policymakers, healthcare providers, we were also trying to get the message out there through social media, through the media, because you just wanted to do whatever you could to prevent other people going through that same experience.
Q. Just finally on the letter, could we go to the final page, please, page 3.

There were a number of asks made to the recipients of the letter. Five of them are set out there: establishment of a working group, commissioning of research, development of protocols and care pathways to ensure that the practitioners are empowered to treat long-term Covid-19 patients, creation of multi-disciplinary clinics, and the consideration of the economic implications.

So that was what you asked for in July, and we may now look at some of the things that did or didn't happen in that regard.

Thank you, that letter can come down.

And I think you make the point in your statement that in September 2020 Long Covid SOS met with Professor Stephen Powis, the medical director of NHS England, and you say it was the start of regular and ongoing dialogue about providing better care for people with Long Covid.

So that was clearly quite an important meeting?
A. It was a really important meeting. And it seemed to be the case that up until that point there had been no attempt to engage with the people that were actually experiencing Long Covid. So you talked about, you know, a growth of awareness within government from -- you know, between April and August, I think you mentioned before, but there was still no attempt up until this point, in September 2020, to engage in any way with the people that were experiencing Long Covid in order to gain a better understanding of it. And, you know, if you like, those early patients were the canaries in the coal mine, they were the people who had the most information about the condition at that time, they were the ones living with it.

So it was, yes, a turning point, in the sense that their opinion was finally listened to in some respect.
Q. Now, also in September 2020 you say that that was the

first official government guidance published by Public Health England, as it then was, into the longer-term effects, and I would just like to ask you about that please.

Can we pull up INQ000272238.

It's a shortish document, Mrs Rogers. It includes, obviously, a list of some of the persistent health symptoms and it says there is some research ongoing in terms of the post-hospitalisation Covid study, but right at the top of the document it says:

"Around 10% of mild [Covid] cases who were not admitted to hospital have reported symptoms lasting more than 4 weeks. A number of hospitalised cases reported continuing symptoms for 8 or more weeks following discharge."

Do I understand it correctly that the Long Covid group have concerns about that highlighted paragraph in blue there?
A. What do you mean by "have concerns"?
Q. I think in your statement you said there was consideration given to the fact the guidance incorrectly suggested that Long Covid only occurs in individuals who have been hospitalised with severe Covid --
A. All right, yes. Yes.
Q. Help me with that. What was the concern?

A. So obviously the biggest concern was the fact that there seemed to be no awareness of the possibility of ongoing symptoms, that was the biggest initial concern we had. Then when there did seem to be some acceptance of that possibility, it was completely focused on hospital patients. So this, again, overlooks -- you asked before about people feeling invisible, it completely overlooks, again, the experience of people that hadn't been hospitalised. And what we were learning was that you could have quite severe Long Covid irrespective of the severity of your acute Covid infection. In fact, you could have a pretty much asymptomatic acute Covid infection, go on to develop quite severe Long Covid. That was one of the issues.

Also the other issue was, of course, as we've previously spoken about, that the threshold for hospitalisation was so high that you also had patients in the community that had actually been severely ill with acute Covid. So that whole cohort of people aren't considered in that paragraph.
Q. Following that guidance, we then come to the video that was published in October 2020.

Can I just look at the press release, please, at INQ000272221.

This press release accompanied the publishing of

the video. It says:

"New data suggests Long Covid affects around 10% of 18 to 49 years olds who become unwell ..."

If we go to page 2, there at the top:

"The Health Secretary urges people to follow the guidelines to protect themselves ...

"A new film ... [features] the stories of 4 people, one aged just 22, who are living with the long-term effects of the virus."

Now, I know -- I think you said that you didn't see the video yourself. Are you aware of how well it was viewed across some of the members of the Long Covid core participant group? Was it highly publicised?

A. No. Nobody was talking about it at the time. It's something that's been discussed, as I said, retrospectively, and the messaging in it is quite good, but who saw it?

Q. Certainly from your experience and those that you represent --

A. And we were people that were actively seeking information.

Q. Aside from this video, are you aware if there was any other press release or a follow-up video ever?

A. No, this is, to my knowledge, the only one that was produced, in terms of videos.

Q. Do you think there needed to be an ongoing campaign?

A. Yes.

Q. And I think we know then that in December 2020 the NICE guide line came out with the first UK clinical definition. I'm not going to ask you about it. That just rounds off 2020.

Can I, perhaps before the mid-morning break, just ask you a bit about treatment and rehabilitation, Mrs Rogers.

A. Yes.

Q. We know that in October 2020, NHS England published a 5-point plan for Long Covid, and there was a task force and there was something called Your Covid Recovery, an online programme. I'd just like to ask you a bit about those matters, please.

Clearly you've told us that initially at least the response focused on those people who'd been hospitalised?

A. Correct, yes.

Q. And prior to the Long Covid clinics being set up, can you help: where were patients referred to before the Long Covid clinics came into existence?

A. Well, before the Long Covid clinics came into existence there wasn't really very much to refer them into. Before and after the clinics came into existence --

I can't remember exactly when Your Covid Recovery became available. The problem with Your Covid Recovery is it's not a resource that was developed specifically for Long Covid, it's a post-hospital rehab programme, and I think it was just, kind of, sort of, regurgitated and rolled out at pace, really. But it certainly wasn't specific to or suitable for people with ongoing symptoms of Long Covid.

Q. Let me pause you there and help you if I may.

Can we look at page 36 in Mrs Rogers statement, INQ000370954.

Your Covid Recovery I think was launched in July 2020, but it's an online tool as I understand it?

A. It is an online tool, yeah. There were two phases to it. There's one that patients can just, you know, freely access, and there was another one, phase 2, that I think GPs had to refer patients into. I think there was a distinct lack of knowledge about how to do so. I know when I eventually got referred to my local Long Covid hub I was working with an allied health professional. And this, by now, about spring '21 that I had this conversation with him. He was aware that phase 2 of Your Covid Recovery as an online tool existed. He didn't know how to access it, nor did

my GP.

So I don't know to what extent phase 2 was used. I do know that people were referred to phase 1 and, as I said, it was very much a rehab programme. It wasn't suitable for people with Long Covid. It had a lot of dangerous advice around goal setting, getting moving.

Q. Can I ask you about that.

A. Yes.

Q. Can you give us an example about what you considered to be dangerous advice that was given for those that registered on the Your Covid Recovery programme?

A. A lot of people were reporting that if they were following this advice of, you know, sort of setting yourselves goals, getting back to exercise, they were trying to do so and then they were just crashing and having a return of incredibly debilitating symptoms, which I have since come to personally understand, thanks to Long COVID Physio, is something called post-exertional malaise or post-exertional symptom exacerbation. So I think that was going on for a lot of people.

There were also a lot of people that had, you know, undiagnosed ongoing organ damage, so perhaps myocarditis of the heart, et cetera. Again, you know, you shouldn't be exercising.

We just didn't know enough about the sort of biological mechanisms of Long Covid for people to be taking this approach, and they were doing so because, you know, people wanted to get better.

Q. Yes.

A. So they were following whatever advice was out there in the hopes of getting better and it was making some people seriously unwell.

So we did approach Your Covid Recovery, as did Long Covid SOS, to make them aware of the fact that we didn't feel that the programme was suitable for people with Long Covid.

Another issue with it was that it just had large volumes of information that you needed to read in order to, kind of, support your own recovery, and that didn't account for the neurocognitive issues, level of fatigue that people were experiencing.

Q. I think you said there that you raised some of the concerns with Your Covid Recovery. Was there any positive outcome once you'd told them of your concerns?

A. Not for a long time. It took a long time and a lot of advocacy for any changes whatsoever to be made. You know, another of our concerns was the imagery on it was very much targeted about, you know, getting back to exercise kind of thing, and these were people that were

just too debilitated, too disabled, at that point, to even consider to being able to do that.

So any changes that were taken on board were incredibly slow. I'm aware that the site has now been taken down, but people are still being directed to it by many hospital trusts, so ...

Q. Is there any replacement that you're aware of now that --

A. No.

Q. One final issue before the break. We heard yesterday from Professors Brightling and Evans about the variation in the services that are available across the UK for those who are suffering Long Covid. Certainly we heard of what are colloquially known as one-stop shops that are available --

A. Yes.

Q. -- and I just wondered, are you able to give us the Long Covid group core participant's view on whether they are a good way of trying to deal with the very many symptoms that Long Covid sufferers experience?

A. I believe so. Yeah, you do need a multi-disciplinary team approach that involves both clinical care and rehabilitation care. It needs to be led by a doctor. You need to have a single person co-ordinating the care of the patient because, as was my experience, my

Long Covid service was set up as -- in an existing respiratory service because Covid was initially believed to be, you know, solely a respiratory disease, and they were kind of dealing with my care from a rehabilitation perspective but I was also having to go through the GP surgery for all other investigations that were required, which involved multiple disciplines, and I was having to kind of co-ordinate and administrate my care through, you know, many different healthcare providers. Which was utterly exhausting. And also letters got lost, I didn't receive the results of tests. You know, there was a point at which I completely sort of fell between respiratory care and cardiology in terms of the diagnosis of what was going on for me. So from that perspective it is really important that somebody has oversight and there is centralised co-ordinated care of patients.

Some services do that well. Others don't. Some services are purely a therapeutic-led service, a bit like mine was. So, where that's the case, they can't diagnose, treat, refer onwards to other disciplines, so you, kind of, are sort of in the service but it isn't fully able to oversee your care needs.

So it is important, you know, that we have that team that can address everything.

Q. I think you say in the statement that certainly Long Covid SOS were of the view that the one-stop shop is what they would consider the benchmark for Long Covid care. I was wondering, does that also stand true for the other three organisations that make up the Long Covid core participant group?

A. Yeah, that's what everybody would advocate would be the best service, both for the patient but also in terms of efficiency of healthcare, because if you're having to utilise all of these different services it's not very economical in terms of healthcare provision.

MS CAREY: My Lady, would that be a convenient moment?

LADY HALLETT: Of course.

I hope you were warned that we take breaks, Ms Rogers. I shall return at 11.30.

(11.14 am)

(A short break)

(11.30 am)

LADY HALLETT: Ms Carey.

MS CAREY: Thank you, my Lady.

Mrs Rogers, I'd like to ask you some questions about Long Covid in children.

A. Yes.

Q. And I think you say in your statement that as at March 2023, ONS estimated that 52,000 children and

young people aged between 2 and 16 had suffered Long Covid for over 12 months.

And it may be that those figures need to be adjusted now in 2024 but it's a significant number --

A. I think they've doubled.

Q. They've doubled. So over 100,000 children now?

A. Mm.

Q. Thank you.

And I think there is concern amongst your core participant group that from the outset of the pandemic there was a failure really to regard the risk of infection in children and indeed then in terms of the long-term consequences that Covid had on children. And in part that led to the setting up of Long Covid Kids; is that correct?

A. That's correct, yes. So I mean, all of the issues that were faced by adults were also faced by children and young people and their families and that was further hampered by the narrative that children didn't get unwell from Covid which was very pervasive from the beginning of the pandemic.

Q. Her Ladyship will recall, I think, in one of the earlier modules there was the impact video with a family talking about the impact of Long Covid on one of their children and there's other evidence we have as well.

Long Covid Kids, is this correct, in September 2020 produced a film called "Our Unhappily Ever After" which was put on YouTube and shared on social media and, essentially, after sharing that film was it at that stage that a number of families contacted Long Covid Kids and kept doing so as the film got shared and shared and reshared?

A. Yes, because again the families were meeting with disbelief. There seemed to be a complete lack of professional curiosity about what was going on with children, and a failure to respond to the emerging evidence that was continually being put to healthcare professionals by, you know, children, their parents, their grandparents so like with the case with adults, Long Covid Kids kind of sort of stepped into that space to try and communicate what was going on for these families in order to try and prevent that happening to other children.

Q. Well, can I -- let's look at how some of the families were affected and put on screen your paragraph 5.3. INQ000370954_45, please.

There's a reference we can see there at 5.3 to the sharing of the film. Clearly each family's experience was distressing, similar and yet unique. In terms of Long Covid in children, all had experienced a lack of

awareness and support from GPs about post-viral conditions. Complete lack of awareness about the incidence of Long Covid in children and indeed in turn the absence of treatment pathways. All had been told or made to feel they were neurotic or over-concerned parents.

So a different form of minimisation but minimisation nonetheless of what the adults were being told when they were telling GPs about their symptoms?

A. Yes, so again there's been this history of attributing unexplained illness to psychological causes. Adults were certainly experiencing that when they were seeking healthcare, but, you know, that was kind of almost ramped up to another level with families in the way that parents were being kind of almost blamed for making up that their children had these symptoms and said before about, you know, my own experience and how difficult it was to communicate and articulate the symptoms that I was experiencing and that's even more difficult for children because they don't have the same communication tools as adults to articulate their experience.

It's a complex multi-systemic illness, you really don't know what's happening to your body, and that's very, very difficult for children to articulate, and often they don't articulate with words, they articulate

through their behaviours. That doesn't mean that the cause is psychological, that there's an underlying physiological illness but it's not yet understood and really what we needed was people just to say: we don't yet fully understand it.

Q. Can I ask you about some of the factors that you set out in your statement that negatively impacted children with Long Covid accessing healthcare.

Could we put up paragraph 5.5, at page 46, of Mrs Rogers' statement.

And can we see at the top of that page there you set out helpfully a number of factors, including there was no information published by the government, the Royal College of Paediatrics and Child Health and by healthcare providers on the risk of Covid-19 to children.

And then this:

"There was no paediatric clinical definition of Long Covid until February 2023 ..."

So the adult definition certainly from NICE came out in December 2020.

A. 2020, yeah.

Q. Two and a bit years on for the clinical definition of paediatric Long Covid to come out.

A. And I know that in that intervening period that is

something that Long Covid Kids were campaigning very hard to have established because, you know, illness in children often presents slightly differently to illness in adults and there just didn't seem to be any urgency to investigate what was going on for these children and families and establish a paediatric clinical definition that would enable people to then go on to access care because of course without a clinical definition for an illness there's no established care pathways and it makes it much more difficult to seek help.

Q. I think you make the point that that delay prolonged Long Covid Kids members accessing help, being believed and, of course, being diagnosed.

A. Yeah.

Q. "... lack of data collection and reporting on hospital admissions, deaths and Long Covid in children."

Why do you think it's important that we have that data available?

A. Well, if you don't measure what's going on you can't plan to deal with it. It's hidden and that was the experience of these families, their experience was hidden and that's meant that, you know, there's been no warning system to prevent other children being affected. There's been no considered need to mitigate better, to prevent children being infected. There's been no

urgency to research the illness in children or to provide care pathways because it's not been measured.

Q. And then finally you say:

"At best, [there was] an adult framework being applied to paediatric problems. There needs to be child-specific data and child centred approach. It is important that children suffering are heard and that there is a voice for all children and young people ..."

Do you know if there is now any child framework being applied to children with Long Covid?

A. There have been I think 15 children and young people Long Covid clinics established. Again, the sort of care pathway that's put in place for them is not always adequate. There's still a lot of attributing the symptoms that children are experiencing to behaviour rather than physiological illness because there hasn't been sufficient research, sufficient focus on establishing an adequate framework on which to diagnose and treat the disease.

Q. I won't go through it now but the statement sets out a number of the steps Long Covid Kids took to try and advocate on behalf of children with Long Covid and if anyone wishes to look at those, they are set out in a number of pages from 51 onwards in Mrs Rogers' statement.

Can I also, through you if I may, urge those watching to read the section of your statement dealing with Long Covid and healthcare. We're going to take up that thread with other witnesses that are coming in the next few weeks, Mrs Rogers, but what I'd like to turn to with you now, please, is really the effect of Long Covid on sufferers' and their families' mental health, well-being, and the enduring physical symptoms.

I think you set some of that out at starting at your section 7 in your report.

Could you just help me with this. What was the impact really on you and your members of having to advocate all the time to say to professionals, "I'm not getting better, I need more support, it isn't a heart problem, it isn't a lung problem"? How did that affect you and the members of those that you represent?

A. Okay, so it's exhausting having to continually fight that hard for recognition. We're talking about people who are sick, really unwell, in the middle of a pandemic. These people want to know what's wrong and they want to get better. That's all they're asking for. You shouldn't have to fight that hard to get help.

Having to fight that hard, you know, being repeatedly gas lit and disbelieved while you are suffering from a really debilitating illness that has

genuine physiological symptoms is going to have knock-on psychological impacts, because, you know, it affects every aspect of your life to be that unwell. It affects your ability to work. Your ability to socialise. Your interactions with your family. Your financial stability.

So, you know, there is going to be straining on your mental health but on top of that you're also having to work really, really hard to try and be recognised and get any form of adequate healthcare.

Q. I think you say in your statement that for those that had to give up work or certainly reduce their hours, obviously there's a financial consequence including people using up their savings, taking out private loans, using debt services and there was a Long Covid Support, I think, survey that said that one in 16 of the respondents were using food banks?

A. That's correct, so I don't think that there's anybody that has been affected by Long Covid that hasn't, you know, had at least some degree of financial harm. There's financial implications to this thing at every step. Loss of income. Sick pay or lack of it, depending on your profession, that has a knock-on effect on your pension, so we're talking about lifelong financial implications. There's the cost of private

healthcare because people are desperate to find answers to help them get better. People are spending their savings trying to do so, if they're not spending their savings trying to put a roof over their head, as you say. There are people that should be able to work that were able to work prior to the pandemic, that were able to engage fully in society that now aren't because they're so considerably disabled.

Q. I think you said one in seven respondents to the survey that Long Covid Support did had lost their job because of reasons connected to Long Covid?

A. Yeah.

Q. Can I ask you about risk of reinfection and how your members feel about that. Clearly we're not in the emergency phase of the pandemic anymore, but it's still with us. How have your members felt and what have they said about the risks of reinfection and how they're treated now given that risk to them?

A. Okay, so since we sort of opened up in the summer of 2022, freedom day, as it was, that was a really difficult day for people with Long Covid because we know firsthand that the virus can utterly destroy your life as you know it and yet the talk was very much about just exposing people to it continuously. People are being infected with Covid several times a year, still.

There's been quite a lot of research about the fact that every time you're exposed to the virus that increases your risk of developing Long Covid. If you already have Long Covid it opens you up to a worsening of your existing symptoms. So naturally it's perfectly rational to want to avoid getting it again. So that has made life quite difficult for people with Long Covid because they are effectively clinically vulnerable to this virus and, you know, they're often having to seek healthcare and there's currently no mask requirements in healthcare, there's not adequate ventilation or air filtration, so they are repeatedly exposing themselves to a risk that they know can do devastating harm.

Q. I think you also say that people with Long Covid are not regarded as a priority group for vaccinations?

A. That's correct. And, again, you know, we don't understand why that hasn't been considered because we are clearly clinically at risk in terms of the health consequences of this virus. That's an established fact. So why are we not being prioritised to avoid getting it again?

Seeing as, you know, the whole underpinning ideology of opening up is that we now have this vaccine that protects those that are at risk and people with Long Covid are at risk, yet that protection has been

removed from them, it's not an option.

Q. Can I ask you a little bit about research because one of the recommendations that you make in your statement is for a more focused and better-funded approach to research. Now, I think we heard that the initial research was into those people that had been hospitalised, then there was cause for research into those people who had not been hospitalised but can you help us, please, Mrs Rogers as to why it is that those you speak on behalf of today are still calling for more focus and a better-funded approach to research?

A. So a lot of those research studies that you refer to were kind of more on the epidemiology and characterisation of Long Covid. We need to be prioritising biomedical research into Long Covid so that we can establish accurate diagnostic tests. We don't have that at present. There's no tests that have been developed that are specific to this condition, although a lot of research has been done that has identified potential biomarkers that could lead to tests for it and then we need to look at developing treatments so that needs to be a priority for research.

There needs to be separate studies into the paediatric population and comparing the burden of Long Covid in children with other childhood illnesses.

I think it is, you know, one of the most significant childhood illnesses presently. So we need to better understand the pathophysiology of what's going on with this illness, how to treat it, and we need to invest in that quickly because people continue to be affected by it all the time.

Q. You set out at the end of your statement helpfully a number of recommendations that you would argue for. There are, I think, 11 in total. I'm not going to go through all of them with you, Mrs Rogers. We just looked at the recommendation in relation to research but you say at recommendation 2 that:

"Healthcare systems can only respond adequately to longer-term sequelae when they are actively monitoring and counting it. The UK should ensure that decision-makers prioritise the early collection of syndromic surveillance data of longer-term sequelae."

Why is it that you argue so strongly for that recommendation?

A. Well, if we aren't measuring, as I said previously, we are not measuring what's going on, we can't adequately plan for it. We are at the moment potentially facing going backwards in terms of Long Covid provision, both in terms of existing research studies winding-up. There's been no further investment since November 2021.

There's significant concern about what is happening with Long Covid clinics because the funding for them is only announced on an annual basis. We don't know whether there's going to be funding for them or whether they're going to be merged into existing services beyond 2024.

Again, if we don't know the number of people that are needing support through healthcare we can't adequately plan for it. And, you know, we need to be aware, 30% of people with Long Covid have been infected in the last year. We often talk about this in the past tense but it's an ongoing problem and we need to measure the problem in order that we can adequately mitigate against future people being infected and also adequately support and treat those who have ongoing health issues.

And I think, you know, Long Covid is a really difficult thing to understand unless you are affected by it or you know somebody that's affected by it. It's in many ways an invisible illness societally and sadly there are people in here that will end up with Long Covid, and until they do so you really can't understand the full ramifications that it's going to have on your life.

Q. Just a final topic and I just want to pick up on what you said there about the invisible illness, and we understand the context you use it in, but can I just ask

you about your group's experience of inequality-related issues with Long Covid because I think you say in your statement that your organisation has observed through your membership that people from under-served groups and areas of deprivation suffer structural barriers to accessing patient support organisations for Long Covid sufferers.

You've already told us about the problems that you've had, but do I understand from that that if you're coming from a black, Asian or minority ethnic background it's even harder to try and seek out the support that you yourself found difficult enough in the first place to obtain?

A. Yes, so I regard myself as somebody that has quite kind of high health capital in terms of my ability to access healthcare. If it's been this hard for me I can't even begin to imagine how difficult it would be for people that already face structural barriers to healthcare, you know, by virtue of where they live geographically, deprivation, from a minority group etc. We think that there's an over representation of women with the illness but that's potentially because there are many groups of people that healthcare or support groups like ours are not able to reach because of the healthcare-seeking behaviours of those groups, because of stigma. Just

not, you know, having that cultural capital to advocate for themselves in order to access healthcare. And you know, it's a worry that because it's viewed as being an illness that largely impacts white women, that that's kind of feeding into the sort of misogynistic view there is of this illness that means that patients are having their symptoms attributed to psychological causes.

There's a lot that we still need to understand and there's a lot of people that we're still not reaching.

Q. I think, in addition to research suggesting women experience Long Covid more, you make the point in your statement that data from Long Covid services suggest the majority of people who access the clinics are white. Yet, as we know, Covid-19 more severely and disproportionately affected those from minority ethnic communities. So potentially under-reporting or people from those communities not, for whatever reason, accessing those Long Covid services?

A. And we saw the example yesterday of the barriers that were faced by the lady that was trying to communicate using British Sign Language throughout the pandemic. So, you know, those barriers are also going to be faced by people for whom English is their second language, but for both language and cultural reasons.

MS CAREY: Mrs Rogers, thank you very much. They are all

the questions that I had for you.

My Lady, is there anything you would like to ask?

LADY HALLETT: No, thank you very much for your help, Mrs Rogers. I do hope the work of this Inquiry will help gain Long Covid the recognition that obviously it deserves. We're doing our best to ensure that it does.

A. I very much appreciate your support.

LADY HALLETT: Whether we can make a difference in other respects will wait to be seen but at least we can get you some recognition, I hope.

A. Thank you.

LADY HALLETT: Thank you very much indeed.

MS CAREY: Thank you very much, my Lady. Can I hand over to Mr Mills to take the next witness.

(The witness withdrew)

MR MILLS: My Lady, may I please call Dr Paul Chrisp who will affirm.

DR PAUL CHRISP (affirmed)

Questions from COUNSEL TO THE INQUIRY

MR MILLS: Your full name, please.

A. Paul Chrisp.

Q. Dr Chrisp you have provided a statement to the Inquiry. For reference that is INQ000438429. You are now retired. Before that, you were the head of publishing and products at NICE. That's the National Institute for

Health and Care Excellence, and during the pandemic you were the director of the Centre for Guidelines at NICE, is that right?
A. That's correct.
Q. In broad terms, please, what are the roles and responsibilities of NICE, the organisation?
A. So, NICE is an independent arm's length body of The Department of Health and Social Care. It produces robust, independent evidence-based guidance and advice.

The aim of NICE's recommendations are to help practitioners and commissioners get the best care to people fast while ensuring value to the taxpayer.

The Centre for Guidelines develops and maintains up-to-date evidence-based guidance to prevent ill health, promote good health, and improve the quality of care and services.
Q. And as for the status of the guidelines NICE produces, can you help us with this. Must they be followed by healthcare professionals, or is there an expectation that they will be?
A. There's an expectation. So guidelines are intended to support professionals and the judgment of healthcare professionals is they discuss and consider options with patients. And this is clearly expressed at the beginning of every guideline. So it's not mandatory to

apply the recommendations. The guideline does not override the responsibility to make decisions that are appropriate to the circumstances of an individual or their families and carers.
Q. A little bit about your professional background, please. I think it's right that you qualified as a pharmacist in 1984 and practised for about a year. What has the focus of your career been?
A. So I had a -- prior to joining NICE in 2009, I had a career in medical publishing and the thread really through my career has been on evidence-based information to inform clinical decisions and therapeutics.
Q. Moving to those early stages of the pandemic, then. When did NICE receive its first commission to develop what became known as rapid guidelines from NHS England?
A. So the first commission was on 11 March 2020 and we were asked to produce guidelines on aspects of managing Covid-19. We had three topics in that first wave.
Q. What were those three topics?
A. They were the management of patients in critical care, the management of patients in the dialysis unit and the management of patients undergoing chemotherapy.
Q. And when were those guidelines published?
A. So we started work on them on 17 March and they were published on 20 March.

Q. We will come in a moment to the standard process for producing guidelines. But just help us at the outset with this. Had NICE ever before had to produce guidelines at such pace?
A. No.
Q. In these early stages, March 2020, did NHS England also assist NICE by producing its own clinical guidance?
A. Yes, NHS England and others produced some other guidance aimed at the NHS.
Q. Was that an unusual thing for NHS England to do?
A. So NICE occupies the guideline space with many others. Royal College, for example, produce guidance for certain specialisms. So it's not particularly unusual.
Q. Did there come a point when NHS England stopped providing clinical guidance and left the development of such guidance, as it were, to NICE?
A. So, yes, the focus moved to NICE producing guidance. We were -- worked very closely with NHS England to produce what we call waves of guidance, so every week we'd get the next three or four topics, over the course of the first three months of the pandemic.
Q. Staying at the mid-point of March 2020, as we are, can I ask you this. Were prioritisation criteria agreed for the work the Centre for Guidelines would perform?
A. Yes, we -- as an organisation we prioritised our work on

the Covid response, guidelines to support the Covid response, and on what we call therapeutically important topics, so, for example, on evaluating medicines for cancer treatment.
Q. At your paragraph 15 you say the purpose at the time of the prioritisation criteria was to avoid distracting the NHS when it was facing unprecedented pressure, releasing frontline healthcare staff who might otherwise have been engaged in guideline committees and as consultees of draft guidelines.

As well as the prioritisation, can we think about the core principles that NICE had for developing guidelines? Did those core principles remain the same for the rapid guidelines, and can you tell us, please, what they were?
A. Yes, the principles for producing guidance remained the same, and those principles are to base our recommendations on the best available evidence, where it exists, about what works and what it may cost. Guidelines are developed by independent experts, committees. We work with lay members, so we retained that in a form, and I can come on to that later. We retained the principle of consultation. All guidelines that NICE produces are signed off by an executive which is a delegated authority of the NICE board. And once

published, all NICE guidelines are maintained and kept up to date as new evidence and the knowledge base changes.

Q. Let's look now at the standard process.

Please can we go to INQ000438429.

This is a flow chart you produce in your statement, Dr Chrisp. It is, is it not, a summary of NICE's standard guideline development process?

A. Yes.

Q. I wonder if you could take us through each stage in headline terms and, as you do, give us a sense of the timings that each of these stages would take.

A. So, starting at the top, topics are usually referred to NICE by NHS England or the Department of Health and Social Care. We then scope the topic, and that's important to understand what the guideline will include and importantly what it will not include. And that can take two to three months and it also includes a two to four-week consultation period, so we consult on the scope of a guideline.

We will amend the scope and then we start the development. The development stage can take anything from 6 to 18 months, depending on the size of the topic. As you can appreciate, some topics can be quite small, and therefore with a smaller evidence base, and we can

move more rapidly. Others have a fairly extensive evidence base and can take a lot of committee meetings to work through the evidence, analyse the evidence and for our committees to reach their recommendations.

The next step consultation would normally take four to six weeks. This is where we ask for the views of stakeholders on the draft recommendations that have been made. The guideline, the draft guideline, is then revised in line with consultee comments, and that can take, again, anything between two to three months. There's then a quality assurance stage of a month or so. The guideline is then signed off and published.

And then the final stage of updating. We have regular checks to see if evidence has changed, if the knowledge base has changed, and there are four outcomes of a review. One would be no update needed. Another would be what we call a refresh, so there might be new evidence published which simply reaffirms or reinforces what's already recommended.

Thirdly, an update. So that may be in full, a full guideline, or a partial update, where we just look at a section of a guideline.

And the final outcome of a review is a withdrawal of the guidance and a standing down of the evidence.

Q. Just to give those timings their total figures then, is

it right that a standard topic would have a 142-week process; accelerated, 86 weeks; short, 44 weeks?

A. Yes.

Q. You were taking us through this flow chart. It does not appear that we see an equality impact assessment in writing within the chart. Before I ask you to explain where that fits in in the process, can you explain what an equality impact assessment is.

A. Yes. So in an equality impact assessment captures and considers any health inequality considerations for the guideline. So the aim is to reduce health inequalities and consider where it may be appropriate to make different recommendations for different groups of people if required.

We look at four dimensions of health inequality: we look at socioeconomic status and deprivation; we look at protected characteristics; we look at specific health groups, for example people who may be experiencing homelessness; and we look at any geographical impacts.

So, an equality impact assessment really looks at whether any emerging recommendations offer the opportunity to reduce health inequality, or to advance health equality.

Q. Can I take it from that then that the assessment process is a critical part of guideline development?

A. It is.

Q. Where then in this flow chart does an equality impact assessment come in?

A. At two places. An equality impact assessment is considered during scoping and also during development of recommendations. So it's specifically we ask our committees as they're formulating their recommendations to consider the aspects of health inequality and health equality that I've mentioned.

Q. As you took us through this process you described the role of stakeholders. There is, I think, a standing stakeholder list; is that right?

A. Correct.

Q. Can you help us with the sorts of organisations that we would imagine are on the standing stakeholder list?

A. Yes. So the standing stakeholder list includes national organisations that would have an interest in recommendations from NICE.

So, for example, I think there's 80 or thereabouts organisations on that standing list. They would range from the Care Quality Commission, NHS England, the Office for Health [Inequality] and Disparities, the MHRA, those sorts of organisations, and groups such as the Richmond group of charities.

Q. Just so I follow, are there any disability charities or

organisations on the list?
A. On that standing list, I don't believe so.
Q. Has consideration been given as to whether there ought to be?
A. Yes. We do reach out to disability charities and engage with them on specific topics.
(Alarm interruption)
MR MILLS: My Lady, I'm not sure I know what that one means.
LADY HALLETT: No, nor I.
UNKNOWN SPEAKER: (Inaudible).
LADY HALLETT: Oh, I see. As long as everything is okay.
MR MILLS: Dr Chrisp, I apologise.
You were just saying you reach out to disability charities and engage with them on specific topics?
A. That's correct. So we know from engaging with patient and voluntary community sector organisations that they would prefer to be contacted on topics which are considered directly relevant for their members rather than being overwhelmed with lots of guidelines. At any one time NICE is working on 20 or so topics and it's a judgment to ensure that we have the right stakeholders involved but not overwhelming people.
Q. Can we move now to consider the changes that NICE made to produce the rapid guidelines then. In what key ways was this standard process amended so that NICE could

produce rapid guidelines within the time it was given?
A. So we tried to stick to the core principles which I've previously outlined, but we had to compress the development stage, initially looking at five to ten days to produce guidance. So some of the development time was done in parallel, the consultation processes were shortened and targeted, and the guidelines were rapidly updated as we became aware of new evidence and the knowledge base changed, in light of findings for what was a new disease, a new condition.
Q. How did NICE ensure, within this truncated process, that expert input could still be secured?
A. So we worked with experts on specific topics. So we worked with targeted experts, usually groups of between seven to ten individuals, for each guideline, to develop the draft recommendations. And then going out to consultation, again that was a targeted consultation, aimed at organisations who we thought would have an interest.
Q. Is it possible, and it may not be so, to say how many experts would typically be involved in formulating the -- a rapid guideline?
A. Yes, so between seven to ten would be normal for that early phase of development.
Q. And is it possible to say from which disciplines those

experts would generally be drawn from?
A. So they were drawn from the specific specialism that we were looking at. So, for example, when we were looking at dialysis we worked with people with an expertise in that particular topic.
Q. Did the Centre for Guidelines maintain equality impact assessments as part of its process during the formulation of the rapid guidelines?
A. So for the first phase we did, however they weren't in the format or level of detail that we would normally produce for a standard guideline.
Q. Are you able to give us an insight into the difference between an equality impact assessment as part of the standard process, and the ones you were able to perform during the first phase of the rapid guidelines?
A. I think the main difference would be the speed, the thoroughness. So we had less time to conduct an equality impact assessment for those first topics compared with a standard process. So we tried to cover those aspects I mentioned in terms of opportunities where we saw them to reduce health inequality and promote health equality, but because we were moving at speed, the process was not as thorough.
Q. With that context, let us consider a particular rapid guideline together, please. That is guideline NG159,

critical care in adults.
Please can we have on screen INQ000474301.
This is -- although it says March 2020 at the top, this is the original version of the guideline as published on 20 March 2020.
Before we move into the detail of it, can you help us with this, please. What was this guideline designed to achieve?
A. It was intended to support clinicians and support patients who were admitted to hospital and the management of movement to critical care.
Q. The request for this guideline came to NICE on 11 March 2020?
A. I think it was 13 March.
Q. The 13th. I apologise.
Did NICE draft this guideline from, as it were, a blank page, or was there something on the stocks already that NICE was able to adapt in order to produce it?
A. So we took the view, the principles that we worked with were to produce short succinct documents with minimal narrative and to link to existing frameworks where they existed. So we drew upon the expertise from the experts we worked with and from their knowledge of the admission of patients into critical care.

Q. If we move to page 2 we read at paragraph 1.1:

"On admission to hospital assess all adults for frailty, irrespective of age and COVID-19 status. Consider comorbidities and underlying health conditions.

"Use the Clinical Frailty Scale for frailty assessment ..."

And it goes on to say where that is available.

The Inquiry heard evidence from Dr Daniele Bryden, the dean of the Faculty of Intensive Care Medicine, she said that the faculty provided advice to NICE about this guidance; is that correct?

A. Yes.

Q. In her evidence she agreed that the Clinical Frailty Scale is not appropriate for use on people under 65 or those with stable disabilities. Do you agree with that?

A. Yes.

Q. Do you agree that this version of the guideline did not make that clear?

A. Yes.

Q. Can we next, please, go to INQ000228378.

We'll look now at correspondence you had with both Mencap, that's Mrs Jackie O'Sullivan, who the Inquiry heard from on Monday, and from Tim Nicholls, of the National Autistic Society, in the days that followed the

publication of the original guideline on 20 March. Here, halfway down the page, we have an email that you received from Mr Nicholls on 23 March. In his second paragraph, third sentence he expressed concern that:

"The list of criteria outlined in the Clinical Frailty Scale, include criteria such as help keeping finances in order, meal preparation and help with dressing. We are concerned that these criteria outline difficulties that many autistic people face -- but that does not make them frail. On the current wording of the guideline, though, this assessment would be carried out. This could lead to doctors making decisions about otherwise healthy autistic people that would put them at serious risk."

When you read this email, did you agree with the concern that Mr Nicholls was expressing?

A. Yes.

Q. We'll come in a moment to the contact you had with Mrs O'Sullivan from Mencap about this issue. For now can I ask this. At this time, 23 March 2020, do you recall whether other disability charities or organisations had made contact with you or someone else at NICE expressing similar concerns?

A. I think it was predominantly Mr Nicholls and Mencap.

Q. If we move to page 1. The email starting towards the

bottom of the page from you on the 25th, your email begins by explaining the consequence of applying the Clinical Frailty Scale to people with autism was not intended and we go on to read the amended paragraph 1.1:

"On admission to hospital, assess all adults for frailty, irrespective of COVID-19 status.

"Use the Clinical Frailty Scale ... for frailty assessment, available from the NHS Specialised Clinical Frailty Network as part of a holistic assessment of frailty."

Now this:

"Be aware of the limitations of using the CFS tool as the sole assessment of frailty. The CFS should not be used in younger people, people with stable long-term disabilities, learning disabilities, autism or cerebral palsy. An individualised assessment is recommended in all cases where the CFS is not appropriate."

Are you able to give us an insight, please, into how this amended language was produced within NICE in the 48 hours between you receiving the concern from Mr Nicholls and sharing it with him on the 25th?

A. Yes, so we're grateful that this was pointed out to us. We're grateful for that to Mr Nicholls and to Mencap for pointing this out to us and we worked to clarify the

wording and when the Clinical Frailty Scale should and should not be used and hoped that this new wording would make that clear. So it was really a dialogue working with the National Autistic Society and with Mencap to produce a form of wording that was clear.

Q. Let us look then, please, at the dialogue with Mencap. We begin on page 10. We see here bottom email that on 23 March again, so the same day that you are in contact with Mr Nicholls, you receive an email from Jackie O'Sullivan of Mencap. She expresses this concern:

"The key concern is that people with a learning disability who need support with daily living would be scored down to a level 5, 6 or 7, meaning that adverse decisions about treatment might be made."

This concern is, in broadly similar terms to that which the National Autistic Society had raised with you. If we move then to the bottom of page 13, into 14, you email Mrs O'Sullivan on 24 March, the following day and you say this:

"As you can appreciate, because of the speed we were asked to produce these guidelines, they weren't subject to some of our usual steps. We are firming up how we get an Equalities impact assessment into all future topics."

You described earlier the amended version of the equalities impact assessment that took place in respect of rapid guidelines. Just so the Inquiry is clear, had such an assessment been carried out before 20 March in respect of this guideline?

A. There was a guideline -- there was an equality impact assessment on this guideline but it wasn't as thorough because of the speed we were working at.

Q. In respect of this particular guideline are you able to assist the Inquiry with what that assessment considered?

A. Yes. I think it looked at age and it looked at -- I think that was the main consideration of the equality impact assessment at that time.

Q. Ought it to have also looked at the impact on those with stable long-term disabilities, learning disabilities or autism?

A. Yes.

Q. Are you troubled, were you troubled, that it did not?

A. Yes.

Q. Can I ask whether any disability charities or organisations had been approached for input during the formulation of this guideline before 20 March?

A. They were not.

Q. Should they have been?

A. Yes.

Q. Let us look then, please, at the revised guidance.

Please can we go to INQ000315780.

If we move first to page 14, this page sets out the various updates within the iterations of this guideline. Do we see, looking down at the 25 March 2020 that there was an amendment to paragraph 1.1, that's the paragraph we've been discussing, to clarify that the Clinical Frailty Scale should be used as part of a holistic assessment but should not be used for younger people, people with stable long-term disabilities, learning disabilities or autism?

And then there was a further recommendation by -- further amendment, I apologise, by 31 March to paragraph 1.1?

A. Correct.

Q. If we move to page 6 we have the revised 1.1. Keeping that up, please, can we have the original guidance side-by-side. That's back to INQ000474301, page 2, so we have the original on the left, the revised on the right. If we compare the two, in the revised we have the warning at the end of the first bullet point:

"Be aware of the limitations of using the CFS as the sole assessment of frailty."

In the second bullet point we have the language, very similar language to that which we have seen in your

emails already that the CFS should not be used in respect of certain individuals.

And then that an individualised assessment is recommended in all cases where the CFS is not appropriate.

In your view did these revisions remedy the concerns that had been raised with you by the NAS and Mencap?

A. I think they did.

Q. Could the need to have revised the guideline on 25th or by 25th March and again by 31st March have been avoided if stakeholders such as Mencap and the NAS had been engaged prior to 20 March?

A. Yes.

Q. In her evidence to the Inquiry on Monday, Mrs O'Sullivan said that despite the revision to the guidance, Mencap remained worried that the genie was out of the bottle. Were you ever made aware of concerns that despite the revision the damage, as it were, had been done and that NICE had lost the trust of those with stable long-term disabilities, learning disabilities or autism?

A. No, I was not.

Q. If we keep up, please, only the revised guideline INQ000315780, this section is called "Admission to critical care", and I'd like to look at what this page

says about DNACPR decisions. At 2.4 we read this:

"Sensitively discuss a possible '[DNACPR]' decision with all adults with capacity and [perform] an assessment suggestive of increased frailty ..."

This is an instruction to clinicians, is it not?

A. It's a recommendation.

Q. Yes. In your view, did the inclusion of a paragraph about DNACPR decisions in this guidance within a section about admission to critical care risk conflating these two issues?

A. The intention was to be clear that DNACPRs should be individualised and sensitively discussed with people, their families and their carers in the normal ethical course of decision-making.

Q. Were you ever made aware of reports that patients with DNACPR notices were not being admitted to critical care to receive treatment?

A. No.

Q. Please can we go to PHT000000112.

Dr Chrisp, this is an extract of Dr Bryden's evidence to the Inquiry on the subject of a prioritisation tool in the event that critical care capacity was reached. If we begin at the bottom of page 152 she said this:

"If I can go back to the NICE guidance, when we

were advising NICE, we had actually identified with NICE that we felt at that point that we wanted something to go into the guidance to say where to look for guidance if the system became overwhelmed but that piece of advice that we gave was never produced into the final document."

Can I ask this. Are you able to recall whether the Faculty of Intensive Care Medicine advised that the critical care rapid guideline should offer clinicians assistance about what to do in the event that critical care capacity was reached?

A. I don't recall that but I do know that prioritisation of treatment in a capacity constrained system was excluded from the scope.

Q. Can you help the Inquiry understand how that exclusion was decided?

A. I think that was in the consultation and amendment of the scope as it was developed rapidly in that five-day working period when we developed the guideline.

Q. Can you help with any of the reasons why the decision was made to exclude it from the scope?

A. I am not sure about that. I can only think that service provision is not normally within the remit of NICE guidelines.

MR MILLS: My Lady, I'm about to move to a new topic.

I wonder whether that might be lunch.

LADY HALLETT: Certainly. I hope you were warned -- well, you probably gather we might have a lunch break, so you'll have to come back this afternoon at 1.40, please.

(12.40 pm)

(The short adjournment)

(1.40 pm)

LADY HALLETT: Mr Mills.

MR MILLS: My Lady.

Dr Chrisp, before we move on from the critical care rapid guideline we were discussing before lunch, can I ask this, are there any final points that you would like to share with the Inquiry that you haven't already had the chance to?

A. Yes, thank you for the opportunity. It goes back to involvement in the targeted consultation on NG159. You asked the question did we involve the groups involved with people with learning disabilities and autism, and we didn't. However, we did engage with the clinical lead for critical care and with The Richmond Group of Charities, who represent organisations for people with long-term conditions and complex needs. So it covers, for example, Mind, the Alzheimer's Society, Parkinson's UK. And the issue surrounding the Clinical Frailty Scale was not raised with us during the

consultation process.

Q. I see. Is it right that in March 2021 this rapid guideline and indeed all the other rapid guidelines NICE produced through 2020 to March 2021 were consolidated into what NICE called the "living guideline", "... managing COVID-19"?

A. Yes, that's correct.

Q. I'd like to ask you a question or two about whether NICE considered including within that managing Covid-19 guideline a scoring system which the inquiry has heard some evidence about called ISARIC4C.

I do so with the caveat that this is not something you have personally assessed in your capacity, as you were then, the director of the Centre for Guidelines, but that you have made the relevant enquiries within NICE so that you are able to assist the Inquiry with the consideration that was given to that scoring system; is that right?

A. Yes.

Q. If we could, please, start by going to INQ000474255. Thank you.

This comes from the expert report the Inquiry has received on intensive care. We read at the start of this paragraph:

"Although ISARIC-4C is the best available numeric

predictive score for Covid-19 outcomes, it is not in general clinical use as, despite the impressive rapidity of development, it was not published and available for use by the time of the first wave peak."

That may well explain why it could not have been considered for inclusion in the early iterations of the rapid guideline critical care in adults. It is right to set the scene, is it not, that ISARIC4C was not included in any further iterations of the critical care rapid guideline, nor was it included in the living guidance managing Covid-19?

A. That's right.

Q. Can you help the Inquiry then in this way. Whether NICE considered incorporating ISARIC4C into either of those pieces of guidance, or indeed any other, and ultimately why the decision was made not to?

A. Yes. So we did look at it. It was identified through our continuous surveillance of the knowledge base as more knowledge and experience and expertise was developed as the pandemic continued.

So we became aware of a number of scoring tools that were being developed, so in October 2020 we conducted a systemic review on risk prediction tools or models for admission to hospital or critical care to understand the broader evidence base. We found a large

number of studies covering a variety of tools and models, and the conclusion at that time -- so this was conducted in October and December 2020. The conclusion at the time was there were a variety of early warning scores being developed, and it wasn't possible to, at that time, determine that one was better than another and therefore should be recommended.

So, that's one aspect of it that's particularly relevant to that particular tool.

And also in December 2020, in step with the way that clinical care was developing, our focus moved away from individual rapid guidelines, as you've indicated, that looked at, for example, admission, moving more toward this consolidated guideline which had more of a focus on management in therapeutics as we developed more knowledge about what management techniques and processes and interventions worked.

So there were two answers to the question:

Yes, we looked at it. It was one of many. There wasn't enough evidence to recommend it.

Secondly, it was this shift away from tools and models for admission to more of a focus on management in therapeutics.

Q. Can I take it then the second part of your answer perhaps explains why further consideration wasn't given

to it in 2021?

A. Again, I think if we were -- and it is a living guideline, if more evidence and knowledge with that particular tool was developing, the team would look at that. And when we talked earlier about updating and reviewing guidelines, if there was enough evidence to suggest a change in a recommendation, so, for example, to recommend ISARIC or indeed any other scoring tool, we would consider that and consider whether it warranted a partial update or a refreshing of the recommendations.

Q. Can we turn finally then, Dr Chrisp, to lessons and recommendations. Can I start with this. In the event of a future pandemic, is NICE in a better position to create rapid guidelines and if so, how?

A. I believe it is. Again, two aspects to that. One was in July 2020, after we'd produced 21 guidelines in three months, very rapidly. We -- during that time we were continually looking at what worked well and what we could do better, and we summarised that in an interim process and methods guide in July 2020, which, if you like, codified a future approach.

So if you recall when we spoke earlier, the first three guidelines were produced in five working days. So NICE had taken that decision to move quickly and condense and company many of its normal processes.

As we progressed through those first guidelines, we learnt that there were some areas that we could actually move back towards a more normal process. So could it work, could it do that better in the future? Yes, we could, and those new ways of working, those methods and processes we published in July 2020.

And in particular I want to go back to the evidence -- sorry, the equality impact assessment that we spoke about earlier. We would take a different approach to a future scenario. We have a greater awareness of the need to involve a wider stakeholder group as we would do normally on a guideline, so that interim process and methods guide for producing guidelines in response to a pandemic, the equality impact assessment element of that has not been condensed. It's the same as it would be in a regular standard guideline.

So that's one learning.

And then the second one is a deeper, more thorough systematic approach the organisation took in 2022 where the executive team looked at an organisational lessons learned, so not just guidelines but what else can we learn.

So the more flexible agile methods and processes and the prioritisation based on what would have the

greatest impact on user needs are now built into the way we work, the way the organisation works. And that further strengthening and signposting of efforts to address health inequalities has been taken to heart.

Q. Those are key lessons that NICE has learnt and acted upon. Perhaps looking forward, are there any further recommendations that you would like the Inquiry to consider?

A. I think the main one would be to -- when I reflect back to March 2020, NICE had a position in the health system as producing guidelines and everybody understood what that meant and what a guideline was and it would take 12 to 24 months. When we were asked to rapidly pivot and produce guidelines within often five working days to fourteen working days I think we could have been more prepared, had we been more involved in the emergency response infrastructure, if you will.

And again, one of the lessons learned that we've put into practice is that our chief medical officer is now part of the national emergency preparedness, resilience and response clinical reference group, which is good, and it's acting more as a system, I think, as early as possible and I think the product would have been better and the advice and guidance we gave would have been better.

MR MILLS: Dr Chrisp, thank you.
My Lady, that's all I ask.
LADY HALLETT: Thank you very much.
Mr Puar.
He's behind the pillar. Don't know if you can see him.

Questions from MR PUAR

MR PUAR: Good afternoon, Dr Chrisp.
A. Good afternoon.
Q. I asked questions on behalf for Covid-19 Bereaved Families for Justice Cymru who are a group of bereaved families in Wales and the members of the group are particularly concerned about the inconsistent application of DNACPR policies.
So my first question is in relation to the guidelines that we've already looked at, the NG159 guidelines.
Upon reflection, do you accept or would you like to comment as to whether the guidelines themselves gave clinicians too wide a discretion to make DNACPR decisions without taking into account the wishes and feelings of the patient and/or their family and/or failed to refer the reader to local policies that were place?
A. So the intent of the guideline was to support normal

ethical decision-making and that shouldn't have changed due to Covid-19. We expected clinicians still to exercise their clinical judgment and in consultation with patients, their carers, and families. So I think -- you asked the question too much discretion. I would say that discretion is part of reaching a DNACPR. It should be individualised, it should be person-centred.
Q. Thank you. And do you think that NICE could or should develop a DNACPR quality standards guideline with significant contribution of patient care involvement so that a uniform standard can be adopted in the UK, and effectively end -- and so that end-of-life care is less a postcode lottery and, if so, what challenges would that task pose?
A. So as I mentioned earlier, topics are referred to NICE through NHS England and the Department of Health and Social Care and they are then assessed by a prioritisation panel within NICE and which guidelines are taken forward depends on a number of factors, including whether the guidance is within NICE's remit, whether there's a gap in a portfolio or significant unwarranted variation. I think the answer to your question would primarily fall within: does it fall within NICE's remit? And to that I would say NICE

doesn't normally produce guidance on professional standards or conduct.
But I think any topic should be looked at through that prioritisation lens and that's how NICE would make that decision, should it be referred to the organisation.
MR PUAR: Thank you, Dr Chrisp, those were the questions I had.
LADY HALLETT: Thank you, Mr Puar.
Mr Weatherby.

Questions from MR WEATHERBY KC

MR WEATHERBY: Just one very discrete and short topic from me on behalf of Covid-19 Bereaved Families for Justice UK, Dr Chrisp.
In April 2020 NICE issued guidance with respect to target oxygen saturation levels with respect to the range for the most acutely ill patients and it reduced the target saturation level from 94 to 98% which was the standard pre pandemic. First of all, down to 92-96% and then down to 90-94% and that was because of a shortage of oxygen, wasn't it?
A. So that particular piece of guidance that you're referring to was an NHS England piece of guidance that was published on the NICE website so it wasn't a NICE piece of guidance.

Q. Okay. You refer to it in your table 4 at page 59 to 60. But my question, is it right? If you don't know obviously say you don't know but --
A. I don't know, I'm sorry.
Q. You don't know, I won't ask you any more then. Except for, do you know that the guidance then went back up to the pre-pandemic level or not?
A. I'm sorry, I don't know.
MR WEATHERBY: Thank you very much.
LADY HALLETT: Thank you, Mr Weatherby.
Ms Hannett -- over that way.

Questions from MS HANNETT KC

MS HANNETT: Dr Chrisp, I ask questions on behalf of the Long Covid groups.
Can I ask you, first, please, about the development of the guidelines on the management long-term symptoms of Covid-19, the Long Covid guidance. Do you agree that there was time lost in starting to prepare guidelines between July 2020, when SIGN first proposed the idea to NICE, and October 2020 when NICE agreed to work with SIGN and RCGP on the guidelines, since treating clinicians were dependent on the guidelines to inform their response to Covid-19?
A. So to produce a guideline we wait for a referral from NHS England or The Department of Health and Social Care

and the referral came in on 30 September. So if we'd have received it earlier we would have started earlier.
Q. Thank you. And I was going to ask you about Long Covid in children and young people. And there were no guidelines issued for Long Covid in children in December 2020 when the NICE guidelines were first published and it wasn't until November 2021 that the NICE guidelines were reviewed with evidence on children and young people. Again, do you agree that there ought to have been some information on care and support for children and young people earlier than November 2021?
A. So I think the scope -- I know the scope included children and young people in the update that you refer to in November 2021, and had there been information in the first version I think we would have included it as well. I'm sorry, I can't recall if children and young people were included in the scope of the first guideline we've produced in December 2020.
Q. Is it right, then, that you weren't then asked to review it until November? There was no -- why were they not then included in the revisions whether -- if it was included in the scope originally, why were they then not included in the revisions between December 2020 and November 2021?
A. So we conducted a review in November 2021 that, was the

first opportunity we had to do a complete review of the guideline, and that included symptoms, referral, and management, because there'd been a lot of new experience and evidence from people suffering from these awful debilitating symptoms.
Q. And were you not asked to do a review before then?
A. No.
Q. Can I just ask you then about post-exertional malaise?
LADY HALLETT: Just before you do, Ms Hannett, could you make sure, Dr Chrisp, that your answers go into the microphone, I'm sorry.
A. Sorry.
LADY HALLETT: That's all right. It is easily done to look towards the questioner.
MS HANNETT: I am sorry, Dr Chrisp, I'm not ideally located to ask you questions.

Would you agree with Professor Brightling and Professor Evans who gave evidence yesterday that clinicians would now be assisted with clear advice on post-exertional symptom exacerbation in the guidelines on treating long-term symptoms of Covid-19?
A. I think there's a research recommendation in the guideline for what's the clinical effectiveness of exercise interventions, so the Long Covid guideline is under continual surveillance and as evidence and the

knowledge base increases there is always a point where there might be a trigger to update the recommendations we make.

So as I said, the guideline has research recommendations because we were unable to make them in November 2021, around the clinical effectiveness of exercise and whether exercise rehabilitation assists in improving symptoms. So there may be evidence and knowledge on that which may be able to trigger an update but, again, I'm not familiar with that, I'm not close to the subject but if there was, that could be taken into account in an update of the guideline.
Q. And can you just on that, on the -- a follow-up question on that, can you explain why there hasn't been any substantive update to the guidelines since November 2021? You've just described there's been quite a lot of knowledge and expertise that's developed since then and yet there's been no revision since November 2021. Can you help the Inquiry with why that is?
A. Yes, I'll try. NICE has a portfolio of, I think, about 350 guidelines, all of which need to be kept up to date, as well as new topics coming in and the decisions to produce new guidance or update whole guidelines or sections of guidelines is taken through this

prioritisation panel that makes a decision on where we should be placing our resources as to which guideline to update on what sort of timeline. So it is one guideline amongst many that NICE needs to consider where it prioritises its efforts to update depending on need, the variation in care, impact on people and impact on the quality of the care they're receiving.
Q. Can I just ask you, though, what about the living guidelines though, Dr Chrisp, that are meant to be consistently updated and why hasn't that process been applied to the Long Covid guidelines?
A. So, again, it's a case of whether or not the team has found the evidence to trigger an update and I'm surmising that they feel that they haven't.
Q. But you don't know?
A. I don't know. I've been out of the organisation for several months now.
MS HANNETT: Thank you, my Lady.

Thank you, Dr Chrisp.
LADY HALLETT: Thank you, Ms Hannett.

I think that concludes all the questions for you, Dr Chrisp. Let me just check.
MR MILLS: That's right, my Lady.
LADY HALLETT: It does. Thank you very much for coming out of retirement to help and I'm very grateful for your

assistance and for your frankness where you thought something may have gone wrong, and for being open with the Inquiry. Thank you.

THE WITNESS: Thank you.

(The witness withdrew)

LADY HALLETT: Ms Carey.

MS CAREY: My Lady, the next witness is Professor Helen Snooks.

PROFESSOR HELEN SNOOKS (affirmed)

Questions from LEAD COUNSEL TO THE INQUIRY for MODULE 3

LADY HALLETT: I see you're still suffering.

A. Yes.

LADY HALLETT: I hope your recovery is continuing.

A. Yes, thank you.

MS CAREY: Your full name, please.

A. Helen Ann Snooks.

Q. I think you have a copy of your expert report in front of you, ending 474285, but I suspect it might be easier to put on screen any passages that we need to look at to save you rifling through it.

A. Thank you.

Q. A little bit about you. You are a professor of health services research, with over 30 years' experience in the fields of emergency and unscheduled care, and particularly experience in emergency pre-hospital care.

You are primarily a methodologist and, is this right, you're not a clinician?

A. That's right.

Q. You haven't worked for an ambulance service?

A. I have worked for an ambulance service. So I have worked between universities and the ambulance service, and in the 1990s I was based at the London Ambulance Service, and employed by the London Ambulance Service as clinical audit and research manager from 1995 to 1999.

Q. Thank you very much for clarifying that. You are a researcher though and you have been the editor for the National Institute for Health and Care Research for over ten years and have recently taken on the role of senior editor for the National Institute for Health and Care Research?

A. Yes.

Q. You were instructed by the Inquiry to look at two different matters: emergency pre-hospital care and the efficacy or otherwise of the shielding programme. And I'd like to concentrate on the former for this reason, Professor, since you were unable to join us a few weeks ago we've heard a lot of evidence about shielding so I'm hoping I can take that a little more quickly than otherwise I would have done. All right?

Can we start then, please, with pre-hospital care,

and I think you set out in your report that calls to 999 are categorised by their urgency. And am I right in thinking that in England and Northern Ireland there are categories 1 to 4 and in Scotland and Wales they are colour coded but essentially four colour schemes, all of them in common have the most life threatening and serious as their first category, if I can put it like that, and all of them have at the bottom end perhaps the less urgent category, those who have tripped over or have got vomiting, matters like that.

I'm not going to go through the precise niceties of each of the different categorisations but one can understand the need to categorise the calls depending on how urgent the call is?

A. Yes, in order to provide a speedy response to the most urgent calls and to provide a less -- a slower response, not such a speedy response, to those that don't require it.

Q. Yes. And I think the category of the call then determines the response time target and each of those vary by nation and each of those vary by category?

A. Yes.

Q. All right. Now that is all set out in the report, if people want to descend to the detail. We may touch on one or two response times as we go through your

evidence.

Can I ask you, please, though about clinical decision support software and the systems that are used across the UK ambulance services.

A. Just.

LADY HALLETT: Sorry, just before you go on, I'm terribly sorry, I meant to ask a question.

In relation to categorisations, so you get categorised as 1, obviously you are top priority. If you get categorised as 2, and I confess here I'm speaking from personal experience, does it make any difference to your categorisation even if you wait for hours because more category 1 calls have come in?

A. No, it doesn't make any difference. If you called back your categorisation could change because your symptoms may have worsened, so you could actually be put into a higher category. But the -- no, it doesn't change from what you've said, you're in that category until the ambulance is available to come to you. And as Ms Carey said, there are response time targets associated with each category. But they're not always met.

LADY HALLETT: I was going to say, that's what made me ask the question about whether if your time target hadn't been met did it make any difference to your categorisation. But not unless your symptoms worsened.

Thank you.

Sorry to interrupt.

MS CAREY: Not at all.

The different pathways that are used by the ambulance services, there are two. One is known as the Advanced Medical Priority Dispatch System (AMPDS) and the other one is NHS Pathways. But can you just give us an overview of what those pathways are designed to achieve.

A. So these are the -- they're the computerised software used by the call takers, so the people that answer the 999 calls, to assign those priority categories. And they go through a set of questions which -- they are slightly different, so AMPDS is more structured than NHS Pathways, but they are aiming to do the same thing: to find a way -- well, to put people into the appropriate category for their need.

Q. So, for example, you might be asked straight away: is the patient breathing? A pretty clear indication of how severe or otherwise. And then the pathways will depend on which one is being used and the questions that are asked to elicit the right response?

A. Yes. Yes.

Q. All right. Understood. I think, pre-pandemic, was there any evidence being conducted of how accurate or

otherwise those two pathways were?

A. There has been some research published over the last, I would say, 20 or 30 years, but there wasn't an awful lot of recent evidence. And it wasn't -- I wouldn't say it was definitive, but -- and a lot of ambulance services have been carrying out their own audits and quality improvement exercises because they have not all selected the same system, so there has been quite a lot of work going on to understand.

And there's a completely different financial cost. So the AMPDS is a commercial -- a company that's paid for, we've a contract for that, whereas NHS Pathways has been derived from within the NHS, in the UK.

Q. Do you know whether there was any evidence conducted into those pathways as to whether the algorithms might have produced unequal results for patients?

A. I'm not aware of that.

Q. So one can't say: well, AMPDS is better at diagnosing this and you get a better response time with that pathway as opposed to NHS Pathways?

A. No. And that -- I don't think ambulance services would have been choosing both if that was the case. So they've been really choosing both based on other decisions, other factors.

Q. Now, your report sets out at paragraph 9 the process to

accessing emergency care in business as usual, so pre-pandemic, times, and I won't go through the various steps but, in short, obviously if you ring 999 you go through to an emergency operation centre, then the call handler takes you through the questions to determine how urgent the response is, and then the call gets processed to a dispatcher; is that correct?

A. Yes. Each ambulance service also has a clinical desk so if further advice is required, the call taker, the call handler, who is non-clinical, can pass it over to -- for clinical advice. This existed even pre-pandemic. And then, yes, it gets sent on it a dispatcher to operationalise the response from the ambulance or whatever.

Q. And then the ambulance gets dispatched and attends the scene or the home or wherever it may be. Ordinarily, is this the position, an ambulance will have two crew members, usually one paramedic, who is educated to degree level, and, indeed, one emergency medical technician, who has done a slightly shorter period of training?

A. Yes, that's the ideal. It doesn't always happen that way. Sometimes you might get two EMTs, the more basic level crew, together, and sometimes you might get two paramedics, but ideally there's one paramedic and one

EMT.

Q. Right.

A. But I would just say that not every call will receive the dispatch of an ambulance. Some calls will end with -- the 999 call -- with other advice, self-care advice.

Q. See a GP?

A. A "no send", yes.

Q. Understood. And then the ambulance crew attends, the decision is made with the patient about whether to convey the patient to hospital, and then, depending on how urgent it is, various notifications go through to the hospital?

A. Yes.

Q. Can I ask you about the metrics, or the performance metrics as they're called, for ambulance response times and your paragraph 10.

Perhaps if we could call up on screen, please, INQ000474285_8 and 9.

I think people will see now why we haven't descended to the detail of all of the different categories. But I want to pick the most serious category for each of the nations so we can understand where we were pre-pandemic.

In England, is this right, since 2018, if the call

to 999 is categorised as 1, being life threatening, so someone has had a cardiac arrest or respiratory arrest, target response time is 7 minutes. Is that 7 minutes till the ambulance arriving at the patient?

A. Yes, from the call to arriving at the patient. And that's on average.

Q. Right. And 90% of the calls must be responded to within 15 minutes?

A. Yes.

Q. That gives us an indication of how truly life threatening category 1 calls are.

A. Yes.

Q. And I think in Northern Ireland, if we just go down to paragraph 12, please, similar category 1 in Northern Ireland, response time there is 8 minutes?

A. Yes.

Q. In Scotland, their most serious category I think is purple; is that correct?

A. I believe so.

Q. And if we look at page 9, there's some bullet points on page 9 -- thank you very much -- in Scotland, the purple category are based on the median times. 6 minutes there, and 90% of the calls have to be responded to in 15 minutes.

A. 95% it says.

Q. Yes, 95%, thank you, not 90.

And finally, in Wales, red calls they're called in Wales, set response standard:

"65% of ... [the] calls are expected to have an emergency response ... within 8 minutes."

So I think it's 6 to 8 minutes roughly, depending where you are in the UK --

A. Yes.

Q. -- for an urgent call?

A. Yes.

Q. All right. Now, I've set that as a base so we can see then what happened potentially during the pandemic. That's clearly if you're calling 999. Can I ask you about 111, please. And are you able to help us, what is the purpose of 111 services?

A. The purpose of 111 is to provide healthcare advice and information to anybody, for free, by telephone. They also provide online services.

Q. Is it for non-urgent calls, urgent calls, everything?

A. Everything and anything, yeah.

Q. All right. And I think there is 111 in England and Wales, and during the pandemic it was rolled out in Northern Ireland; is that correct?

A. I believe so, yes.

Q. And in Scotland it is operated by someone called NHS 24?

A. NHS 24 is the service, and it's operated by -- I'm not sure but it's not the ambulance service. Whereas 111 services are often, not always but often, operated by ambulance services in England, Wales and Northern Ireland.

Q. All right. But if I understand it correctly, certainly by the time we were in the pandemic, all four nations were operating not only 999 but a 111 type service?

A. Yes.

Q. All right.

And 111, is that a service that also relies on algorithms to talk through the level of care and the kind of advice that might be needed to be given to the patient?

A. Yes, absolutely.

Q. And in 111, again, is the call handler not clinically qualified but, where necessary, the caller can get a call back, a nurse or a paramedic?

A. My understanding is that varies between service. And I know in the past they've -- I'm not familiar with the current situation. In the past there have certainly been some services which have provided that call taking facility with a clinical -- a clinically trained call handler. So it has varied by service.

Q. But generally speaking, two different ways now people

can ring if it's really urgent or ring 111 if there may be some doubt in their mind about how urgent. But I think you make this point: if you ring 111 and it's urgent you can be transferred to 999.

A. Yes.

Q. Understood.

A. Sometimes they're in the same room, literally.

Q. You make the observation that you have less direct expertise and knowledge of preparedness but, based on your research, the preparedness for 999 and 111 service prior to the pandemic had predominantly been placed around major incidents as opposed to a nation-wide pandemic; is that right?

A. That's my understanding but I haven't done direct research of my own in that area.

Q. Now I'd like it ask you, please, about what is called "Protocol 36".

And can you help us in layman's terms, if I may put it like that, what was Protocol 36?

A. So Protocol 36 was a specific protocol that was added in or brought into use within the pandemic to assess calls of patients with or patients with suspected Covid infection. So it was noted very early on in the pandemic that the generic priority, assisted priority dispatch system, AMPDS, did not have a specific protocol

for dealing with the pandemic situation. And there was that protocol available but it wasn't in regular use. So it was brought in and introduced in, I believe, early April of 2020. That was to services that used AMPDS. And NHS -- services that used NHS Pathways, the other priority dispatch system, developed their own tailored protocol for responding to suspected Covid-19 calls.

Q. So this was to really try to help the ambulance services work out who did or may have Covid-19?

A. It was in order to assess their need for the response to that. So it was a specific way of asking questions to callers with suspected -- with symptoms that might be Covid-19, to assess those specific symptoms in need -- in terms of their need for an emergency response. Which it was felt that the generic system wasn't able to do, was under -- not taking enough account of specific symptoms that were coming up in Covid-19.

Q. Can I perhaps put it another way. If someone is ringing up saying they have a cough, they have a fever, they've lost their sense of smell or sense of taste, it might be difficult for the ambulance service to work out how serious or otherwise the symptoms were. Was Protocol 36 designed to try to work out: this person might have Covid and might need to go to hospital?

A. Yes, it was precisely to understand, in the context of Covid-19, when the need for the emergency response -- what priority should that patient be given in a specific circumstance.

Q. And I think you say in your report that, in fact, this protocol had been around since -- was developed in the time of swine flu and was brought back in then -- into play during the Covid pandemic.

A. It's sometimes called "card 36". If you see that, it's ...

Q. Can I just ask you the sort of bald question. Given that that was its aim, was to work out if you had Covid, and if so if you needed an emergency response, in general terms are you able to say whether Protocol 36 actually achieved its aim?

A. So I don't think it was to work out if the patient had Covid-19, it was to understand, if they thought they might have Covid-19, what was the response required. How well it performed that function does come up in other parts of the report through research that was carried out.

Q. Are you able to give us an overview before perhaps we descend to some of the detail?

A. Yes. So, overall, I think I just need to say that triage or sorting patients out and the priority of

patients is absolutely key to the provision of care to patients in an emergency. And it might be easy to think, well, why not just send the highest response to everybody, but that carries its own risks. So it's very important to not over-respond to people because that puts the whole system under pressure, as well as if the patient, for instance, has Covid-19 but does not need emergency transportation to hospital then it's exposing more people to the risk of transmission and the ambulance crew as well.

So I just wanted to preface that because I think people might think, well, why not just send the top response to everybody. But that's risky in its own way.

So it's very important to not over-respond or under-respond and to try to sort out which patients are needing this highest level of response. That inevitably means that whilst trying to not over-respond, sometimes the services will under-respond.

The research shows that those using card -- Protocol 36, those instances of under-response, when the patient wasn't given enough priority were relatively rare. They did happen but they were relatively rare. But this was kind of at the cost of over-response to quite a lot of patients.

Q. We might look at some of the detail, but that just gives

a sort of overview of what it was aimed to do and the pros and cons, if I may put it colloquially, of what the service is trying to achieve.

A. Yes.

Q. Can I ask you, before we look at that, about some trends in 111 and 999 use during the pandemic. And I think you and a number of your colleagues conducted a survey of all the UK ambulance services and received data from 12 of the 13 ambulance services?

A. Yes.

Q. And what was the aim of the survey that you were conducting which I think you did from February to June 2020?

A. We wanted to gain a snapshot picture of what was the volume of demand, what was the pressure on ambulance services overall and also in terms of Covid-related calls, and what was the effect on their response times, and also we asked all the services about what changes had they implemented during that period.

So it was partly about providing us with statistics, which weren't routinely available, and it was partly about asking them, well, what happened in the control room and how did you change practice during that period?

Q. 12 of the 13 ambulance services across the UK responded.

It was Northern Ireland that did not reply as I understand it. So you just don't know whether they had the data and didn't give it to you or they just didn't have a chance to get around to replying to you.

A. Yes.

Q. But can we have a look at the call volumes, I think you say that the highest proportions of suspected Covid-19 calls were all recorded in the weeks of 23 or 30 March. We went into lockdown on the 23rd. And then we get the calls here on screen identified as suspected Covid-19 by the ambulance services and it's -- you haven't named them but we can see there are 12 and they are given in different colours and lines.

But if we look at, along the bottom, at around the 23 March, 30 March, 6 April, and we track up -- and it may be that our evidence handler can add an arrow, but you can see, going up the page, a huge spike, certainly for ambulance service 3 -- thank you -- on receiving, where we were, a relatively low number of calls in February up to nearly 20,000 calls in 23rd and 30 March?

A. Yes. I mean, I think it's obvious from here that the peaks of demand in terms of Covid-related calls did not hit each ambulance service at the same time. So whilst there is that overall generalised spike there, and

I think ambulance service 3 is here in London, but there were other services where the peak hit a bit later, and there were some services which were not affected by that massive peak in the same way. So it was very different between services and over time. Reflecting the transmission and spread of the pandemic across the country at that time.

Q. Acknowledging all of those comments, though, clearly a huge jump, if one takes ambulance service 3 there, and do you know whether there were sufficient call handlers to be able to deal with spikes like that? Has there been any research done to understand whether we were ready for it, if I can put it that way?

A. At that point I'd say no, not for a huge change like that. I mean, that was like New Year's Eve every day and so the London Ambulance Service put into place the New Year's Eve protocol of when to send, when to not send, and to calling back to tell people there was not an ambulance service available. But that was more extreme than anywhere else. There were definitely shortages of call handlers at a point, yes.

Q. And this is calls to 999?

A. This is 999 calls and it's just the Covid-19, suspected Covid-19 calls.

Q. Looking at 111, I think you make the point in your

report that from February 2020 the public were encouraged to ring 111 as their first point of contact and so I just want to bear that in mind when we look at what happened with the calls in relation to that, but I think you say there were huge increases in 111 demand.

In England, and if we could have up on screen page 17 and figure 4, this is the number of calls to 111 that were either abandoned, answered within 60 seconds or answered in over 60 seconds, and it's in the millions down the left-hand side of the graph. So we can see as we start very early on, 2014, roughly relatively stable numbers and then if we go to the huge spike there in March/April 2020 there was, I think, 1.5 million calls in January 2020 and it spikes to just over 2.5 million calls going to 111 in March 2020. And is this right, over 1.1 million of those calls were abandoned?

A. Yes.

Q. And only 30% were answered in 60 seconds?

A. Yeah.

Q. So having told the public to ring 111 as their first point of contact --

A. Yeah.

Q. -- 1.1 million out of over 2.5 million were abandoned at some stage during the call.

I think you say there was a similar pattern in Wales to that demonstrated in England, and although not quite the same data in Scotland -- could we call up on screen INQ000474258_33 -- NHS 24 did provide some data. It's not quite in the same format but if we see there these are the calls offered, calls answered and the average time to answer. Beginning of March 2020, 8,157 calls, 6,249 of which were answered. Average time in about 10 seconds.

And if we go down to 23 March, up to 12,000 calls, only 3,324 of which were answered, and it's gone from being answered in 10 seconds to an average answer time of 1 hour, 11 minutes and 34 seconds.

So significant pressures on 111?

A. Yes.

Q. I think, can I just deal with Northern Ireland. Did you have the data for 111 in Northern Ireland?

A. I don't think we did. Is it not in the report?

Q. No, it's not.

A. No, we weren't able to retrieve that.

Could I just say that we were only -- for this report only accessing data that was already in the public domain. So we weren't doing any sort of request, new request for data. So if we couldn't find it we haven't reported it.

Q. Can I stick with 999 and 111 calls, having looked at the various peaks of them, and just try to understand the impact that the peaks were having on the quality and the safety of 999 and 111 calls during the pandemic. And perhaps we'll deal with that as a section and then come back to some other matters.

If it helps you, can we call up on screen page 22 of INQ000474285.

And I'd like your help, Professor, with this section of your report. You've explained why triage is important and I think you set out here that there was a study. It was originally designed after the flu pandemic but was hibernated and so therefore woken up during March 2020.

Help us with what the PRIEST study was set out to analyse, please?

A. So the PRIEST study was looking at both calls to 999 and the 111 services that were categorised as potentially or suspect Covid-19 and was able to link those calls to outcomes to find out what was the accuracy of prioritisation really in terms of dispatch of an ambulance or conveyance to hospital for the 999, and for 111 the advice that was given, whether it was self-care advice or whether it was advice to seek further care to understand the accuracy of those

categorisations, whether they were working well.

Q. I think it's just analysing data from one ambulance service; is that correct?

A. Yes, it's from the Yorkshire Ambulance Service and it's for a fairly restricted period of time between April and June 2020.

Q. Even with that caveat to one side, one can see there they're still analysing quite a lot of data from 40,261 adults who contacted that ambulance service alone in that period of time, 111. There was over twelve and a half thousand that rang 999. And over seven and a half thousand adults that went by an emergency ambulance.

A. And these have all been categorised as suspected Covid-19 cases. This is not the whole workload of these services.

Q. No, this is just focusing on suspected Covid-19. So if you rang up because you had had a heart attack you're not going to be included in this data?

A. Yeah.

Q. Right, understood, thank you.

Now, can I ask you about your paragraph 61 which looks at NHS 111. Help us there:

"The risk of an adverse outcome ..."

Where you refer to that you mean where the patient

died or needed major organ support?

A. Yeah, this is the definition used in this paper -- well, there's two papers, one for 999 and one for 111 but they used the same definition.

Q. And so where it says "The risk of adverse outcome was 3% in adults calling NHS 111", what does that actually mean in lay terms?

A. So it means 3% of people that called 111 and were categorised as having suspected Covid-19, ended up at 30 days having died or needed major organ support.

Q. If I follow you then, 11% of the adults that rang 999 either died or needed major organ support and 17.6% of those who were taken to hospital by ambulance either died or needed major organ support.

A. Yes.

Q. They're just the bare facts, if I can put it like that, but what does it actually tell us about how 111 and 999 was operating and how safe or otherwise it was?

A. Well, very broadly, there's an indication that there's some kind of appropriate triage going on there, that -- and although there were adverse outcomes for people that had called 111, they were at a lower rate than people that had called 999 and then with -- in terms of the 999 response, that that was a lower -- it was a higher rate again of people that were taken to ambulance --

taken to hospital by ambulance had these adverse outcomes.

So in very broad terms that is reassuring.

Q. Looking perhaps at the detail of paragraph 62 which focuses on 111, is it most patients who contacted 111 were given either recommendations for self-care or seek a non-urgent assessment and the adverse outcomes were -- when I say "only", I don't mean it like that, but were 1.3% of people who rang 111 died or needed major organ support?

A. Sorry, 1.3% of people that were recommended self-care or to seek non-urgent assessment.

Q. Thank you. Right.

A. So 60% of patients that contacted 111 were recommended self-care or a non-urgent assessment. In other words, not referred to the ambulance service or told to go to the emergency department.

And of that 60%, 1.3% had an adverse outcome, meaning death or organ support at 30 days.

Q. Right.

Are you able to help us with whether that is a tolerably acceptable percentage of an adverse outcome or not?

A. I think it's a judgment call. It is a small proportion but it's a significant proportion and an important

proportion. Whether that is inevitable is another question. Could triage have been better? Maybe but maybe not. This is not a question that I can answer directly. This would be -- you might get a different answer from a different person because it's a judgment call. And it's also: what is achievable in this circumstance?

So this is not really about whether -- the speed of response of the ambulance service or whether -- this is about the decision made using the algorithm, the computer decision support, as to whether the person, what did that person need? And of those that were told they could look after themselves, and usually it says "call back if symptoms worsen", but of those that were given that advice then a small proportion did unfortunately have a very poor outcome.

Q. And it will be for others to judge whether that's a good outcome, a bad outcome, one that we accept or one we think is totally unacceptable. All right.

So that's if you rang 111, were recommended self-care or not to seek urgent assessment, there was a 1.3% risk of an adverse outcome.

If we go to paragraph 63 I think this looks at those that contacted 999 and you say there most patients in this study that contacted 999 received an emergency

response. 84% it was. Patients contacting 999 who did not receive an emergency response, so 16% didn't receive an emergency response, had a 3.5% risk of an adverse outcome.

And, again, I presume the same answer whether that's a good outcome, bad outcome?

A. Yeah, I just want to explain that receiving an emergency response means essentially being sent an ambulance or some kind of face-to-face -- it could be a motorbike, but a face-to-face response for assessment face to face.

And yes, there's a slightly higher risk here of an adverse outcome for those that actually did not receive an emergency response and that might have been for many reasons they did not receive an emergency response. And it may have been in this case a lack of a response to send.

Q. Right.

A. But it -- but that also may indicate that people that called 999 were maybe sicker than people that were calling 111, which is what you would expect.

Q. I was going to say, does it seem out of kilter with the figures of adverse outcome that we looked at for 111 services?

A. No, it feels, again, what you would expect.

Q. And then paragraph 64, most patients, 65% who were

attended by an ambulance were taken to hospital. Of those that were not taken they had a 7.9% risk of an adverse outcome. So higher again for those that didn't go to hospital.

Again, does that strike you as being out of what you would have otherwise expected for those patients that rang 999 but decided for whatever reason not to go to hospital?

A. Yes, that's actually a bit more concerning, I would say, because they've had a face-to-face response from probably a paramedic and then the decision has been taken not to take them to hospital and they are at higher risk of an adverse outcome. So one would have hoped that would be lower, I think.

Q. Are you able to opine as to what the reasons might be for why people were not taken to hospital, given that we know they had an ambulance response?

A. So earlier on you did say it's a joint decision and to some extent it's a joint decision, but I think patients usually will go with the advice of the ambulance crew and -- but they could refuse. So the patient could have refused, the ambulance crew may have advised them that they didn't need to go to hospital or that there are a lot of patients queuing outside hospitals in ambulances as well at this time. So I can't really

comment on which of those was happening. But it's -- you would like to see a lower rate than -- of that.

But it also could be that people deteriorated later. So at the point that decision -- because this is a 30-day outcome. So at the point that they were seen by the ambulance crew maybe they didn't need to go to hospital. Maybe a week later they needed to. So it's easy to jump to conclusions, I think, but actually it's very complex.

Q. There's a number of reasons why it may be that on that given day they weren't taken to hospital?

A. Yes.

And they may not have needed to. I think that's important because people's symptoms were varying and people did deteriorate very quickly during the pandemic, so it might have been entirely appropriate on the day.

Q. Can I ask you about your paragraph 67 which is about some research undertaken during the pandemic which identified that:

"... 111 triage may have overestimated the importance of chronic lung disease as predictors of adverse outcomes and underestimated the importance of diabetes and repeated calls to the service as predictors of adverse outcome."

A little bit of a mouthful there.

Can you help us, Professor, with what was the concern you were trying to bring to our attention here in this paragraph?

A. So this is the same study, the PRIEST study, and this is 111 calls. And in addition to looking at how well did the call outcome, whether it's self-care advice, referral to 999 or whatever, how well did that match with then what happened to the patient, they looked at that and they looked at well, what factors were involved in that and what factors influenced the outcomes. So -- and they found that the -- that in decision-making that some factors were given too much priority and other factors were under-considered.

So, for instance, diabetes and more than one call to the service were found to be actually associated with poorer outcomes, which they had not known before. So this information can help with improving the algorithms and the decision support tools for the future. But that was -- that's what they found in the PRIEST study and the 111 calls.

Q. Do you know having -- the study having reported its findings, were any changes made to the algorithms to correct either the underestimate or overestimate?

A. I don't know but I can't imagine that the timeliness would have worked for that but I'm not sure.

Q. Whilst we've got this page up on screen, I think at your paragraph 69 you make reference to false positives and false negatives certainly lower down the page. Just help us with what you mean by that, please.

A. So a false positive is when somebody is allocated a higher response when they didn't need it. So they were thought to be in an immediate and life-threatening situation when they weren't. We call that a false positive. And whilst that is going to put pressure on the whole system and you don't want to over-respond to calls, it's not putting an individual in danger.

But the false negative is putting an individual in danger because it's when a patient who should have had a high priority is given a low priority and so it's a false negative and that is -- it happens more rarely, it doesn't happen as often as the false positives but it does happen and that's a situation which is dangerous or lacking safety for the patient.

Q. I think you're saying there, though, that in fact no triage tool always gets it perfectly right all of the time. You say there will always be false positives and false negatives but you reduce them to what is called an acceptably low level where the test is worth it despite the occasional errors?

A. Yes, and that is actually a decision -- that is a sort

of policy decision or a clinical policy decision for the service as to the trade-off really between sending to -- when a patient didn't need that level of response, and/or not doing that but occasionally missing someone that does. Just to say that, to remind everybody really that this is done on the basis of information given over the phone by non-clinical people, members of the public calling with information about maybe they're in a very highly stressed situation and it's not an easy job to assign that priority.

But where the acceptable levels are is not something I can comment on really.

Q. You do make the point in paragraph 69 though that results are not presented by ethnicity which is seldom coded in the ambulance call centre and often missing on the scene. Can you help with why there's no coding either at the call centre or indeed on the scene for ethnicity?

A. So we're actually doing a study about this right now. So this is why we know this in more detail. But I think to present ethnicity, to get ethnicity data the question has to be asked. And in the context of a 999 call one could imagine that that's not the priority to ask -- they're looking -- the call takers are looking for the priority of the call, and the name and address: where do

we need to send the ambulance? And other questions are not generally asked.

So whether it should be is another matter but that is the current situation and I think it's understandable, but on scene when patients are attended by ambulance crews there's much more information filled out and there's an opportunity then, unless the patient is in a critical situation or unconscious, there's generally the opportunity to ask for ethnicity. But we have found that ethnicity data is very, very often missing.

And where -- for instance, we're doing a study now where an ambulance service told us that we have ethnicity on 80%, 84% or something of our patients. But when we came to look at it they were the white British patients that were marked down with ethnicity. And the missing ethnicity, there were very, very few other ethnic groups coded so we assume other ethnic groups are going into the non-coded -- we can only assume that it's a reluctance on the part of the ambulance crew to ask those questions in the emergency situation.

Q. Do you think it would be helpful, let's take the call centre out of it because I take your point about it may be urgent and different priorities, but do you think it would be helpful if in future there were at least on the

scene ethnicity data recorded?
A. Yes.
Q. And can I then just bring this to -- this section to a conclusion and I think you say at your paragraph 78 that clearly 999 and 111 services were overwhelmed at times with great degree of variation depending on which service it was. Are you able to help, though, with whether 111 effectively reduced the pressure on the ambulance services and the emergency departments as was the aim by telling people to call 111?
A. I actually think it's impossible to tell that because when NHS Direct and then 111 were first introduced that was the aim of the services, and it actually seemed to generate new demand, and so the extent to which people who called 111 would otherwise have called 999 we just don't know.
MS CAREY: My Lady, would that be a convenient moment?
LADY HALLETT: Yes, certainly. I shall return at 3.10.
(2.53 pm)
(A short break)
(3.10 pm)
LADY HALLETT: Ms Carey.
MS CAREY: Thank you, my Lady.
Professor Snooks, can I ask you, please, about two other services that were set up in the pandemic to

support NHS 111. We've looked at, obviously, the real spike in the number of people calling them and the impact that had but I think it's right that you set out in your report that there was something called the Covid Response Service that was set up, and then another service called the Covid-19 Clinical Assessment Service.
Can you help me with both of those, what were they trying to do and did they achieve it?
A. So I'm less familiar with these services. I know that they varied across the UK so there were different local responses and these services set up but in terms of how they all fitted together this is not my area of expertise.
Q. Fine. I think you did include in your report, though, some of the call volumes that went to both the Covid Response Service and indeed the Clinical Assessment Service. And correct me if I'm wrong, is this people that are ringing 111 and then are diverted again to one or other of these two services; is that the aim?
A. Yes, I also believe 999 were diverted to these services. I'm not sure if I'm right on that.
Q. Okay. I think -- can we look on screen at INQ000474285_21.
CRS, the Covid Response Service was set up in March 2020, and the CCAS, the clinical assessment

service, was only started in April, which is why there's a zero in that column.
It might be easier, Professor, to look on the screen if that helps you.
A. Yes. No, I was looking at the purple still.
Q. Ah, thank you, feel free to jump in if there's anything that you want to add, but we can see for those people that ended up being diverted to the CRS in March 2020, quite a large number there, 851,000 calls offered, answered, 779 of those, abandoned, 38,000, so the abandonment rate was 4.5% and, as we can see, CCAS wasn't up and running then. There's quite a large volume of calls through CRS in March, April and May of 2020. And I think, did it -- did CRS operate at different times which is why we have got periods where there's no data?
A. As I said, I'm sorry, I'm less familiar with this service.
Q. I think it just gives us an overview, really, though, of the number of people trying to ring and find out more advice and seek assistance in relation to Covid calls. And if we just look down the CCAS calls, they were, I think, a remote clinical review of patients that then directed them on to the most appropriate care and you can see there, 62,000 people ringing that in May of 2020

and then diminishing numbers and varying in numbers depending on where we were in the peaks and the waves of the pandemic.
In your report you make the observation that those people working in the emergency operations centres providing the immediate response to 999, they were trained but not clinically qualified; is that correct?
A. Yes.
Q. Ambulance services increased the number of clinical advisers to support the increase in the volume and they diverted clinically qualified staff from other roles to help in that response?
A. Yes.
Q. And you say in the Welsh Ambulance Service many clinical advisers switched to working from home leading to reported increased levels of autonomy but some concerns about clinical supervision and support. Are you able to expand on that at all, Professor?
A. Which paragraph?
Q. Paragraph 53, your page 20. If it helps you, we are going to put it up on the screen.
A. So this is taken from this paper by Brady and Harry. I don't think I can further comment on that.
Q. So you wouldn't able to help with what clinical supervision was provided to the workers at home or

anything of that nature?
A. No, or how it differed from what they would get if they were in the call centre.
Q. That was the other question I was going to ask.
A. Sorry.
Q. I fear you won't be able to help. All right.
Perhaps a topic you will be able to help us with, Professor, is the trends in ambulance responses and handovers. And it starts at your paragraph 79. And clearly, you say, response times were variable at the start of the pandemic. People will be familiar with delays to ambulance response times even outside of pandemic times but you say, for example, it might be easiest to look at figure 6 on page 26.
So Category 2 calls in England, not the most urgent but the next one down, it would include people having a stroke and with chest pains. This is the mean ambulance response times in England and we can see there in January '19 the position and the dotted line running across the bottom there I think is the line at 18 minutes which is the target response time for a Category 2 --
A. In England.
Q. -- in England. So you should get an ambulance with you in 18 minutes. 90% of calls to be responded to within

40 minutes. And then if we track across we can see that in March 2020 in London, which is the black line, response times jumped to over an hour.
A. Yeah.
Q. Go on again, a dip in the summer, a rise again then in autumn and winter into 2021 and then, Professor, we get a significant increase as we go through 2021 into 2022 and albeit outside of our relevant period, a spike of over 2 hours 30 minutes response time by the time we get to November/December of January 2022.
A. Yeah.
Q. Now, I'll come to the end but we can see there a rise throughout the pandemic albeit perhaps less severe waves -- can you help with why it was rising throughout 2021 and 2022?
A. So -- it's complex. So it's important to remember these are not the Category 1 calls which are immediately life-threatening calls which are prioritised really at the expense of Category 2 and other calls.
So it's very related to demand. So at peak times of call demand then we're seeing these higher response times. They're very variable, so they're not affecting everywhere at the same time but it's complex because with the increased volume and also the increased complexity of calls with Covid-19, the job cycle time,

which is the time from when the 999 call is made till when that vehicle is free again, really increased dramatically and we saw ambulances queuing outside hospitals more than we'd seen before, which is then impacting further on the availability of ambulances to respond to the next calls.
So this is a complex picture of demand and coping with that demand by the services. So it's -- and it is demand but it's more than that and the availability of staff as well, because of the high sickness levels. So all these things are coming together to mean that at times ambulance services, I would say, were overwhelmed by their demand.
Q. In fact, we can see there a shift from London being the spike at the beginning of March 2020, and if we go to the spike in March of 2022, it's now the south-west of England that's got the worst response time and, indeed, it remained in the south-west of England by the time we got to the end of 2022?
A. Well, you can see there in that spike, the London Ambulance Service -- the spike for the London Ambulance Service is higher than it was in the first year.
Q. Yes.
A. So yes, it was generalised but it didn't affect everyone at the same time.

Q. It's nonetheless, though, a long wait from the 18 minutes that should have happened at the beginning of the pandemic to waiting over 2 hours plus for a Category 2 response?
A. Very much so.
Q. Let's look at Wales briefly.
Can I have up on screen figure 7.
These are Amber calls which, again, is not immediately life threatening, as I understand it; is that correct?
A. Yes. I think it's equivalent to Category 2 for England.
Q. Are you aware that Amber was subdivided into Amber 1, life threatening, and Amber 2, serious but not immediately life threatening? Were you aware of that?
A. Yes.
Q. And in Wales here are the health board's response times and we can see in 2020 they start to rise significantly as we go through the pandemic and again a significant spike as you go through again towards the end of '22 and into the beginning of 2023.
A. Yes.
Q. I think there's no set response time; is that correct?
A. That's right.
Q. There's no baseline of 18 minutes or the equivalent in Wales?

A. Not for the -- yes, they only have the 8-minute response time for the immediately life-threatening one.
Q. Life threating, thank you. But again, nonetheless significant waits by the time you get into 2021 and 2022, if you are in the Amber category, including up to nearly 4 hours by the time you go through 2021 and 2022. And not an equivalent set of data for Scotland but -- just give me one moment. Data for Scotland I think shows again that there was a significant rise in the average turnaround time from 30 minutes pre-pandemic to nearly an hour at the end of June 2022. So not in the same category as England and Wales there but a rise nonetheless.
Are you able to help at all as to why there was a rise but not such a steep rise in Scotland?
A. Can you point me to where you saw the turnaround time?
Q. Yes. It is in paragraphs 82 and 83 in your report. And I think it was in data provided by Scotland that showed the turnaround time?
A. I can't see the Scottish data there but I just wanted to say that turnaround time is not the same as the job cycle time that I referred to earlier. Turnaround time is the time specifically at hospital to offload the patient, pass on -- clinical handover and then the ambulance being free, for which there are national

standards of 15 minutes and the turnaround time you are talking about now is that handover and handover delay which is what is referred to in paragraphs 82 and 38.
Q. Fine. So we don't always have the equivalent data in terms of the length of time you wait for an ambulance. In Scotland, though, we do have the length of time at hospital, is that the --
A. I don't think so. Because 82 and 83 are not about Scotland.
Q. Right, have a look on the screen because we have called it up onto the screen now in front of you, and we have got the turnaround times for Scotland where we can see it rises quite significantly as we go through 2019, 2020, and throughout then our relevant period.
A. As it did across the UK, I believe.
Q. All right.
A. But yes, the individual datasets and definitions are not exactly the same so it's quite confusing to try to pull this data together in a consistent manner.
Q. Thank you. That's all I wanted to ask in relation to that aspect.
Professor, if it helps you, although you've set out in your report some of the impacts that the pandemic had on the ambulance service workforce, we've actually heard some evidence from other witnesses about that so

I won't ask you about it.
Can I change topic completely, please, and deal with parts of your report in relation to shielding and I'd like to, please, start at the end, as it were, and before I do so, is it right, Professor, that you in fact were on the shielding patient list yourself?
A. Yes, that's right.
Q. May I ask you at the outset, and I don't mean this impolitely, has your personal experience of being on the shielded patient list affected anything that you've included in your expert report?
A. I think being on the shielded patient list myself only made me really keen to gather some evidence about the effectiveness of shielding. So I was very committed to being able to carry out some research and evaluation in this area, but not in terms of the interpretation and the results provided.
Q. Thank you very much. All right. Can I put up on screen, please, page 52 of your statement which is where you deal with your summary.
Now, you make the point that shielding was implemented and evaluated in the context of almost simultaneous introduction of general lockdown and therefore we have to keep that in mind when we look at some of your conclusions. And you say this at

paragraph 147:
"There is no evidence of overall reductions in Covid-19 infection associated with shielding, except in a subgroup of rheumatoid arthritis. There is evidence that hospital acquired infection was higher in the shielded group. As the mechanism for protecting [clinically extremely vulnerable] people from serious harm or death during the pandemic is to avoid infection, these results cast doubt on the effectiveness of the shielding policy."
And in coming to that conclusion you make the point:
"There is little high-quality evidence on the impact of shielding on mortality but those researchers that have investigated this have not found consistent or sustained effects."
And then you set out various other things.
Now, I just want to ask you, given that you accept there is little high quality evidence on the impact of shielding on mortality, and given that we've got to bring into it a caveat we're in lockdown generally across the entire population and I think you make the point there is no clear control group to say, well, if you hadn't shielded this is what would've happened, why is it that you come to the view that the shielding

policy was perhaps not as effective as it might otherwise have been?

A. Because shielding -- so the shielding was introduced against the background of generalised lockdown. And that's just context. That's not a caveat really, that's just context. Shielding was not evaluated as a standalone policy because it was introduced almost at the same time as lockdown. So that's -- and nobody could look at shielding outside of lockdown. That was the background.

Because shielding was introduced as a public health policy across the UK, at one time, there was no possibility of carrying out any kind of randomised trial or experimental research to see whether it was effective or not. There was no evidence of effectiveness that it was based on. It was introduced only in the UK and in Republic of Ireland, nowhere else in the world.

So, in that context, we've looked at the best quality evidence that was produced, through several high-quality research studies, but they were not randomised control trials, which were impossible.

So my view then is that you make the best of the evidence that you have, and several of these studies constructed the best control group or comparator group possible by, for instance, constructing a similarly

vulnerable group. They couldn't be exactly matched because the shielding policy included entire clinical codes. So you couldn't have matches for those clinical codes. And so every study that has used some kind of propensity matching, which is sort of trying to identify other people that were equally vulnerable, none of those studies, including one that I led, was able to do that perfectly.

Nevertheless, the comparisons between people shielding, the best comparator group available, and then the general population, several studies have come to the same conclusions. There may have been isolated short-term regional improvements in one aspect or another but, overall, no consistent evidence of an impact on infection rates or Covid-related mortality, which is what shielding was trying to achieve.

Q. May I understand this though, would you not expect a higher rate of mortality in people because they're CEV? It's their underlying comorbidities make them more at risk so it's not surprising, is it, therefore, that more of them died?

A. Well, I -- so when -- most studies have found a higher mortality rate, which I would expect, but a higher Covid-19-related mortality rate one would have hoped not to see. And in particular there is a much higher rate

of hospital-acquired infection amongst people in the shielding group to their comparators, which I think -- this is the interpretation that we've come to, that that's the reason it couldn't work.

Whilst people might have been shielding from their neighbours, their friends, their families and so on, they were having such a high contact with hospital staff and healthcare practitioners that, whilst healthcare-associated infection was not under control, shielding didn't seem to be able to -- was not -- was not able to be effective.

Q. So does your conclusion come to this, that whilst hospital-acquired infection rates were high then shielding itself could not have been effective as a policy?

A. Yes. Yes, as a public policy. Not on an individual level. I want to make this really clear, because I know this is really a sensitive subject, that this is not saying that individuals should not have isolated at all.

This is saying: as a public health policy, should this have been -- was there evidence? Should this have been produced? Should it be introduced in a future pandemic? And my conclusion from this, all this research, is that whilst hospital-acquired infection is so high then shielding, as it was introduced last time,

simply couldn't be effective.

Q. What about those shielders who didn't need to attend hospital? Presumably there's no evidence about what the effect the policy had on people who weren't going into hospital for appointments and scans and the like?

A. But I think there were very few people in the shielding group that were not having contact with healthcare professionals. And the hospitalisation rates were much higher amongst shielded people than the other groups. But there may have been pockets of people. We did look in subgroups. We didn't find any evidence within those subgroups -- clinical subgroups -- of reduced infections and reduced Covid-related mortality. We were looking but we didn't find it.

And if ours was the only study done that's one thing, but ours was not an outlier. Each of the studies we looked at, the large-scale studies, were coming up with the same conclusions.

Q. Of course, if the people who shielded did not suffer hospital-acquired infection, is there anything to suggest that shielding policy wasn't effective for those people?

A. This would require a further look at the data. Which could be done, hasn't been -- as soon as you start separating out groups it becomes very complicated,

because then you're looking at: well, who is our comparator group? And is that -- so in the other vulnerable people group, who were comparators, do we then take out the people there that were -- went into hospital.

As soon as you start doing that subdivision the comparisons become less and less credible, and valid. So we can look at that more but that hasn't been published to date.

Q. I'm asked to ask a number of questions of you on this topic, and I suppose one of the matters I think you are aware of is we asked Professor Whitty about your views and he made the observation that you'd set out the various studies in the way that you have in your report, but essentially said he wouldn't go as far as you in interpreting them in this way. He said that he is not excluding the possibility that you're right but that certainly wasn't the intention. And certainly he says there's -- effectively, an absence of evidence one way or the other doesn't mean that the shielding policy did not work.

Can I ask for your views on that, please, Professor.

A. I think this comes down to whether, in a situation where you cannot carry out a randomised control trial, which

is generally seen as the gold standard of evidence, in that situation any other study is going to be -- have its caveats and its limitations. And -- but I don't think -- it's a sort of do you throw the baby out with the bath water. We still have to try to gather the evidence that we can and interpret it to the best of our ability. So these are very large scale studies.

The study I led was the whole population of Wales, a 130,000 shielding people and 130,000 comparators, so these are not small studies. These are over considerable time as well.

And so my response with that would be we are taking the best studies we can with the best evidence we can and making the most of that.

For instance, the Medical Research Council funded our study, was £1 million to do that study. I wouldn't like to sit here and say, oh, we didn't find anything out. We found what we found, which was no evidence of an improvement in Covid-related infections. And higher Covid-related mortality. And much higher hospital-acquired infection. So I feel duty bound to report that and make the best of that evidence that I can. But I understand that others will criticise that.

Q. Or have a different view?

A. Yes.

Q. I ask you though because actually when it comes to your ultimate conclusions in your report, you said:

"We cannot recommend that shielding is introduced in a future pandemic as the best current evidence does not show that it was effective in terms of reduced infections or Covid-19 related mortality."

And you say that:

"In a future pandemic we recommend attention needs to be paid to healthcare transmission as a priority because shielding cannot work while infection rates from hospital and other healthcare contacts are high."

I'm going ask you, do you think that's overstating it and it may be that it might not work whilst infection rates are high, because clearly there are plenty of people who didn't go into hospital who were shielding?

A. I don't believe it's overstating. I've considered this and reflected and considered, because I've been challenged several times during the course of putting this report together on this, and have come back to the same conclusion from our research and from the research that others have carried out in this area.

That's the conclusion and the recommendation.

And that's also taking into account that -- the cost to the public purse and alternatives that have not

been able to be done, and also the restrictive nature of shielding and the adverse effects on people's psychological well-being. So it's not like there's no costs to shielding. There are both financial and costs in terms of harms to patients through the shielding -- and protective effects. Both. And it's trying to get a balance of that out.

But whilst -- the whole point was to reduce infection rates. And if it couldn't achieve that, whether it be through the overall infection or the hospital-acquired infection, then it doesn't feel to me that we could recommend it in a future pandemic. That the priority should be on reducing hospital-acquired infections.

And it is absolutely not to say that individuals should not or should not have self-isolated. This is not what we're saying here. We're saying: as a public health policy, did this work?

Q. Hence why you say you've come to the conclusion that you have.

Can I ask you about perhaps a more positive aspect of the shielding programme. I think you said that if you are on the shielding programme you're more likely to be vaccinated?

A. Yes.

Q. And was that not a positive benefit?
A. Yes.
Q. Particularly to those -- later, once vaccines were available and being rolled out?
A. Absolutely. It wasn't the purpose of shielding but it provided a really good vehicle for rolling out vaccinations to the most vulnerable people first. And we did find both a higher proportion of people vaccinated than our matched group, and much higher than the general population, and also they got vaccinated earlier.
Q. Professor, would you give me one moment. I just want to check that I have covered all of the questions I need to ask you in relation to the shielding programme.

(Pause)

Only this, and I suspect I know the answer, but I'm asked to ask whether it's more accurate and nuanced to say that the effectiveness of shielding would have been better enhanced by better controlling rates of nosocomial infection rather than saying we shouldn't have the programme in the future at all; what do you say that to that?
A. Well, we don't know the answer to that.
MS CAREY: My Lady, they are all the questions that I have. There are a number of core participant questions though

for the Professor.
LADY HALLETT: I think we begin with Mr Rawat.
MS CAREY: Yes.
LADY HALLETT: Over that way, Professor.

Questions from MR RAWAT

MR RAWAT: Good afternoon, Professor Snooks. My name is Bilal Rawat and I am here on behalf of the United Kingdom Health Security Agency, or UKSA as it has been described during the course of the inquiry.

I have a number of questions for you which relate to some of the studies on shielding that you've cited in your report for this Inquiry. My time, as you may find out, as I may find out, is limited, so I'd be grateful, if you can, if you can keep your answers relatively short.

My first question relates to the 2021 paper by Jani and others, which is the Glasgow study I think. Can you confirm that that study considered three different groups with three different levels of risk for catching Covid and for dying if they did catch it?
A. Yes.
Q. And would you agree, therefore, that the Jani study did not account for all confounding factors, an obvious one being the levels of comorbidity, because the three groups in the study had, by definition, three different

risk profiles?
A. Sorry, I don't think I'm understanding the question. I mean, one -- I don't think we can ever account for all confounding factors but the comorbidities would have been indicative of the risk category they were put into, so, in a way, it was -- they were considered, I believe. Am I answering -- I'm not sure if I'm answering your question.
Q. Well, I'll take your answer so that I can move on to my next question.
A. Thank you.
Q. And I'll move on to the Liverpool study, which was the one by Filipe, Barnett and others.

That was a study, wasn't it, where there was an attempt to match a comparator group; is that right?
A. Ooh. I believe so.
Q. Because I think from our reading of your report and the study, it compared a shielded and non-shielded group, matched, for example, for age, sex, diagnosis with a long-term condition. So there was an effort to find a comparator group, wasn't there?
A. In the Liverpool study?
Q. Yes.
A. Yes.
Q. The authors of that study found and I quote:

"Shielding was associated with a 34% reduction in the risk of dying ... compared with a propensity-matched non-shielded group."

Would you agree that this was a reasonable conclusion for these experts to reach based on the data available to them?
A. So, my reading of that study was that there was at one point in time a reduced risk of mortality but then over a longer period that reduced risk of morality disappeared.

It's quite confusing to understand their results, I do -- I agree. But that's what I understand from that study, that it was a short-lived -- and it was also in just that one area, in one region -- but it was a short-lived reduction in mortality. But then over the longer period it disappeared.
Q. Thank you. If I move on, and I'm going back to a point that was canvassed with you by counsel to the Inquiry, and my question is this. Given that those shielding (a) could attend hospital appointments, (b) were likely to have to attend hospital more frequently than those who were not shielding, and (c) were, by virtue of pre-existing factors, more at risk of acquiring an infection when attending hospital, would you agree that the incidence of hospital-acquired infection in the

shielding group is not a viable measure of the efficacy of a programme that was intended to reduce the exposure of the most vulnerable to community transmission?

A. I think that's fairly nuanced. I think actually the point -- the point is that shielding was intended -- my understanding, that shielding was intended to reduce Covid infections overall in the clinically extremely vulnerable. And where they got it is -- it doesn't feel like it's really the point.

But you would hope that -- I would have hoped that hospital-acquired infection would be -- I mean, it's dreadfully sad -- it's all sad but it's dreadfully sad when the infection is picked up in hospital.

So you're asking me whether it's an unfair comparison because they had to go to hospital; is that right?

Q. Well, my question is directed to the use of the incidence of hospital-acquired infection as a measure of a programme that was intended to reduce community transmission.

A. Okay. I guess that's a fair point.

We were looking at that point. This was not our primary outcome. Our primary outcome was infection and Covid-related mortality. The hospital-acquired infection was an attempt to understand the mechanism.

Q. Thank you for that.

Can I move on to my last question for you. It's this. And it picks up on a point that was put to you about Professor Whitty's views on your report.

Would you agree that it is near impossible to conduct a meaningful analysis of the shielding programme, not only because of the limitations in relation to a comparator group, but also because it's difficult to disentangle shielding policy during this pandemic from wider societal measures such as social distancing and lockdown?

A. Sure, it makes it more challenging, but we did -- our study and other studies did not -- I said this at the beginning -- did not evaluate shielding. It was not a standalone initiative.

In the study that we looked at in Wales, we did send out questionnaires to people in the shielded group and in the also vulnerable matched control group, and there was a distinct difference in terms of behaviours. So people in the shielded group both originally and one year later were still isolating a lot more than people -- were reporting that they were self-isolating a lot more than the people in the matched control group.

So it -- and for people who were affected by shielding, I think they will understand that shielding

was a level above general lockdown, so general lockdown was, of course, restrictive to people, but shielding was on another level. So to be asked or instructed, however you saw those initial letters, to take one's meals separately from one's family for the next 12 weeks, to not be in the room with family members during that next 12 weeks, it was -- it was a step up -- much higher than general lockdown.

So I think -- well, as a researcher, and as a health services researcher, it's absolutely my -- it's my obligation to try to understand how well that worked and is that something that should be done again.

MR RAWAT: Professor Snooks, thank you for that.

My Lady, those are our questions.

LADY HALLETT: Thank you very much indeed.

Ms Mitchell. That way.

Questions from MS MITCHELL KC

MS MITCHELL: Professor Snooks, I appear as instructed by Aamer Anwar & Company on behalf of the Scottish Covid Bereaved, and I'd like to ask you some questions on a matter which hasn't been touched on in any great detail so far. And I hope you're able to assist me. If it's not within your area of expertise, please just obviously let us know.

The Inquiry has heard a lot about the

precautionary principle, and perhaps it's something that seems easy to say, and quite a few people disagree what it is, but going on the basis that using the precautionary principle is, in layman's terms, better safe than sorry, would, in your opinion, the availability of powered respirator hoods have helped reduce infection rates in paramedics?

A. So, I'm very sorry, but it is outside my area of expertise. I'm not able to answer.

Q. I did preface my question as I wondered, having reflected, whether or not that was in your area.

And I have no further questions, my Lady.

A. I'm sorry I couldn't answer that.

MS MITCHELL: No problem.

LADY HALLETT: Thank you very much, Ms Mitchell.

Mr Puar.

Questions from MR PUAR

MR PUAR: Professor Snooks, good afternoon. I ask questions on behalf of Covid-19 Bereaved Families for Justice Cymru who are a group of bereaved families based in Wales.

Can I ask you a question about 999 and 999 in Wales. In the statement to this Inquiry from Jason Killens, who's the chief executive of the Welsh Ambulance Service NHS Trust, he describes a system that

existed before the roll out of the intelligent routing platform in November 2022 where those that made calls to 999 who were based on the Welsh borders, particularly when they made that call on their mobile phones, were often responded to by providers in England and then would have to be retransferred to callers within the Welsh Ambulance Service NHS trust.

First of all, were you familiar or are you familiar with that system?

A. I'm familiar with it broadly but not in great detail.

Q. All right. Well, I'll just ask you some follow-up questions on that and see if you can assist us with it.

Did that system add at all delays in responding to 999 calls by having to transfer to England and then back to Wales?

A. I would have thought it would have improved the response because they were transferred, I understand, when calls were not being able to be picked up quickly within the one service. I may be misunderstanding.

Q. Okay. And can you explain, in practical terms, how call handlers were trained when they were based on the borders?

A. I'm sorry, no, I'm not able to answer that.

Q. Fine. The next topic I want to ask you about is 111 calls within Wales. And you state at paragraph 43

of your report that Welsh Government data demonstrated a similar pattern to that of England in terms, at least as I understand it, the volume of calls that took place at the start of the pandemic but does it follow as well from your paragraph 43 that performance in Wales also reflected the performance in England?

A. I believe so but I don't have the specifics of that.

Q. Okay. In that case, can I ask you, also again in practical terms, when calls weren't answered on 111, did it go through an automated system at all or did it just simply continue to ring, or you don't know?

A. I don't know but I would -- I don't know. This is the answer to that. And the term "abandoned" is a bit like abandoned by the caller or abandoned by the service and I think it means it wasn't answered. The term "abandoned" is slightly not helpful there, I think.

Q. My last question is just in relation to calls not being answered on the 111 system, what was the expected alternative for families who couldn't access the service, what was the advice or what were they supposed to do in that situation?

A. Well, I don't think it was expected that 111 wouldn't answer their calls but then they would be falling back on the other providers of unscheduled care, be it their out-of-hours GP, or in hours, depending on the time of

day or the 999 service or the emergency department. Those would be the sources of advice available but they were all compromised at the same time.

MR PUAR: Yes, thank you.

The remainder of my questions have already been answered in the course of your evidence, so I'm grateful.

LADY HALLETT: Just before you sit down, Mr Puar.

Can I just pursue a matter that Mr Puar was asking you about. I am afraid I didn't appreciate this until Mr Puar's questions.

If you're on the Welsh border and you basically need a response from the Welsh Ambulance Service, but you're using a mobile phone so your area can't be tracked -- which I think is the point of using the mobile phone, Mr Puar; is that right?

MR PUAR: Yes, as I understood it, it was that the call centre pylons, whatever, pick it up.

LADY HALLETT: Okay, yes. So basically it's picking up somebody who is on the English/Welsh border but can't actually pick up that they live in Cardiff, or wherever, I'm just thinking about the -- so supposing it's rerouted to an English call handler, their first questions aren't going to be "Where do you live?", are they?

A. Are we 999 -- 999?

LADY HALLETT: 999.

A. The first questions are: is the patient conscious, breathing?

LADY HALLETT: Exactly.

A. Yes.

LADY HALLETT: So it must cause a delay, mustn't it, if the call hander has to go through all the process of what's your categorisation triage process before they even get to the address and the postcode?

A. I don't think necessarily because that call prioritisation could be passed back to the Welsh Ambulance Service, they wouldn't have to go through it again. But I'm sorry, I misunderstood at the time because there are also systems for when services are at over capacity and they can't answer their calls for neighbouring services to be handling those calls and that's what I thought you were referring to at the beginning. So this is a different issue.

I don't think, in principle, that should lead to a large delay, but at a time when services were so stretched I can't answer if it actually did, in practice.

LADY HALLETT: Did I get the wrong principle, Mr Puar?

MR PUAR: No. Can I ask one further question arising from

that, then?

So, there's a delay initially when calling 999 to get through to an operator.

A. Very short.

Q. So the operator in England, then, is ringing on the same system or can they transfer directly to a --

A. Yes, I don't know about the telephony arrangements they have in place but -- so when you call 999 first you get through to the generic responder asking: fire, police ambulance? When you get through to the ambulance service those pick up those -- those answering the phone delays are very short and I believe remained very short during this period. And so then the call prioritisation would happen and then it would get transferred back. In principle, there shouldn't be a big delay involved in that unless the receiving service was very stretched with its -- with answering and dispatching, which they were at this time, but in principle I couldn't see that that in itself should be causing a delay.

Q. All right.

A. But I don't have the data to back that up.

MR PUAR: Thank you.

LADY HALLETT: Thank you very much.

Mr Wagner.

Mr Wagner is over there. Can you see him?

Questions from MR WAGNER

MR WAGNER: Good afternoon, Professor Snooks. I want to ask you first about what I've come to think of as the frying pan and the fire issue.

A. Sorry, could you just let me know who you are speaking on behalf of.

Q. I'm sorry, I'm speaking on behalf of the Clinically Vulnerable Families.

A. Thank you.

Q. So for many clinically extremely vulnerable people, on the one hand they were being told they needed to stay at home because they were at high risk from Covid, that community transmission point, and on the other, they knew or at least suspected that if they went to a healthcare setting for an appointment they could be at high risk of contracting Covid because of lack of adequate protection and mitigations in those settings.

Do you agree that that led to extremely difficult choices for those clinically extremely vulnerable people, perhaps including yourself, about deciding whether to attend healthcare appointments or not?

A. Absolutely, yes.

Q. I want to ask you, secondly, about the end of shielding which you haven't talked about in the oral evidence but you refer to in your report. So when shielding came to

an end, was lifted, in March 2021, other protective measures such as mask mandates and social distancing requirements were lifted around the same time and at that stage vaccines and antivirals were still not widely available and in fact they hadn't -- vaccines hadn't been given out to even all of the clinically extremely vulnerable. Do you agree that the combination of those factors would have caused very significant stress and anxiety to the people who had been told up to that point they should shield?

A. Yeah, I think that was a very difficult time. But we did find very, very high rates of vaccination amongst shielded people at that time but still that wouldn't have -- that would have maybe gone to some level to mitigate that but, yes, I think that was a very anxious time. And we did find that the effects of the -- well, the association between being in the shielded group and strictly isolating was still going -- was still much higher in that group than other vulnerable people, even a year, 15 months after the start of the pandemic in March 2020. So 15 months, 18 months later there was still a very high level of self-isolation, self-isolating behaviours going on and some fear of going outside.

Q. I want to ask you about the effects of the shielding

programme, and trying to distinguish it slightly from the sort of, if I put it like this, a brute focus on mortality as the outcome. And just on a couple of positive effects and just see whether you agree or not. Firstly, shielding, it functioned as a passport which gave access to various forms of support, so entitlement to deliveries, at home with food parcels, priority access to supermarkets, home deliveries of prescription medication and, very importantly, Statutory Sick Pay for those not eligible for furlough. Do you agree that just in terms of helping people on an individual basis protect themselves in the community, do you agree that was a positive aspect of the scheme?

A. Yes, absolutely, and I also think that in considering the future, although shielding as it was implemented during this pandemic may not be appropriate and was -- we didn't find it to be effective in terms of, as you say, the brute outcomes but I do believe that there should be some consideration given to how people who are maybe eligible or need or wish to self-isolate, how they can do that because taking away shielding would be taking away all those benefits as well and I'm very aware of that.

Q. And secondly, the ability to communicate and for members of the public to readily understand, so for example

an employer, that those shielding had an urgent and legitimate need to reduce their risks, quite different to the other population, the general public, do you agree that educational aspect, communication aspect was a positive effect?

A. I think it was but I also think that there were people that were not categorised as require -- as clinically extremely vulnerable who then kind of missed out on that and some of those people felt that should have been in the shielding group. So it was in some ways almost an arbitrary cut-off between shielding and -- well, clinically extremely vulnerable and clinically vulnerable.

Q. Well, that just brings me neatly onto the final question I have for you which is about who got in and who didn't.

So, obviously clinically vulnerable people, and when I speak about clinically vulnerable I'm excluding clinically extremely vulnerable just for now.

A. Yes.

Q. So the people who wouldn't have been told to shield, but they were still at higher risk of dying from Covid, weren't they, by definition, and having bad effects from Covid; is that fair?

A. I think so, yes.

Q. Would you agree that more learning is required for

a future pandemic to think through how better to protect those individuals who were given none of the protections that clinically extremely vulnerable people were and perhaps there could be more of a spectrum?

A. Yes, I think that could be considered, definitely, yes. And as Ms Carey had said earlier, perhaps look in more detail of -- a secondary analysis of some of the data of some of the studies that have already come out, to find these pockets if those pockets exist of people that actually benefited from shielding for instance or didn't, to help contribute to that formulation of policy for the future.

MR WAGNER: Thank you. Those are my questions.

LADY HALLETT: Thank you very much, Mr Wagner.

Mr Weatherby.

Questions from MR WEATHERBY KC

MR WEATHERBY: Thank you.

Professor Snooks, just one topic from me and I ask questions on behalf of the Covid-19 Bereaved Families for Justice UK group and it's simply the extent to which people with different characteristics, the needs of people with different characteristics, whether they were sufficiently and adequately catered for by the 111 and 999 services.

So you were earlier taken to paragraph 78 of your

report, where your key points were that the services of 111 and 999 were at times overwhelmed and you then go on to say that existing inequalities may have been exacerbated by those factors. Firstly, in terms of ethnicity you then indicate, as you indicated to Ms Carey before, that there's a lack of data?

A. Yes, there's a lack of coding.

Q. Yes. Now, you've already helpfully given evidence about the difficulties of collecting data in an emergency situation, but without collecting data then, of course, first of all, we don't know?

A. Yes.

Q. And secondly, we can't put it right if we don't know?

A. Yes, exactly.

Q. So something has to be done?

A. Yes, yes, so we're currently doing a study exactly on this in injuries and this is where we found that there is no data in ambulance control about the ethnic, I was going to say case mix, but the ethnic profile of the 999 callers but they can be linked. So if you can link those callers to other datasets then ethnicity is available.

Q. Yes.

A. So this can be done but it isn't routinely done at the moment.

Q. No. So, again, that's a call for optimism there that work is -- it is in fact being addressed?

A. To some extent but it needs more, yes, it does need more attention --

Q. Indeed.

A. -- because that work is, it's been partially done ad hoc here and there but not been done systematically.

Q. Sure. Just to take this point a little further paragraph 73 you refer to the Healthcare Safety Investigations Branch 2022 report on the 111 service and part of that you note that they raised questions rather than conclusions about the efficacy of the service, about a number of matters but including language difficulties. So that would include the potential problems of people whose first language wasn't English. And again, this is an area where there's a lack of data, is that right?

A. Absolutely. Again, I don't think there's any data on this at all. So this would have to be the subject in the first place of actually funded research, commissioned research to look at this.

Q. Yes, so that should happen.

A. We cannot get that from routine information.

Q. And from family members that we represent, we know that on occasion questions were asked of them about them or

their loved ones which assumed that they were white.
A. Right.
Q. For example, had lips turned blue or skin colour turned blue? Again, this may indicate a wrong assumption being put forward by call handlers or the algorithms, and would you agree that there needs to be work done to identify those problems and to rectify them if they are --
A. Absolutely, yes, I would definitely support that.
Q. Okay, same point but moving away from ethnicity.
At paragraph 73 you highlight the fact that the algorithms didn't take sufficient account of comorbidities and can you help us with that, but I think that what you're driving at there is that because there was insufficient account of -- taken of comorbidities then it was less efficient at people being signposted to what they needed or emergency treatment being provided?
A. Yes, we're quoting from this study by Rick Body, I believe, and so this is their conclusion. I'm quoting them but I would support it.
Q. You would support that. Again, this is a deficit which needs to be looked at --
A. Yes.
Q. -- and addressed?
A. Yes.

Q. Can I take that one stage further. Would you agree that not just the algorithms but perhaps call handler training needs to be improved in terms of taking account of people with comorbidities or perhaps people who have neurodiversity?
A. Yes.
MR WEATHERBY: Thank you very much, Professor.
LADY HALLETT: Thank you, Mr Weatherby.
Professor, that concludes, I think, all the questions that we have for you. Thank you for your help, and I hope that the recovery continues apace.
THE WITNESS: Thank you very much.
LADY HALLETT: I hope you haven't been too uncomfortable.
THE WITNESS: No. Thank you.
LADY HALLETT: Very well, 10 o'clock tomorrow, please.
(Witness withdrew)
(4.05 pm)
(The hearing adjourned until 10.00 am on Thursday, 31 October 2024)

INDEX