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Monday, 28 October 2024

(10.30 am)

LADY HALLETT: Good morning, everyone. Today is the first day of the second tranche of hearings for Module 3, impact of the pandemic on healthcare. I hope people have been able to get some kind of break in between the hearings, although I know many will have been working

hard to prepare for the next few weeks.

We shall begin with the second part of the impact film. It lasts about 14 minutes -- 13 minutes, 35 seconds, to be precise -- and it contains footage of people from across the United Kingdom talking about the impact that the pandemic had on their lives and the lives of their loved ones.

The range of topics covered include Covid, pregnancy and birth, cancer treatment, and lack of or delayed treatment for other conditions, end of life palliative care, bereavement and mental health. Some may therefore find the second part of the film distressing, as many of the films to date have been.

So I suggest that anyone in the hearing room who wishes to leave, should do so now. And those following online may wish to press "pause" on the recording.

When the film is over we shall reconvene and counsel to the Inquiry, Mr Mills, will call the first

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1 **A.** Yes.

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- Q. Can we begin your evidence, please, with your experience
 of contracting Covid-19. Take us back to the
 24 March 2020. When did you realise that something was
 wrong?
- A. It was actually my mother's birthday and I was baking
 brownies for her and my son commented on the lovely
 smell in the house, which I couldn't smell, which seemed
 a bit odd, I couldn't smell anything at all, which was
 a shock at the time.

I knew that something was wrong but I didn't realise it was linked to Covid, so the first thing I noticed was lack of smell.

- Q. Over the next days, and weeks, how did your symptomsdevelop?
- A. Well, from the start there was no smell, which
 continued, and then I got a sensation, a burning
 sensation on my tongue, which I'd never had that
 experience before, and I contacted the doctor, which was
 difficult because it was lockdown, that had started, and
 it was all telephone consultations.

So I had to email with my GP, which was very difficult to explain what my symptoms were, particularly the burning on the tongue. They thought maybe an infection. I was given a spray, which didn't help.

witness of these hearings.

2 Play the recording, please.

(Video played)

4 **LADY HALLETT:** Thank you very much. We shall resume the hearing now.

Mr Mills.

7 MR MILLS: My Lady, may I please call Dr Sarah Powell.

Interpreters sworn

DR SARAH POWELL (affirmed)
Questions from COUNSEL TO THE INQUIRY

11 MR MILLS: Your full name, please.

12 A. Sarah Kathryn Powell.

13 Q. Dr Powell, you have provided a statement to the Inquiry.

14 The reference is INQ000421866.

You are a highly specialist clinical psychologistworking with deaf people?

17 A. Yes, that is correct.

18 Q. You have been deaf since birth?

19 A. Yes

20 Q. And your primary language is British Sign Language?

21 A. Yes.

Q. A little bit about your family. Your husband is alsodeaf and a BSL user?

24 A. Yes.

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25 Q. And you have two sons who are hearing?

I was given antibiotics three times. In the end the doctor decided not to prescribe any more.

3 So the symptoms I was having, I had pains in my 4 leg, my arms, my joints, and I was completely worn out, 5 and I could not understand what it was. My eyes felt 6 dry. I had headaches. I couldn't name everyday 7 objects. I remember clearly I was trying to remember 8 the word for "slippers", and I could -- what, those 9 things what you wear, house shoes. I couldn't actually 10 remember the word for "slippers". So all of these 11 things were happening to me and I didn't know what was 12 going on and it was awful.

13 Q. Can I ask, during this time, were you able to have14 face-to-face meetings with your GP?

A. No. It was either through email, because obviously
 I don't use a telephone, being deaf, so it was written

17 through e-mail. And I think twice I had to --

18 face-to-face appointments, but the doctor wore a mask,

19 I wore a mask, interpreters weren't allowed to attend

20 the appointments at the time, because of infection

21 control and only two people were allowed in the room at

22 the time. So I had to write again. The doctor didn't

23 really understand what I was trying to describe. I just

24 felt as if I was being gaslit. It was difficult that he

25 didn't take on board what I was trying to describe.

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- During those appointments, did you ask whether your 1 2 symptoms were linked to Covid-19?
- 3 A. Yes, I did, yes. It just seemed -- prior to this I was
 - very healthy, I used to run. And suddenly I couldn't do
- 5 those things. I was so worn out. And at the same time
- 6 my husband had been hospitalised and he'd been -- it was
- 7 confirmed that he had Covid-19. So when I asked, doctor
- 8 said, "No, you haven't got, because you have not tested
- 9 positive for Covid-19", but all of the cough -- the
- 10 symptoms I had, such as the sense of smell, were --
- you know, weren't the ones that people would have put 11
- 12 down to Covid-19, such as the high temperature and the
- 13 cough.

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- 14 Q. So at that time, can I ask this, did you think then that 15 you did have Covid-19?
- 16 A. Yes, I did. I did.
- 17 Q. Moving to September 2020, had your condition become
- 18 worse?
- 19 Α. Yes. Yes. indeed. It was much worse. At that time
- 20 I was not sleeping well at all, I was having vivid
- 21 dreams, it was impossible to sleep because of the pain
- 22 that I was feeling. Specifically down my back. And
- 23 I emailed the doctor about this, I explained that the
- 24 symptoms were getting worse. They said: possibly you've
- 25 got a blood clot.

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- 1 receive that diagnosis?
- 2 A. Yes.

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- 3 Q. Can you help the Inquiry understand how that delay had 4 affected your mental health?
- 5 A. Yes, well, I'm actually a clinical psychologist but this
- 6 was a massive test for me in terms of my mental health
- 7 because I felt so isolated. There was nobody that
 - I could talk to who had the same symptoms as me. I was
- 9 trying to Google, as you do, to find out what is going
- 10 on with me. There was nobody to talk to, and people
 - were looking at me saying, "But Sarah, you look fine."
- 12 But I wasn't.

And I use the example of a car. So it is like the car looks fine on the outside. However, the dashboard is telling you there is all kinds of lights coming up saying there are problems. That's how I felt and doctors -- this particular doctor, it was wonderful in the end because I had been back and forth myself to my own GP, which took so much time. I was given medication that didn't work, that wasn't necessary and I was so

So I eventually joined a group on Facebook for Long Covid, and at last I felt I was in a community that understood my symptoms -- I think that was around about

the July time. I was determined to sort it out and

So I was sent to hospital to have this checked out. But actually it turned out to be a positive thing because I finally was validated, because the doctor at the hospital himself had Long Covid and, the symptoms I described, he said, "You've got Long Covid". So I felt completely validated, at last, that somebody understood what I was going through.

8 Q. Can I ask, how were you able to have that conversation 9 with that particular doctor?

10 A. Well, obviously to begin with we had masks on. 11 I explained that I was deaf and relied on lip-reading, so thankfully the doctor removed the mask. And as you 12 13 can imagine, at the time that was a risky thing to do. 14 So I was able to lip-read the doctor and explain what my 15 symptoms were, rather than having to write down.

> Also the appointment took a lot longer because I was writing things down, lip-reading, so the doctor was patient with me.

Also on the same day -- I beg your pardon, at the time we weren't allowed to have interpreters in the room, so I had no choice but to manage with the GP -the doctor, I beg your pardon, through lip-reading.

- 23 Q. You said you felt validated?
- 24 Yes, I did. Yes, I did.
- 25 It had taken from March until September for you to

still my doctor wasn't taking on board the things that I was telling him until I had gone with my lung to the hospital and got the diagnosis there.

So that doctor had said to me, "You need to check the antibodies through a blood test to see if you have had Covid", and the numbers came back really high. So I was able to show my doctor this and -- I knew I had the Covid, I absolutely knew I did, but anyway, in the March time -- because my husband had tested positive in the March, I knew how bad it could be, but my doctor had never said, you know, "You've got a positive Covid test."

My life changed so much during that time, and that's the way it was.

- 15 Q. Even after your Long Covid diagnosis, did some medical professionals dismiss your concerns about your health? 16
- 17 A. Yes. I will never forget one particular person, one 18 doctor said, "Oh, Long Covid isn't even a thing", and I said, "Well, why are blood donors not allowed to 19 give -- why are people with Long Covid not allowed to 20 21 give blood? Why are they not accepted to give blood? 22 And also why have the Long Covid clinics been set up?"

And I felt like I was arguing with this medic, an NHS doctor and I was having to convince him that Long Covid was an actual thing.

frustrated over the whole thing.

Q. Can I ask you about your experience of Long Covid
 clinics. Can you describe the treatment you have
 received at those clinics?

A. So when I was diagnosed with Long Covid I was put on the waiting list for a Long Covid clinic. One year later, eventually I got to meet and attend those clinics, five different clinics. My eyes -- you know, my eyes were really bad and as a deaf person that's critical because obviously I use my eyes to see everything and to communicate. They were awful from Covid. It was -- but very frustratingly, over the five clinics, they did book interpreters. I arrived at those clinics, ready to go in, but unfortunately they said an interpreter can't be present because the room was only big enough for two people, obviously myself, the doctor, they hadn't considered the interpreter was attending also.

So, I've been waiting for this appointment, waiting for this clinic and an interpreter still wasn't able to attend.

So they tried to find different rooms. Obviously they were at full capacity at that time, you know, they had so many things going on and they were full, so that meant the interpreter couldn't attend and the appointments were cancelled, which made it more frustrating because obviously I had waited so long,

worse. So certain foods I can't eat, obviously cakes and biscuits. I've had to reduce my carb intake. Caffeine, I can't tolerate caffeine anymore. It makes the pain worse in my body. I just have to drink water constantly. I can't function for one hour without water, I have to -- you know, because I have excessive dry mouth still.

I can't remember when the pain actually — a day without pain actually. I have to have a bath with Epsom salts. Every morning I have to have that, I have to, to help me to be able to function in the day. You know, things you take for granted like cleaning the house I can't do, I have to do one thing so, for example, cleaning the sink. Before I could clean the whole house in one go, now I can barely clean one sink. I really have to plan things in advance and the number one thing that helps me is pacing myself. I have to plan. You know, if anything happens unexpectedly, you know, then I'm going to be — it's going to ruin my routine and I'll be wiped out. You know, if I'm doing something in the evening — if I'm doing something in the day I can't go out in the evening also.

You know, activities such as going out, you know, on a Saturday or Sunday, I have to book the Monday off if I do Saturday and Sunday. You know, that's my

you know, I thought the interpreter was sorted, but it still wasn't possible.

So that wasn't a one-off, this happened
repeatedly. And I felt that my treatment was prolonged,
that I wasn't getting the treatment that, you know,
I thought I'd get from the start because of not being
able to have interpreters present.

- Q. One of the things you say in your statement is that
 medical professionals had told you to exercise more.
 Can you tell the Inquiry about the impact that
 exercising had on your symptoms?
- 12 A. I think one of the big reasons I had Long Covid because
 13 I carried on exercising. You know, I'm still, you know,
 14 pissed off about that at the moment. At that time I was
 15 absolutely wiped out. You know, I couldn't function, as
 16 I've explained, and the doctor said, "Okay, well, it's
 17 better that you exercise some more, just carry on". And
- exercise, absolutely, but that didn't work in this case
 and I honestly believe that if I hadn't exercised then
 these symptoms -- I wouldn't have these symptoms today.

as a, you know, psychologist I know the benefits of

- Q. Can you help the Inquiry understand how you have had tochange your lifestyle as a result of Long Covid?
- **A.** Well, I mean, sugar. For one, I've had to cut out sugar because of my burnt tongue sensation. Sugar makes it

holiday that I'm having to take just to recover, you know, it's -- rather than actually going on holiday, going for day trips, I'm booking that extra time for recovery.

Walking is painful. I have to plan to make sure these are just short walks. Public transport is incredibly painful, you know, going on the Tube, the stairs are absolutely awful, I'm having to take painkillers to manage that.

You know, I have a blue badge now. I never thought that I would need a blue badge now, you know, but I have to. It does help me to reduce the walking to different places, reducing, you know, how many stairs I have to do. But people look at me, even now, and I feel judged, actually saying, "Well, she looks absolutely fine". But, you know, I might be looking like I function okay but inside I'm absolutely not.

It would be lovely to do things without having to think about them. I would absolutely love that and to not have to pre-plan. I wish I could.

- Q. Can I move now to your husband's experience. I believe
 his Covid-19 symptoms started on 23 March 2020, is that
 right?
- **A.** Yes.
- 25 Q. Can you tell us about the symptoms he experienced?

A. It makes me smile actually, because his symptoms at that time -- he lost his taste, but we didn't realise at that time, and he blamed my cooking. And he said, "Oh gosh, your cooking tastes awful", and I was thinking: okay, well, maybe -- I've lost my sense of smell so maybe that's affected my cooking. So, okay.

The next day still, you know, he was complaining about my cooking, and I thought: okay, do you know what, maybe you need to go to Marks and Spencer and buy ready-made meals. Okay? Still he was saying, "It doesn't taste right". And this went on Monday, Tuesday, Wednesday.

By the Thursday, he started to be very tired, very fatigued, and I was thinking something is not right. So I decided to -- for him, he booked Friday off, sorry. So he booked Friday off work. And we are both key workers so we -- you know, we were still working through lockdown, but we decided to -- he decided to book Friday off. So that was -- and he took to his bed. So that was fine. You know, I thought, well -- you know, not really worried, you've gone to bed.

By Saturday he was sleeping non-stop. I had to really nudge him to wake him up. I wanted him to have fluids. He's got kidney issues so I thought it is really important that he keep drinking. So I would wake

have a temperature or cough but something felt like it, and I decided to stay in the room with him and I slept on the floor that night. But -- you know, I wanted to be around for him, and I still felt, you know, in my gut something wasn't right.

So I rung 111 again and they said they're going to call me back. And I explained, well -- you know, we have a telephone system called Typetalk which means the hearing person can make the telephone call, they -- and the operator types your message and gives it to me as the deaf person, I will read what you've said and typed and I will type back and we do it through that way. But you need to use a prefix, a number 1, to use this service, and I knew, NHS 111, their computer system would not accept that prefix. So they would not be compatible.

So I tried to explain this. I said it wouldn't work, "You won't be able to call me back", but they were adamant. They said, "No, we will call you back", and I said, "Okay, well, I've got my laptop ready", you know, for this Typetalk. You know, I'm ready and waiting.

About 1 o'clock in the morning and the phone was ringing, and I have my phone vibrating in my pocket and they are talking to me. So I ran frantically to wake up

him up to drink fluids. But he kept falling fast back to sleep and I thought, actually, something's not right.

And at that time I thought maybe there's an infection, maybe sepsis, you know, because he was not going to the toilet, you know, after these fluids. So I rang 111, through BSL, and of course had to wait a long time. You know, at that time, everyone -- there were a lot of waits. So, you know, they explained to me, you know, advice and they thought: actually we think it is an infection. But they are going to send for an ambulance. And because of Covid at that time we had to wait a long time for an ambulance. I think it was a few hours before the ambulance arrived.

So then when the ambulance did arrive, they were in masks, you know, all PPE, gloves, everything, and communication was incredibly difficult, having to write things down. So I had to ask my son to help with communication, because, as I said, my son is hearing, trying to explain the symptoms to the paramedics. So the paramedics said, "Actually it is an infection but we don't think it's sepsis, so it's best you call the doctor on Monday."

Okay, so I thought -- but I still thought: okay, something still doesn't feel right, and at that time I thought possibly it could be Covid. I know he didn't

my son. I mean, poor him, I had to ring -- wake him up. And then it cut off, they stopped ringing. So I said, you know, "I'm sorry" to my son and went back to bed. Then again the phone rang and I'm running again to my son's room, waking him up, and again they hung up, so -- and it cut off. So it meant no phone calls could get through.

About 5 o'clock in the morning my husband, you know, nudged me in a sort of frantic -- he nudged me and said "I can't -- I'm having trouble breathing, I can't breathe."

At that time there was no 999 BSL, you know, no 999 service, so you had to do an emergency text to 999 and explain -- I explained that my husband couldn't breathe, he was sweating profusely, I -- absolute panic, it was a terrible moment. And about for half an hour, you know, which is a long time in those sort of moments, an ambulance came with a doctor -- absolutely awful because, you know, my husband couldn't breathe and it was -- you know, we were having to really struggle with breathing, communication was nowhere, I had to again wake up my son.

So I woke up my son -- sorry. Sorry, it's difficult because for the first time I had to use my son for communication. I'm, you know, adamant I don't want

to use my children for my communication needs but, you know, I could not communicate with paramedics or the doctor. You know, we couldn't write things down to explain what was happening. There was no time. This was an absolute emergency. It was, you know, life or death: my husband couldn't breathe. So I had to use my son for communication.

And I don't know what it was like for him. I can only imagine. You know, to see his father in this state, the ambulance, the doctor.

Anyway -- thank you.

Anyway --

- 13 Q. Take a breath, Dr Powell. Take a breath.
- 14 A. His oxygen level was really low and they decided to take
 15 him to hospital. So they went to hospital. I stayed
 16 home. I had to stay home. And I was consoling my son.
 17 You know, it just all happened so quickly.
- 18 Q. During his stay at the hospital, how was your husband able to communicate with staff there?
- A. Well, he didn't. Originally he went along to A&E, he
 was taken to A&E, and he described it that the staff
 were in these suits, these hazmat suits. And they were
 completely covered, their faces, with masks and what
 have you. And so he explained that he was deaf and used
 BSL. He wrote that down. And they said: well, you

BSL. He wrote that down. And they said: well, you 17

know, we can't get an interpreter, it's impossible because of the restrictions with the Covid. You're going to have to write with us. He was very poorly at the time.

Now, normally deaf people might use a video message to communicate with one another but he wasn't well enough to do that, so it was very brief texts between him and I. So I was at home, not really knowing what was going on in the hospital, and my husband must have been terrified, because he was alone, he didn't have me with him, and everybody had masks on or the haz suits. He was having difficulties breathing, he was using oxygen, and they were monitoring all of his levels.

The hospital wrote to him that it may be Covid-19, Coronavirus, and they said they'd have to test him. But I can't imagine that -- he told me about the staff coming with a hazmat suit on and a box with, you know, the skull and crossbone symbol on the box, and that's what my husband saw and he didn't know what was in the box. He knows now but at the time it was all new to him and he wondered: well, what is in this box? What are they planning?

Two days later he did test positive for the Coronavirus and was put on a ward for that reason.

- Q. I think on his third or fourth day you received
 a message from him asking you to translate a note
 a doctor had written to him. Can you tell us what that
 note said?
 A. The note said that he was getting worse and wasn't
 - A. The note said that he was getting worse and wasn't responding to treatment and that he would have to be ventilated, and so the doctor was asking for consent.

 And my husband -- there was no communication from the hospital, appropriate communication. And I didn't realise it was that bad until I saw the note that my husband asked me to translate.

I couldn't translate it into BSL -- because normally if my husband's not understood something, I would do a quick video and sign to him what a written information might say, but because I was so upset by the content of the note, I couldn't describe it in BSL, so I had to do a very plain English translation and said to him, "Speak to the doctor and ask them about your treatment". I just said that, "You're going to need different treatment that may help. They may need to put you to sleep to help you breathe."

I wanted to say more than that but I was terrified for him because he was so isolated in hospital, he was so alone with no communication and no support. No interpreter provision.

Q. Was ventilation necessary in the end?

A. No, thank God. They were preparing to move my husband
 across. They wanted to do one more test before and his
 oxygen levels started to go up, so they didn't -- they
 said: let's just wait and see. And eventually they
 decided they didn't need to ventilate. Yeah.

- Q. A few days later I think, you received a message fromhim to say that he could come home?
- A. Yes. Yes. It was strange really because I'd had no contact from the hospital. I'd had to -- and I felt --I wondered if I was hearing, if I wasn't deaf, would there be more contact. Because it seemed that hearing family members were getting information about their loved ones, and they weren't prepared to communicate with me. And all the information that I got about his healthcare and what was happening in the hospital was coming from my husband, not from the hospital staff.

Can you imagine that? He was so ill, so poorly, and he had to take control. He'd send me photographs of the drapes and the equipment they were using, his oxygen, with a few words.

Anyway, he text me to say he was coming home, which I thought was odd. And they had written him a note, so he took a photograph of the note that the staff had written for him, and they said his symptoms

28 October 2024

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were stabilising and he was okay to go home to recover. Which of course I was delighted about. But at the same time I thought: is he really ready to come home, because he had been so, so ill? And how are we going to cope at

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Anyway I realised that they were short of beds and they needed to get other people in, but -- I know that now, but at the time I didn't realise that.

When I went to pick him up I was sat outside the hospital in my car waiting for him. Now, they were waiting -- the staff were waiting for the corridor to be clear before they could bring my husband out. He was in a wheelchair. And -- so, for me, I thought: he is really -- he's still ill.

So I got him into the car and my husband burst out crying. He burst out crying because of the awful experience he'd had in hospital and he was so happy to be with me, to be able to communicate on a one-to-one with me.

- 20 Q. How would you describe your husband's symptoms when you 21 collected him and then over the next few days?
- 22 A. Well, he'd lost weight. He'd lost weight. Because he's 23 a big man. And it was so obvious that he'd lost weight. 24 He was weak and tired. So, so fatigued. We went home 25 and he went straight to bed. I kept checking, "Are you

an infection. He was given antibiotics and came home.

So it worked so much better having that communication on a one-to-one and I was so anxious that I didn't want him to go through that experience again that he had had through the hospital and, as I've said, interpreters weren't allowed to be there face to face, hence the online.

- 8 Q. Can you describe the long-term impact that Covid-19 has 9 had on your husband?
 - A. We both had different symptoms. His main symptom is fatigue; very fatigued. Loss of taste, still has loss of taste, and has pain, joint pain. His memory is very -- he forgets easily so it's hard for both of us to sort of adapt to that because he has loss of memory and it's difficult to remember things, so I try to be very patient. Obviously, that doesn't always work, but, you know, we try to have different plans and systems in place, having sort of things visual to help remember.

He was diagnosed with -- he was diagnosed with a blood clot, an unprovoked blood clot, but we knew it was linked to Covid-19 and recently the -- he had an infection and his body couldn't cope so he had to stay in hospital for a number of days for that infection. His immune system was so low, that's similar to me. You know, he has had terrible, you know, trauma,

okay?", and he said, "Oh, I'm just worn out." He couldn't really walk, he couldn't manage the stairs very well so stayed upstairs in the bedroom, and then he started to get some chest pain. So I was ever so worried about that, contacted 111 again through the BSL system, explained what had happened, got a call back -they said, beg your pardon, "We'll call you back", and I said, "No, that system doesn't work, we are not doing that this time." And they said, "Well, you know, he's been" -- I insisted that he was seen by someone at this point and eventually they said, "Go to the Covid centre."

I wasn't allowed to go with him but I didn't want him to have the same experience again with the communication breakdown and so I contacted a team of interpreters that I work with regularly through my employment and managed to find one and said, "Will you be able to work with my husband online whilst he goes to this appointment", which we paid for, from our pockets, because the experience had been so bad and we wanted to avoid that.

So we went along to the Covid centre and the interpreter was working with him remotely and it went really well. My husband felt so much better. He was able to describe what was going on. They diagnosed

experience from what has happened. He still can't talk about really what has happened and he struggles and he has that trauma from that experience in hospital still.

- 4 Q. Finally Dr Powell, can I ask you this: what could have 5 been done to improve both of your experiences of the 6 healthcare system during the pandemic?
- 7 A. Four years later, my husband went to hospital actually 8 recently, I stayed for six days and there was still no 9 interpreter. So things haven't changed from then until 10 now. So that's a clear example of that.

I wish, you know, there'd be automatically flagged up on the medical system to say: this patient is deaf, they use BSL. You know, there's a system for accessible information standards, but still it's not widely known. I wish it would automatically flag up to show that I'm a deaf BSL user.

I wish their computer system would allow the prefix to use -- to make that phone call, you know, because not all deaf people can, you know, whilst they use BSL, they can't use Typetalk. It is very primitive, the access at the moment still. They should be able to have -- you know, to be able to access that communication. They should be able to have the interpreter the same day of admission, either face to face or use a remote device. Anything -- you know, that 24

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they can have that, BSL, and they are able to articulate how they want to -- their chosen language, which is BSL using an interpreter, rather than us having to write, you know, scrappy pieces of notes, you know, English, how do you articulate that, these very complex things that are going on in hospital? So this access absolutely needs to improve.

And I feel mine and my husband's symptoms, they've been prolonged because of these barriers in communication and access.

But also I wish the doctors would accept more about Long Covid is a thing rather than having to prove myself, showing different things to show that I have Long Covid, to have this explanation, I wish that they got it straight away from the symptoms and, you know, the impact that that has had. I accept that there is still not much known in terms of the treatment for Long Covid, I do understand that, but what I want is that acceptance that Long Covid is a thing and that's really important for me.

You know, it was such an awful experience to be dismissed by medical professionals, to experience those barriers, arriving to an appointment, you know, saying the appointment room isn't big enough, not considering the interpreter, you know, come on!

1 (Witness withdrew)

2 MR MILLS: My Lady, may I please call Caroline Abrahams.

CAROLINE ABRAHAMS (sworn)

Questions from COUNSEL TO THE INQUIRY

5 MR MILLS: Your full name, please?

- 6 A. Caroline Susan Abrahams.
- 7 Q. Ms Abrahams, you are the Charity Director of Age UK?
- 8 A. I am.

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9 Q. You have provided a statement to the Inquiry. The 10 reference for that is INQ000319639.

Can you begin by describing in broad terms the work of Age UK?

13 **A.** Age UK is a national charity for older people. We have 130 component parts. We have 120 local Age UKs which offer services and support to older people in their local communities.

> We also have Age Scotland, Age Wales, Age Northern Ireland, and there's a national charity that provides information and advice, and that also lobbies and campaigns on behalf of older people and a sister charity called Age International that supports older people in low- and middle-income countries.

23 Q. First topic, please. The heightened risk that Covid-19 24 posed to older people.

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At paragraph 10 of your statement you identify

You know, I've got an appointment finally for rheumatology but they are saying it is a telephone appointment. Why did they not read the notes to say I'm deaf? So even now they are offering me a telephone appointment. That appointment now has had to be cancelled so I will have to wait some more until they can find me a face-to-face appointment.

8 So it is still ongoing. We are still facing these 9 barriers.

10 MR MILLS: Dr Powell, thank you.

My Lady, that's all I ask.

LADY HALLETT: Thank you very much indeed for your help, 12 13 Dr Powell. I'm very grateful. I just hope that the 14 symptoms that you and your husband are suffering do ease 15 in the foreseeable future, I appreciate how difficult it 16 must have been. I've become very conscious since 17 I started chairing this Inquiry of how acceptance of 18 Long Covid is so important to sufferers like you.

> I also hope you have forgiven your husband for his monstrous remark about your cooking.

21 A. Yes.

22 LADY HALLETT: Thank you very much.

23 A. Thank you.

24 LADY HALLETT: And thank you very much to our excellent

25 interpreters.

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1 that age is the single biggest risk factor for 2 experiencing severe illness and dying from Covid-19.

3 A. Correct.

4 Q. In doing so, you refer to a study by the Intensive Care 5 National Audit & Research Centre. I wonder whether you 6 could tell us what that study found.

7 A. Yes, certainly. It found what you have just said, which 8 is the older you are, the more likely it is that if you 9 do contract Covid-19 you will suffer serious illness or 10 death, and it goes up very steeply with age.

11 Q. I wonder if we could go on screen, please, to

12 INQ000221437.

13 This is an extract from a paper by the Office for 14 National Statistics about Covid-19 deaths which occurred 15 in April 2020. Can you help us, please, Ms Abrahams 16 with what this graph illustrates?

A. Sure. So if you look at the green on the far left those 17 18 are the people who have died from Covid-19 aged under 65, and then everybody else, all those other colours, 19 20 are the people over age 65 who died from Covid-19.

21 So you can see just how much bigger your risk is 22 if you were not a working age.

23 Q. So those are the figures. Can we consider the reasons 24 behind them. Why is it, please, that age is such a risk 25 factor?

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A. I think it is important to realise there is nothing magical about your numerical age. It isn't that you reach a certain number of years and then immediately you are bound to have a certain outcome. It is much more complicated than that. It is partly, and probably mainly due to the fact that as we get older we are more likely to get certain long-term health conditions that undermine our health and our resilience. So if something like -- a virus like Covid-19 comes along we find it harder to fight it off.

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shows

People are perfectly able to live with those long-term conditions, but they do make you more vulnerable. And in turn, those conditions, whether you have them or not, partly due to luck, partly genetics, but also very importantly, your social and economic status.

- 17 Q. At your paragraph 17 you comment precisely on that. You list four reasons why older people in the least advantaged circumstances faced both a higher risk of exposure and increased barriers to accessing services. I wonder whether you could take the Inquiry through those reasons, please?
- 23 A. Yes. People from lower socioeconomic groups are more 24 likely to have long-term conditions, to acquire them 25 earlier on in life, to have them more severe, and at the

2 A. I can't honestly remember when that first became 3 apparent. There was a lot of public conversation during 4 the pandemic about the heightened risk to people from 5 minoritised communities. Very rarely was it said that 6 they were almost all older people. So the debates 7 happened separately, which was bizarre because really we 8 were talking about, almost always, older people but from 9 minoritised communities and, of course, not from all

minoritised communities as the highlighted section

disparity started to come to your attention during 2020?

Communities where there was more affluence were more protected so -- but certainly what we know more generally about the lives and experiences of older people across the board would have led us to believe anyway that people from minoritised communities would be impeded by structural racism as we say indeed in our consultation response.

- 19 You said the debates happened separately. In your view, Q. 20 why did that happen?
- 21 A. I think because of ageism actually. And, of course, 22 that was one of the big problems for the people we're 23 talking about here. They not only faced problems of 24 discrimination due to their age but also because of 25 their race and that was mirrored in the public debate.

same time they face problems in accessing healthcare for a variety of reasons, and their overall circumstances living at home may be more difficult. They may not be able to afford to keep their homes warm. They may not be able to afford special diets, or to eat and drink well enough to sustain their health as well as it might be, and their resilience.

So, they face a cluster of problems which made them much more likely to be at risk during the pandemic. Q. Can we also, next, think about how an older person's

10 11 race increased their risk.

Please can we go to INQ000217401.

This is Age UK's consultation response to the Commission on Race and Ethnic Disparities which was published in November 2020.

16 A. Yes.

17 Q. If we move to page 2, the last paragraph of the 18 introduction, three lines down we read:

> "The latest ONS data shows that all ethnic minority groups (except the Chinese community) have higher rates of deaths involving Covid-19, with black Caribbean men aged 65+ having the highest rates of deaths at ... almost 2.3x higher than white men [of the same age]."

> > Are you able to say first when evidence of this

Please can we next go to INQ000176650, page 20.

This is a page from a study published by Age UK based on surveys conducted in August and September 2020. What do we learn here about the reasons for the higher incidence and severity of Covid-19 in older BAME people?

A. Yes, one factor definitely is people are more likely from these communities to be living together with younger members of the family, or to be interacting more with younger members of the family, making it more 10 likely that they would acquire the virus in the first 11 place.

> Might also be dealing -- living in homes that were not decent in the technical sense of not being warm, and also other health risks that these people were very often living with, underlying conditions including obesity, diabetes and heart disease all of which lowered their resilience, made it harder to overcome the virus if they were to acquire it.

19 Next can we consider the unequal impact that the Q. 20 digitisation of healthcare services had on older people.

Please can we go to INQ000217404.

This graph comes from a briefing paper published by Age UK in December 2021 called Living in a Digital World after Covid-19. To orient ourselves, we see the proportion of recent internet users by age since 2011,

the blue line representing those between 65 to 74; red line, 75 and over.

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What do we learn here, both about the internet use of these age groups going into the pandemic and during?

A. Well, the first thing that this graph tells us is that the older you are the less likely you are to be online so there is quite big gap, isn't there, between the 75 and over line and the 65 to 74 line?

And in both cases the trend is upwards, more older people are going online over time, but there still remain a significant proportion who are not online. And there are other reasons for us to feel, at Age UK, that actually these statistics overstate the digital competence of the older population, because we know it is not just about whether you are online or not, it is whether you have the skills and the confidence to be able to do quite sophisticated things, as were required during the pandemic.

In fact, about half of the over 65 population, we think, either isn't online at all or is not able to go online successfully and safely.

Q. If we move, please, to page 4 of that document and it is the third paragraph, last sentence:

"For example, in early 2020 just 53% of people aged 65+ in Great Britain used a smartphone for

didn't have it use it for work for whatever reason, then you can reach 60, 70 now and have had very little contact with it.

MR MILLS: Relatedly, what challenges did those telephone and video consultations pose for older people during the pandemic?

A. Absolutely enormous challenges, and frankly continuing challenges today, because what happened was, although there was a trend which -- a policy trend within the NHS of starting to use interactive technology, it got a huge boost in terms of acceleration because of the circumstances of the pandemic.

And what this meant was that some older people found that overnight the way of getting hold of your GP, for example, changed from being able to walk to your surgery and have a conversation with someone behind a desk to having to navigate that process online or possibly over the phone, using telephone prompts. And so that was very, very destabilising for some older people.

Q. At paragraph 26 of your statement, you say this:

"People struggled to understand how to reach their GP if not in person, not helped by the fact that most signposting information and advice was available online ..." 1 private use ..."

Does that also tell us something about those internet use figures?

4 A. It does, indeed. Having a smartphone or some way of
5 being able to interact digitally is absolutely key. And
6 we also know of quite a few older people who have maybe
7 been given one by a son or daughter for Christmas but it
8 sits in a drawer rather than being actively used.

And, you know, I don't want to overstate it, some older people are very competent and avid users of the internet, but very many aren't.

12 LADY HALLETT: Can I just ask a question.

13 You said many older people are not able to do
14 things that are considered more sophisticated. I was
15 thinking that there is something that most younger
16 people wouldn't think was sophisticated which is just
17 doing a Zoom call, doing a remote call.

18 A. Yes.

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LADY HALLETT: And a number of people I know, who are older,
 are basically terrified, they've no idea how to do
 a remote call, and that is something that younger people

22 wouldn't think was sophisticated at all.

A. Yes, it makes a difference if you've grown up with the
 technology. And of course, by definition, this age
 group hasn't and have been later acquirers. And if you

A. Yes.

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Q. "... overlooking the fact that large numbers of olderpeople are not digitally enabled."

4 A. Yes, the system forgot about older people not being
 5 online. And of course GP practices and their staff in
 6 many cases were trying this out for the first time, and
 7 frankly didn't always get it right.

Q. In some cases, are you aware anecdotally of older people
 being asked to perform tests or checks on themselves
 during a remote consultation?

A. Certainly. And then being asked to do things like: take
a photo of that wound you are worried about on your leg,
and upload it to our website or attach it to an email
and send it to us. And that requires a degree of
sophistication that is likely to be beyond somebody, for
example, who only uses the internet to go on Facebook or
to play sudoku, which is not unusual amongst older

to play sudoku, which is not unusual amongst olderpeople.

19 Q. At your paragraph 29 you say there was an increase in
 20 expectation for patients to do basic checks, such as
 21 blood pressure and pulse readings.

22 Did you receive reports that older people lacked 23 confidence in performing those checks?

A. Yes, because these were things that throughout their
 lives they had gone to a GP, sat in front of a nurse,

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and they'd done it for them, so this was something new
 and different, which they weren't being particularly
 well supported to do for themselves.
 MR MILLS: My Lady, I'm about to move on to a new topic.
 LADY HALLETT: Certainly.

As you will remember from the last time you helped me, we take a regular break for the sake of the stenographers, so I shall return at 11.55.

9 (11.43 am)

(A short break)

11 (11.57 am)

12 MR MILLS: Ms Abrahams, next topic please, suspension ofroutine care.

At paragraph 12 of your statement you say this:

"... the older population are far more reliant on routine health ... services."

Can you help us understand the impact of the suspension of these services on older people during the pandemic?

A. So we have already talked about the fact that as people get older they are more likely to have a number of long-term health conditions. In the past these are things that might have killed us but now, thanks to medical advance, we are able to help people to live with them, things like many cancers, diabetes, kidney

shortages during the pandemic, which was another barrier for people being able to get what they needed quickly.

Q. Please can we go to INQ000217383.

What does this graph illustrate about the relationship between age and the number of medications a person is likely to need?

A. So as we get older, not only are we more likely to have multiple long-term conditions, it follows we are more likely to be given medication of various kinds to deal with those things, and you can see it is a very clear straight upward curve as we get older.

12 Q. Does it follow then that the consequences of the
 13 barriers to accessing medication would have been more
 14 severe the older a person was?

A. Absolutely, and we have to remember that some of the
 conditions that people are living with in these older
 age groups are ones that can kill you if they are not
 properly controlled.

Q. Next, please, can we consider the approach of older
 people to engaging with the healthcare system during the
 pandemic.

Please can we go to INQ000176650, page 10.

This comes from the Age UK report we have already looked at. I'd like to consider the quotation in the top left. This comes from a man between 70 and 74:

disease, but people do need to be monitored, their treatment needs to be updated sometimes and so you will often find older people in that situation with one or two appointments every week or so having to go to hospital, or for tests of various kinds or to clinics and during the pandemic, a lot of that stopped, and so people with these health conditions very often found they got worse, there wasn't the ongoing supervision. One of the points of these clinics is to pick up when something is getting worse early on so you can intervene

Q. Was one result of that that patients presented later on
 with a more advanced form of the illness they had been
 suffering from?

quickly but that opportunity was often lost as well.

15 A. Absolutely. Unfortunately so.

Q. At your paragraph 40 you explain that access to routine
 medication was made more difficult for older people.
 Can you describe to us what the barriers to access were?

A. Firstly, if people were having problems contacting their
 GP they couldn't ask for repeat prescriptions or new
 prescriptions. That was the first barrier.

But then even once the request had been accepted some older people were too frightened to go out or to visit a chemist, to pick it up, because of fear of contracting the virus. There were also medication

"Due to the stress and anxiety I have experienced severe headaches and migraine type attacks of flashing light in the eyes."

Now this:

"Also frightened to go to hospital when offered when I felt extremely anxious on one occasion."

In your answer a moment ago you alluded to older people being frightened to go out to a pharmacy. Does what this man says here about going to hospital reflect a fear that was common amongst older people during the pandemic?

Yes, we certainly heard this a lot from older people who were watching the news, listening to the news conferences, and I think often associating hospitals, not as places of healing, in some cases, but of places where people were dying and certainly a fear that the virus would be found there and that they would be at an enhanced risk of contracting it should they attend.

But that wasn't the only factor. The other factor putting people off was, I think, some of the messaging which was about protecting the NHS and not going to hospital unless you really needed to, and we know at Age UK that when older people hear messages like that, even when they are not really directed towards them, they often do react in ways that are very responsible,

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- 1 socially, so they would be less inclined to go.
- 2 Q. And at your 65 you refer to a fear of overburdening the 3 NHS?
- 4 A. Yes, exactly that.

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- 5 Q. Do we imagine a pervasive sense of guilt about going to 6
- 7 A. In some cases, yes, and of course we have to remember 8 the wider context to that at the time which was lots of 9 conversation in the media and elsewhere about really 10 this being a problem about older people not about the whole population. So I think older people did feel 11 12 stigmatised by some of that and it would have made them 13 more worried about burdening very important public
- 15 Q. Can I ask, in your view, in respect of older people, did 16 public messaging strike a right balance between on the 17 one hand protecting the NHS and on the other making sure
- 18 older people sought healthcare when they required it?
- 19 A. I think the problem is, as I've just or tried to 20 describe, the blanket message about Protect the NHS, 21 stay away unless you absolutely have to go, wasn't ever 22 really designed to be heard by older people, but that is 23 exactly the group that reacted to it probably most 24 strongly, so that had an unintended consequence of

25 putting older people off when they really should have

> should be to ambulances and to the public about who was to be taken to hospital and who wasn't, particularly around, for example, older people living in care homes and whether they would actually ever be given an ambulance to go to hospital or would be expected to stay in the care home and be dealt with and cared for by the staff, which sounds okay, except, unfortunately, care staff are not medically trained and for periods during the pandemic it was very difficult for many care homes to get the clinical support they needed.

MR MILLS: Please can we have on screen INQ000408832.

This is an iteration of the Covid-19 decision support tool to manage access to critical care as developed by the Department of Health and Social Care's Moral and Ethical Advisory Group.

At paragraph 56 of your statement you say this:

"... in a system with significant pre-existing evidence of age discrimination there were huge and unacceptable risks that [this tool] would be misused to deny acute care to older people ..."

Can you set out, please, the four major concerns that Age UK had with this tool?

Α. Yes. First and foremost because this was produced and was being discussed very near the beginning of the pandemic in March 2020, when we still didn't know very

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1 gone to hospital and doctors and nurses wanted them to 2 go to hospital.

3 Q. As well as the public messaging and the impact of that, 4 anecdotally were you made aware of instances of older 5 people being discouraged or prevented from accessing 6 healthcare services?

- 7 A. Yes, absolutely, and that was the other side of the 8 coin, that there were a number of policy initiatives and 9 more ad hoc things that we heard about from local areas, 10 where it was made very clear to older people that they 11 should not go to hospital, that an ambulance wouldn't 12 take them and they wouldn't be received into hospital 13 were they to go, regardless actually of the condition 14 with which they were presenting.
- 15 Q. Can we move now to consider older people's access to 16 critical care.

17 LADY HALLETT: Before you do that, Mr Mills, sorry to 18 interrupt.

> The policy initiatives you are talking about there, about ambulances not taking them, they shouldn't go to hospital, can you give me an example of what you

23 A. Yes. This is what's referred to, I think, in the 24 statement as non-conveyance where there were discussions 25 with NHS England and others about what the guidance

> much about the disease, the data and the evidence about it was still very much emerging.

Secondly, because the policy implicitly relied on the idea that you could correctly and easily assess somebody's frailty status and their relevant long-term conditions and we know that is very hard to do at the best of times, let alone during a pandemic when everybody is in a great rush.

Thirdly, because we were worried about the ability of the NHS to implement this policy fairly and consistently.

And lastly, because we thought that if knowledge of this tool was to be shared or to escape to the public, that it would cause enormous panic amongst our older population, and undermine trust in the NHS at exactly the time when we needed to sustain it. And this was the single most difficult thing that we dealt with as Age UK during the pandemic and the thing that gave us the greatest concern because, just to be clear, what this shows is that somebody who is aged 80 and who is in good health would automatically not get help from intensive care, should they need it.

And the problem is that age impacts us very differently and so of course there might be an older person who's 80 who was very unwell who was reaching the

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end of their life. But equally, we could have someone 1 2 who's just run the marathon. And this blanket policy at 3 a time of enormous public disquiet, great turmoil within 4 the NHS could far too easily have resulted in people 5 being denied care simply on the basis of their age, and 6 we considered this to be totally unacceptable, to the 7 extent that when I had the opportunity to talk to 8 somebody from the committee about it, I said that unless 9 they stopped it we would leak it to the media and we would kill it because that's how strongly I personally 10 11 felt about this.

- 12 **Q.** What was the outcome of the interaction you had with the13 group?
- A. In the event, fortunately, thankfully, conditions within
 our hospitals improved just in time to mean that there
 was never a need formally to put anything like this into
 practice, although unfortunately we do know that
 something like this was used in some local areas at
 times, which was very sad.

I suspect the fact that I said what I said may have made a small difference, but I think really, ultimately, thankfully, the position in our hospitals improved, and that was the key factor.

24 Q. Thank you, that can come down.

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Next please, Long Covid. At paragraph 79 of your

A. So I will pick out three. The first and probably the most important, that there needs to be a much stronger rights-based framework embedded in how our health system works to challenge and root out the very obvious age discrimination that exists and that became very apparent during the pandemic, with that decision support tool being the most flagrant example but not the only example.

Secondly, getting it right in the community and with primary care, with GPs, with community services. Making those strong enough to be able to still provide good care even under the most stressful conditions is very, very important.

And finally, because unfortunately tackling the ageism within the NHS will be a marathon not a sprint, the importance of the NHS and government working more constructively with the VCSE and with social care during an emergency like this, because had that happened we would have been able -- we saw some of this coming and we could have alerted politicians and policymakers in time for them to change some of their decisions in a way that I think ultimately would have saved lives.

MR MILLS: Ms Abrahams, thank you.

My Lady, that is all I ask.

25 LADY HALLETT: I think we have some questions for you 47

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statement you raise the concern that Long Covid symptoms in older people are at risk of being written off as age-related. Are you able to provide some examples of the types of symptom that are at risk of being written off?

6 A. Yes. I think a very obvious one is delirium which is 7 often anyway mistaken in hospitals for dementia, and it 8 is a reaction to stress and uncertainty and different 9 sorts of living conditions, which older people quite 10 often can display when they are taken into hospital, 11 because it is new and foreign and they are not very 12 well. And it seemed all too easy, and from what we have 13 heard from older people, for those who may have 14 Long Covid simply to be old, "Oh, it's just your age". 15 And there isn't enough research at the moment 16 specifically looking at how Long Covid impacts different 17 age groups, particularly older people, who do, as I say, 18 respond differently sometimes to illness.

Q. Finally, can we turn to the lessons of the pandemic.
 Your statement concludes with this observation:
 "The pandemic has highlighted and exacerba

"The pandemic has highlighted and exacerbated pre-existing discrimination towards older people."

What are the key recommendations you would like this Inquiry to consider to ensure that this does not happen again in a future pandemic?

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Ms Abrahams. I think we start with Ms Mitchell, who is that way.

Questions from MS MITCHELL KC

MS MITCHELL: Obliged, my Lady.

Ms Abrahams, I appear as instructed by Aamer Anwar & Company on behalf of the Scottish Covid Bereaved.

Hearing what you have said about advice you just tendered there, I'm going to ask you the same to see if there are some recommendations that might assist.

It's the experience of the Scottish Covid Bereaved that older family members were asked to sign DNACPRs, and even when they didn't sign it they were worried that this would impact upon the medical treatment they would receive. First of all, was that something noticed by you in any feedback that you got?

16 A. Yes, it certainly was, I'm afraid.

17 Q. And secondly, given that is so, in what way can the
18 trust be rebuilt between healthcare, government and
19 people of age to give older people the confidence to ask
20 for their healthcare needs to be met when the next
21 pandemic comes?

A. Yes, well, again, that is going to take time and hard
 work. And there is nothing wrong with advanced care
 planning but it needs to be advance. It can't be done
 in a rush, in an emergency. And if that happens we

can't expect the outcomes to be good.

So I think the answer is to take advance care planning more seriously right across our society and not just see it as something to be used in extremis.

- Q. Do you think that would have the effect of allowing people a confidence in their own autonomy over their health or the right to demand healthcare when it's required?
- 9 A. Yes, as long as it is done properly and well and,
 10 ideally, well in advance of any of us ever needing to
 11 face these decisions in reality. People of my age
 12 should be doing this now.
- Q. My next question is also in relation perhaps to some
 assistance you might be able to give. Some of those
 that I represent in Scottish Covid Bereaved have
 experience of family members, particularly older family
 members, having been isolated and unfortunately
 thereafter becoming ill with Covid and dying.

You in your statement talk about the isolation for older people sometimes and the issue of loneliness.

How important do you think it is for consideration to be given to tackling or at least not exacerbating loneliness when promulgating policies during a pandemic?

A. I think it is tremendously important, and it was the
 need for older people in particular, especially if they

Our questions are due in today for our healthcare minister so that may be a timely opportunity for us to pose that question.

I'm obliged, my Lady.

LADY HALLETT: Thank you, Ms Mitchell.

Just pursuing that, one of the reasons, obviously, people feel isolated was they're in their own homes, they don't have family nearby and any family that can visit, they are stuck outside. Trying to look after people like that depended a lot on local communities and people who were prepared to go and collect the medication, deliver supplies. Are you confident that enough work is going on involving the voluntary and community sector in making sure that if anything like that does happen again that there are people who can step in to try and relieve some of the loneliness and isolation?

A. I think you are absolutely right. We certainly saw during the pandemic that people stepped up. There were amazing examples of formal organisations but informal groups, too, getting together to support older people, in particular, who really benefited from it. But that's all gone, and unfortunately not only is the same impetus not there now, we are also seeing voluntary organisations in local areas closing because they can't

were living alone, or if they were in a care home of course, in a residential setting or a hospital, to have people they know and love and trust around them wasn't properly understood, but we can certainly see it now because I think many older people emerged from the pandemic with significant mental health problems, created by the isolation that they experienced at that time.

Q. And I think we saw in the document that my learned friend brought up earlier, about the feelings of anxiety that many older people are feeling. Again, the same question that I asked before in relation to the other matter: given that there is that anxiety, is there anything that could be put in place to try and ensure that people can gain confidence that their healthcare will be met in the next pandemic?

A. It is a big ask, isn't it, but I am reassured that these messages about taking older people's health needs seriously are being listened to, at least in England. I cannot say whether it is the same in Scotland but policy developments underway now from our new government should help us get to a place where older people's needs are better met at home and in the community, but it is going to take time.

MS MITCHELL: I'm obliged.

afford to keep running. So taking support, taking infrastructure seriously in the community and building it up would definitely put us in a better place should we face another pandemic.

5 LADY HALLETT: Thank you.

Mr Weatherby, I think you are next.

Questions from MR WEATHERBY KC

8 MR WEATHERBY: Good afternoon, Ms Abrahams. I ask questions
 9 on behalf of Covid Bereaved Families for Justice UK.

Just one very short topic but it is an importanttopic and you have touched upon it already.

In your statement -- for the record paragraph 62-63 -- you refer to evidence that Age UK had, I think early in the pandemic, but ongoing, evidence relating to the blanket use of DNACPRs and denial of care policies relating to age.

And earlier in your statement you had referred to the fact that Age UK was a major charity, had a major qualitative and quantitive research programme and collected insights from literally hundreds of thousands of older people. So when you refer to evidence in your statement, it is widespread evidence; is that fair?

23 A. Yes, and I think as with so much during the pandemic, it24 was patchy.

Q. Yes.

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- A. 1 So there were some areas --
- 2 Q. I see.
- 3 A. -- and some places where we know that these practices 4 happened. They were relatively isolated.
- 5 Q.
- 6 Α. But within a very broad, national context.
- 7 Q. Yes.
- 8 A. There wasn't a simple pattern.
- 9 Q. No. And that caused you, I think, to pressure
- NHS England, initially, to take steps, and they did take 10
- 11 steps to indicate to stakeholders that policies such as
- 12 these were unacceptable; is that right?
- 13 A. Absolutely.
- 14 Q. Yes. However, you do go on then to say that in fact you
- 15 then had evidence of the practices continuing, and you
- 16 subsequently issued a series of public statements
- 17 between March and November 2020 relating to these issues
- 18 to highlight them; is that right?
- 19 Α. Correct.
- 20 Q. The statements were co-signed by your partners and other
- 21 partners from Wales, Scotland and Northern Ireland.
- 22 Does that reflect the fact that the concerns were
- 23 widespread not just within England but in fact across
- 24 the UK?
- 25 Α. Absolutely.

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this morning. And also barriers around English as not a first language.

Would those things have been improved, access to information, if family carers had had more involvement in the delivery of healthcare?

6 A. Yes.

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- 7 Q. And how might that be changed in the future?
 - A. Well, I think there was a long debate, a very intense
- 9 debate, throughout the pandemic, about the extent to
- 10 which family carers were equal partners in the care of
- 11 their older relatives, together with the NHS and social
- 12 care. I think many people assumed at the start they
- 13 were equal partners but some of the events that
- 14 happened, the policies that came into place, caused that 15

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So, taking forward those principles, I think they will probably be discussed in a future module obviously, in particular of this Inquiry, would make a difference. But of course we also have to remember that a lot of older people don't have family carers and are completely on their own, have nobody to advocate for them, and in the end it is those older people who we at Age UK

- 22
- 23 worried about the most through the pandemic, and they
- 24 probably had the worst outcomes of all.
- 25 Q. Thank you.

Q. Finally, this. In respect of those statements, that

series of statements over those months, to what extent,

3 so far as you are able to say from the evidence that you

- 4 are able to collect, to what extent did those statements
- have an effect? 5
- 6 A. Very hard to say, I'm afraid, but I think the fact that
- 7 the organisations and individuals, who included
- 8 appointed commissioners for older people in
- 9 Northern Ireland and Wales, came together to express
- 10 such strong concern --
- 11 Q. Yes.

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- 12 A. -- I think was heard, where it needed to be heard.
- 13 Q. Thank you very much. That is all I ask.
- 14 LADY HALLETT: Thank you very much, Mr Weatherby.
 - Mr Wolfe.

Questions from MR WOLFE KC

17 MR WOLFE: Morning, Ms Abrahams.

> I ask questions on behalf of the Patients Association, Care Rights UK and John's Campaign. I just have three brief topics, if I may, arising from your

21 evidence.

> The first one relates to barriers to older people accessing information during the pandemic. You mention in paragraph 17 and 27 of your witness statement barriers around technology. You have talked about that

Second topic, if I may. Access to healthcare for people with dementia. In paragraph 38 of your witness statement you explain that dementia patients experienced a rapid deterioration in cognitive functions. Some were left alone without visitors and with no understanding what was going on around them with no family access.

Do you think sufficient consideration was given to the needs of people with dementia during the pandemic whilst in hospital?

- 10 A.
- 11 Q. And might that have been affected again by the 12 involvement of family members and family carers?
- 13 A.
- 14 Q. Again, how might that change in the future?
- 15 A. I hope that new laws and regulations will come into 16 place to make it clear that if somebody with dementia is
- 17 in hospital or is in a care home that their family
- 18 carers, under certain conditions, should always have the
- 19 right to be with them. That would have made an enormous
- 20 difference to the well-being, and the survival I think,
- 21 of some older people during the pandemic.
- 22 Q. Third topic, if I may. Your organisation gave evidence 23 to the Joint Committee on Human Rights. One of the
- 24 topics it talked about was the need for individualised
- assessments and an individualised approach. 25

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1 Again, how do you think that played out in 2 a pandemic? Was there a sufficiently individualised 3 approach?

- 4 A. Absolutely not. All the things I have talked about 5 today, our biggest concerns for older people during the 6 pandemic, were when blanket policies were imposed, or 7 when sweeping assumptions were made about older people 8 all being the same. And older people are not all the 9 same. And we need to improve the sophistication of our 10 analysis of how our systems work to take that fully into 11 account.
- 12 Finally, if I may, one aspect of those individualised Q. 13 assessments: reasonable adjustments under the 14 Equality Act. Again, any observations on how reasonable 15 adjustments, including possibly, again, involvement of 16 family carers as a reasonable adjustment, took place 17 during the pandemic?
- 18 Well, as far as we're aware, they didn't, or not very Α. 19 much. And more generally, the fact that age is 20 a protected characteristics under the Equality Act is 21 often overlooked.

Disability is talked about much more often, and that is nothing wrong with that of course, but enormous numbers of our professionals and people who interact with older people are totally unaware that the

- 1 the director of strategy and influence.
- 2 Q. I apologise.

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- 3 A. That's okay.
- 4 Q. But thank you for that correction.

Can you, though, please tell us a little bit about Mencap, its role generally and its role during the pandemic.

A. Yes, of course. So we are a learning disability charity. We support around 4,000 people in social care settings. We have a further 2,000 that we support through employment programmes and various other community activities. We have a network of over 300 independent organisations and through them we have contact with 40,000 people with a learning disability.

We also run an information and advice service and deal with 12,000 calls to our helpline every year and around 40,000 visits to our website every month, and we campaign, particularly on health, on employment, and getting people out of assessment and treatment units.

- 20 Q. Is it right that Mencap's remit is in England, Wales and 21 Northern Ireland but not in Scotland?
- 22 A. That's right. That's correct.
- 23 Q. I want to ask you today about some of the concerns that 24 Mencap had predominantly during the relevant period of 25

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Module 3. If we can start, please, with the

Equality Act applies to older people too.

2 Q. I get the impression that almost you would say the 3 Equality Act was suspended during the pandemic; would 4 that be a fair assessment?

A. That assumes it was ever applied properly to older 5 6 people in the first place, which our view is it isn't.

MR WOLFE: Thank you, Ms Abrahams. Thank you, Chair.

I think that completes the questions we have for

8 LADY HALLETT: Thank you very much, Mr Wolfe.

10 you, Ms Abrahams. I think I may have said it when you 11 first helped me in Module 2, I think it was, I'm really 12 grateful to you for your help. You are an excellent 13 communicator and a superb witness and everything you 14 have done so far -- and I'm sorry it is "so far", 15 because I fear I may be calling on your help again in 16 a future module -- has been extremely helpful. Thank 17 you very much indeed.

THE WITNESS: Thank you. 18

19 (Witness withdrew)

20 MR FIREMAN: May I please call Jackie O'Sullivan.

21 MS JACKIE O'SULLIVAN (sworn)

22 Questions from COUNSEL TO THE INQUIRY

23 MR FIREMAN: Ms O'Sullivan, you are the chief executive of 24 the Royal Mencap Society; is that correct?

25 No, I was the acting chief executive but I'm actually

1 disproportionate number of deaths amongst people with 2 learning disabilities. Your witness statement sets out

3 that pre-pandemic --

4 A. Yes.

5 Q. -- NHS England's 2019 Learning Disability Mortality 6 Review demonstrated that women with a learning 7 disability died 27 years earlier than the general 8 population and men 22 years earlier than those in the 9 general population.

Do you recognise those figures, first of all?

- 11 A. Yes, absolutely. And we knew, going into the pandemic, 12 that it was likely that these health inequalities would be exacerbated and I'm afraid that was the case. 13
- 14 Q. The Inquiry heard a couple of weeks ago --
- 15 A. Yes.

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16 Q. -- from Mr Matthew Stringer on behalf of the Disability 17 Charities Consortium, and he gave evidence that during 18 the pandemic people with a learning disability were six

19 times more likely to die than those without learning

20 disabilities and that this was 30 times more likely for

21 adults between 18 and 34.

22 A. Yes.

23 Q. Again, are you familiar with those figures?

24 Yes, I am and that is backed up as well. So we had some 25 data from CQC in June 2020 which showed 134% increase in

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the number of deaths of people with a learning disability and the age group that was particularly affected was 55-64, so people were dying at a younger age. Obviously then we had the PHE data, which you referred to just now. And then the Office for National Statistics that showed that disabled people were -- 60% of the deaths due to Covid were from disabled people.

So we suspected that people would be severely impacted and then we heard about this anecdotally. The way we were set up because we have so much direct contact with people in our day-to-day lives, we were picking up on early signs. We were getting calls to the helpline. A lot of the organisation was focused on supporting the people we have direct responsibility for through this.

But my role particularly was thinking, how are we going to show up for the wider 1.5 million people with a learning disability in the UK and what do we need to do?

So we were picking up on news reports, on government announcements, on people calling the helpline, on things that we were hearing through our services and through our network partners, and just trying to do our best to support people through the pandemic, because we knew that people were likely to die

If we could take a look at the critical care guideline which NICE produces, INQ000474301.

The Inquiry has looked at it before but I just want to give you the opportunity to explain, from Mencap's perspective --

A. Yes.

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7 Q. -- what your concerns were.

> If we could go to the next page of this guidance please -- yes -- there we can see the criteria that was being proposed as to how to assess adults upon admission to hospital.

Can you just explain in your own words what the concerns were from Mencap's perspective? A. Well, this makes it clear that the Clinical Frailty Scale should be applied to all adults irrespective of age, and that comorbidities -- and doctors would consider a learning disability often to be a comorbidity -- or an underlying health condition should also be affected.

If you look at the Rockwood scale, which is attached to the Clinical Frailty Scale, that shows very clearly that if you need extra support with your household affairs, your shopping, your bills, maybe taking medication, then you were unlikely to get a ventilator and unlikely to be treated for Covid in

1 in greater numbers and then the evidence started to 2 unfold and, sure enough, that was the case.

Q. You mentioned your suspicion that that may have been the case early on during the pandemic. What do you consider to be the main reasons -- both that you had that suspicion and indeed that in fact it became a reality, what do you consider to be the main reasons for the disproportionate number of deaths amongst people with learning disabilities?

10 A. So in some ways they weren't thought about, they weren't 11 considered, and we see that in general that people 12 sometimes are after thoughts, that reasonable 13 adjustments aren't made for people and that some of it 14 relates to attitude as well.

> So of those deaths, we know that before the pandemic 1,200 deaths were avoidable and there were a higher proportion of those that were taking place in healthcare settings and related to healthcare than there were for the general population, which suggests that people weren't getting the treatment that they should have and, as a result, were dying.

22 Q. One of the most significant concerns that you raise 23 within your witness statement relates to critical care 24 guidance and whether that had a bearing on the outcomes 25 of people with learning disabilities.

1 hospital.

So we saw this came out, this NICE guidance came 3 out on 20th.

4 Q. 20 March?

> A. Yes, 20 March. We picked up on it on 22 March because the Rockwood scale was published in the Sunday Telegraph. And we were immediately alarmed by it because essentially it meant that most people with a learning disability, even people with mild and moderate needs would be ineligible for treatment.

So we were very concerned. We got hold of NICE. I had multiple emails and also a meeting with Paul Chrisp at NICE about this. He said during the course of that that they were still firming up how they could get in place equality impact assessments due to the speed of turning the guidance around and it was clear to us that people with a learning disability had not been considered as part of this.

19 Q. And part of the reason for that, I understand, and 20 the Inquiry has heard that the Clinical Frailty Scale is 21 not validated on people under the age of 65 or with 22 long-term stable disabilities; that's right, isn't it?

23 A. Yes, that's right, that's the case.

24 Q. And you mentioned -- that can come down, thank you --25 that you were immediately in correspondence with 64

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1 Dr Paul Chrisp, I think that's the director of the 2 centre of NICE guidelines, who the Inquiry will hear 3 from later on in the week. And is it right that you 4 advised him immediately of the concerns --

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6 **Q.** -- that Mencap had about the content of that guideline?

A. Yes, I did. Yes, I did. And then we had email exchanges and a meeting as well because we eventually agreed the changes which obviously were still put in place, although I must note the even the amended guidance has the same date of the 20th on -- but the final email from Paul was on 31 March and that said that he had made the changes and it was due to go live.

But we were also concerned because this had been communicated out quite widely and we were worried that the genie was out of the bottle, really, and that it had been in the media and how was this then going to be communicated to healthcare professionals who were probably working under the assumption that it was

And we saw this -- we saw this during the course of that week, so on 24th March some of our services alerted us to the fact that they were receiving letters dated 24 March that essentially said: if anyone in your service gets Covid, they are unlikely to be treated and

share on the date of publication.

So we would have done everything we possibly could to help NICE get this right. But we weren't asked. **Q.** Turning to another of your concerns, that of DNACPRs.

There are three issues I'd like to go through with you. Broadly they are: inappropriate use of DNACPRs, lack of communication around DNACPR notices, and the possibility that DNACPR notices were being confused with

9 Do Not Treat orders.

10 A. Yes.

Q. Am I right that Mencap was made aware early on in the pandemic around particular issues with GP surgeries sending letters to individuals and, indeed, groups of individuals with learning disabilities indicating that they may want to consider having a DNACPR on the patient's file?

A. Yes, we were, yes. Some of our support workers flagged it. It turned out that there were two letters that we supplied but those weren't the only ones where people were reporting all over the country getting copies of letters, similar letters, and some of the care providers, as well, that we are in contact with also reported this as well.

We also picked up on instances of individual DNACPRs being applied without proper consultation.

therefore please don't bring them to hospital. 1

2 Q. Thank you. And we will look at some of the 3 correspondence you refer to later on.

But just going back to the engagement you had with Dr Paul Chrisp. You mentioned that after having had some correspondence with you there was -- there were amendments made to the guideline.

8 A. Yes.

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Q. Her Ladyship has seen the amendments previously, so I don't propose that we go to them but they essentially added a number of caveats, didn't they, to the use of the Clinical Frailty Scale?

13 A. Yes, yes.

14 Q. Is it right to assume, then, that prior to the publication of the initial guideline you were not 15 16 contacted by NICE or anyone else involved in the 17 publication of that document?

18 A. No. And if they had contacted us, we would have helped 19 them and we would have pointed that out. At the same 20 time, I was involved in a working group on the Care Act 21 easements. We turned that around in a week. There were 22 a group of charities like myself and representatives and 23 we were literally, you know, commenting on things 24 overnight, it didn't slow up the process, we even 25 produced an Easy Read guide for officials to be able to

So I will give you two examples of this.

One was the parents of a teenage person with a learning disability who got a letter asking them if they'd agree to a DNACPR for that individual.

And the other one was a conversation that happened and fortunately one of our support workers listened in on the call, and it went along the lines of: I'm just calling from the doctors to see if it is okay to put a DNACPR on your file and when the person said, "What's that?", the doctor said, "Well, you know, it is nothing to worry about but if something bad happened to you they wouldn't give you the kiss of life", to which the person replied, "Well, I wouldn't want that because I might catch Covid", and that was the end of the conversation.

And if the support worker hadn't been in the room at the time that DNACPR would still be on that person's

It follows, then, based on what you are saying that that 18 19 particular concern is a concern about not necessarily --20 it may well be that there was a concern about the 21 appropriateness or otherwise of a DNACPR but that's 22 about the communication of the decision, isn't it?

23 A. Well, I think it is both really, isn't it? Why would you expect in your 40s to have a conversation like that with your GP? And if you think about the fact that this

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1 is somebody in authority having this conversation, it is 2 completely out of context. I think it is inappropriate 3 for the conversation to be had in the first place let 4 alone for it to unfold in the way that it did.

- 5 Q. When you say it is inappropriate, that's on the basis, 6 is it, that this individual did not have any other 7 particular concerns, comorbidities, simply they had 8 a learning disability?
- 9 A. Yes, yes, they had a learning disability and they were 10 living in a care setting. So I think there was quite 11 a lot of confusion around that as well. That people 12 with a learning disability live in supported living 13 settings which are everyday homes. They live everyday 14 gloriously ordinary lives in everyday homes with, 15 you know, two, three, four people living in the same 16 setting and these -- these letters were sent as if it 17 was a large care home full of very frail people and they 18 are not, they are people living everyday lives, working, 19 going out, having -- you know, very healthy people, full 20 of independence and possibility.
- 21 **Q.** Can we have a look, please, at one of the letters that 22 you have appended to your witness statement. This is 23 INQ000505520.

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And this is a letter that's has gone to a number of people, I think a home, or a setting on 24 March 2020

- Q. Is it right that you had some concerns that the 2 production of these letters had, whether directly or 3 not, been influenced by the publication of that guidance?
 - A. I do. And I think around that time we had the message to Protect the NHS and I think that led to the Clinical Frailty Scale. This was all about relieving pressure on hospitals, and if you were a GP and you looked at that Clinical Frailty Scale and, actually, these letters have text to that effect, that actually there is no point this person going to hospital because they are not going to get any treatment so we may as well apply a Do Not Resuscitate notice and then we will give them palliative care at home. And I think that was the thought process.

So I think we ran very quickly from "we are going to protect the NHS" to NICE issuing the guidelines and those being communicated out, to -- and everybody was working at speed and under a huge amount of pressure, but then GPs thinking actually it's in people's best interests to send these letters and to apply the DNACPRs and if they didn't send the letters they were increasing the number of DNACPRs that existed and we also had cases where old DNACPRs were brought into play and people refused conveyance to hospital on the basis that when they had a broken ankle ten years beforehand a DNACPR

and if we could go to the second page, under the title "Cardiopulmonary Resuscitation - CPR", just looking at the second paragraph there it says:

"The chances of success in CPR for a patient with advanced disease or frailty are virtually zero. CPR is therefore not appropriate for the vast majority of these people and should only be attempted if it is considered that it may be successful. For these reasons, many people decide in advance not to have CPR, and choose to be allowed to have a natural and peaceful death."

That paragraph may seem relatively anodyne but why was that particularly concerning for you?

- 14 Because this letter was sent to a household of people 15 who were not frail and were not at the end of their 16 lives and I think this is the issue here, that there was 17 a blanket assumption that anyone that got care and 18 anyone who had a learning disability had a comorbidity 19 or was frail and therefore advance care planning should 20
- 21 Q. Going back to something you said earlier. This letter 22 was sent on 24 March 2020.
- 23 A. Yes.
- 24 Q. The guidance from NICE was published on 20 March 2020.
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1 had been put in place.

> And so you can also see how these were then confused with treatment.

So, you know, whilst actually, you know, intervention, intubation, CPR in its true sense may be something that people might not want to avoid, it doesn't mean that they are signing away their rights to any treatment at all and that's, in practice, what was happening, that people were not getting treatment, they were not getting conveyance to hospital.

- Q. A point of clarification, Ms O'Sullivan. The Inquiry heard from Mr Stringer on behalf of the Disability Charities Consortium a couple of weeks ago and he said there was evidence from Mencap of a GP applying blanket notices to people then under the care of a Mencap institution -- those were his words. Is that the sort of thing that we just saw in that letter, is that what he is referring to?
- 19 Yes, that's the sort of thing. And there were obviously Α. 20 other letters and also phone calls as well.

Can I just -- just, again, as a point of clarification, we don't have any institutions. We campaigned heavily to get rid of institutions, successfully, and these -- these are social care services. Everyday homes. It is -- the word

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"institution" conveys an idea of, you know, an isolated 2 hospital, and that's absolutely not the case. 3 Q. The point you are making, really, is that these 4 individuals are living ordinary lives, albeit supported 5 by carers?

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- 6 A. Absolutely, Absolutely, yes. Typically it will be 7 a normal house, everyday house. There will be a team of 8 carers that may go in and out during the day. Some 9 people only get a few hours a week. Some people might 10 have 24/7 care. Some people might have someone sleep on 11 site just in case there's a problem in the night. But 12 it very much is -- it is ordinary people in ordinary 13 homes.
- 14 Q. Finally on this topic, can we please go to 15 Ms O'Sullivan's statement paragraph 16. 16

I'm not sure if I read this out before, but it's INQ000479878.

And we're looking here at paragraph 16 and at an example that you have given of something else happening in relation to communication around DNACPRs.

I'm just reading from the second sentence where it says:

"In one such case, the person we supported was admitted into ... hospital on 31st March 2020 due to sepsis diagnosed by the GP. He was in hospital for

1 likely to get treatment for Covid. And level 5 was 2 someone who needs a bit of additional help with their 3 shopping, their household finances, their medication. 4 That's the majority of people with a learning 5 disability.

- 6 Q. Focusing though on the communication around these 7 decisions, who would you have expected to have been 8 contacted to discuss the decision to provide a DNACPR to 9 this individual?
 - A. Well, firstly, if the individual lacks capacity then it would be their families and if the family wasn't around then it would be carers. So we would have expected conversations with -- and it may be that the hospital would have attempted to have a conversation with the individual and the team might have facilitated and helped that in terms of communication.

But what was happening was even where there were -- there was one case where a family member was asked. She said she needed to go away and consult her mother and her sister about it. Before she even had a couple of hours to do so, the sister was denied a routine scan in hospital that then resulted in her death a few days later. And when the family asked for an investigation, it was shown that there was a do not attempt resuscitation notice on the patient's file that

5 days, and was successfully treated. On arrival back to his home, which was a supported living service, staff discovered a DNACPR form at the bottom of his bag. There was no reason stated for its issue. The person had no pre-existing health conditions and was in good health prior to his admission for sepsis. The team who supported him were not contacted with regards to the DNACPR decision, and the person would not have had capacity to make the decision, if an attempt to discuss it with him was made."

So how did you then come to be aware of this particular incident?

13 A. Well, this would have come through our teams and we had 14 multiple cases like this. We also got examples through 15 our helpline and families contacting us asking for 16 support and advice.

> So in March 2020 we had a bereaved family saying that their loved one had not received any treatment whilst in hospital and that a DNACPR had been applied without their knowledge, and had been done so according to their functional status because they were dependent on care. So this to me suggests a real link with the Clinical Frailty Scale, which clearly said -- the Rockwood scale and the article in the Sunday Telegraph, clearly said if you are level 5 or above you are not 74

they had not agreed to, but the records suggested that the sister had. And that was quite common as well.

So families were left with the grief of losing somebody but also an insinuation that they had actually agreed to something that they felt very strongly they hadn't.

7 Q. That can come down.

> Are you aware that NHS England did put out a bulletin, a primary care bulletin, on 8 April 2020 reiterating the key principles around DNACPRs, that it needs to be an individual assessment and preferences must be taken into account and that blanket DNACPRs are not appropriate?

- 14 A. Yes. And we pushed for that and we also pushed for the 15 letter that went from Claire Murdoch to PCTs on 3 April 16 as well, so I must say when we raised things people were 17 responsive and tried to put them right, but I do think 18 the genie was out of the bottle.
- 19 Turning to a different topic: the impact of infection Q. 20 protection and control measures on those with learning 21 disabilities.

Can you explain your concerns in particular about the restrictions on visiting and how they impacted those with Mencap support.

25 **A**. Absolutely. So family members and carers are absolutely

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vital for people with a learning disability and it was treated a little as if it was a nice-to-have in some instances and people were denied access. But it is absolutely important.

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People can help with communication. We see a lot of diagnostic overshadowing, people not displaying pain in the same way that perhaps you might expect from a member of the general public. And also family members have a lot of information about the way that their loved one behaves in stressful situations. So actually visiting wasn't just something that would provide reassurance for the family member and the individual, but it was absolutely vital if the care was to be successful

And we know that anyway. We have campaigned for a long time on reasonable adjustments and the right for families and carers to be listened to.

So what we saw were people going into hospital in distress. The distress was exacerbated because they were alone. There was no one to help interpret what their needs were. In some instances they weren't allowed to take hospital passports because paper wasn't allowed in.

Q. Just pausing there to explain what the hospital passport

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patient wasn't speaking to them. To which they replied, "It is because she is non-verbal". And the hospital for four days had no idea that the patient couldn't communicate with them verbally. And she then was discharged two days later and she was covered in bruises and traumatised and we had no idea what had happened. The team think that they also didn't realise -- she wasn't able to take her wheelchair with her in the ambulance, and the team think that they didn't realise that she was immobile as well and probably got her to try to walk.

- 12 Q. And is this an issue that arose from this individual not 13 having a passport or is it an issue that she wasn't 14 allowed to bring it in?
- A. She wasn't allowed to bring it in. So she had one but 15 16 wasn't allowed to take it. And the team weren't allowed 17 to accompany her and they weren't allowed to visit her 18 and there was very poor communication between the 19 hospital and the team.
- 20 Q. Are you aware that the guidance did change, I think it 21 was in October of 2020, to allow visitors to accompany 22 those with learning disabilities?
- 23 A. Yes, yes. So on 25 March we were told no visitors. On 24 9 April, some exemptions were made, but it wasn't clear 25 or clear enough, and then in May it was re-issued and it

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A. A hospital passport is a document that would set out your needs if you were admitted to hospital. And we 3 encourage everyone with a learning disability to create 4 one. It will set out your communication preferences, it 5 will set out medications, dietary requirements, things 6 like that. But also it will say if you don't exhibit 7 pain in the same way a healthcare professional might 8 expect you to, and it will give clinicians -- the idea 9 is that it will help clinicians assess you.

> So I will give you an example of what happened here. In March 2020 we had an individual of 49 years old with Down's syndrome who had never been alone in their life, ever. The family were barred from visiting. They didn't have a hospital passport. The person died and then the family were called and informed that they passed away.

Another one, in one of our settings, it was a person with a chest infection that was resistant to antibiotics. She was taken into hospital, put on a Covid ward but repeatedly tested negative for Covid, and eventually she was given the antibiotics and started to recover.

The team called the hospital every day. They weren't successful in speaking to people. On the fourth day they were and the hospital team asked why the

was much clearer. But even then it wasn't always accepted by hospitals and nursing staff.

3 Q. You also raise a concern in your witness statement on 4 a very similar note about the wording of ambulance 5 guidance in relation to conveyance to hospital.

If we could, please, show on screen INQ000498063.

And I'm looking here at the heading 10.2 "Using the most appropriate conveying resource", and the second bullet point up from the bottom where it says:

"non-essential persons (such as observers, family members) are not to travel within the patient compartment with a suspected or confirmed case, unless the patient is a child who requires conveyance."

Just going to pause there. There is obviously an exception there for a child. Does it follow that you would have expected there to also have been an exception for, for example, a person with a learning disability?

A. Yes, absolutely. It would be a reasonable adjustment 18 19 that should have been made and should have been 20 respected despite the circumstances of the pandemic.

Q. And is the issue with this particular guidance that the phrasing "non-essential" is really open to significant interpretation as to whether or not a carer is or is not or a family member is or is not essential to that individual?

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1	A.	Yes, yes. And I believe that's how it ended up being
2		poorly applied, even after the guidance had been
3		clarified, that it was the what constitutes
4		an essential person.
5	Q.	If that can come down.
6		Is it right you campaigned to have this guidance
7		changed?

nce changed?

- 8 A. Yes, yes we did.
- 9 Q. And did it change?
- 10 A. Yes, it did. It did. But we still got -- we still had 11 issues where people were using the old guidance and interpreting this wrongly. 12
- 13 Q. And given the number of issues which Mencap has raised 14 in terms of the way in which guidance was produced and 15 the wording of that guidance, is there any thought, from 16 your perspective, about the involvement that Mencap has 17 or individual organisations such as Mencap has in the 18 production of guidance going forward?
- 19 Α. Well, this is the thing that really -- you know, if 20 anyone had asked, if anyone had shown us this guidance 21 we would have happily looked at it and we would have 22 happily advised on it, and I think we could have avoided 23 a lot of these issues had that happened. 24

So, we know -- in slower time, we would expect to actually co-produce things with people with a learning

disability and really get -- but in the absence of -and at speed, we do have colleagues with a learning disability who will gladly look at guidance, turn around Easy Reads. We have lots of policy experts who can help and support.

So even in the times when everything was so pressured, and we were operating at speed, we could have helped with a lot of these things.

- 9 Q. Did you also have concerns about the use of PPE and its 10 impact on those with learning disabilities in healthcare settings?
- 11 12 Yes. I mean obviously PPE reduces people's ability to A. 13 take verbal -- visual clues from the way people are 14 presenting and talking, and especially compounded with 15 if you can't -- if you're in hospital it is 16 a frightening experience at the best of times. You do 17 not necessarily understand what is happening to you, 18 what is going on. And then if you are approached by 19 strangers wearing masks, you can't pick up on visual 20 clues in terms of smiling and things like that. So it 21 absolutely did. And it is important to note that PPE 22 was also used in social care settings for a very long 23 time after it was no longer required in healthcare 24 settings. And again, that was problematic for people in

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terms of communication.

1 So, yes, absolutely it was an issue. 2 MR FIREMAN: My Lady, I'm going to turn to a slightly 3 different topic. That might be an appropriate time. 4 LADY HALLETT: Yes, of course. I hope you were warned that 5 we break at this stage for lunch? 6 A. Yes. 7 LADY HALLETT: Are you okay to come back this afternoon? 8 A. Yes, absolutely. LADY HALLETT: I shall return at 2.05. 9

11 (The short adjournment)

12 (2.05 pm)

(1.02 pm)

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LADY HALLETT: Mr Fireman. 13

MR FIREMAN: Thank you. 14

> Ms O'Sullivan, a slightly different topic to what we were talking about prior to the break, that of learning disability nurses and the role they play in supporting people with learning disabilities within a healthcare setting.

Could you just give us a sort of explanation as to how vital the role that learning disabilities nurses play is?

23 A. It's absolutely vital. So they support by giving expert 24 advice. They have a deep knowledge of people with 25 a learning disability, they can help with communication 83

issues, they can help with treatments. And what we saw during the pandemic was that many of them were redeployed into ICUs and other areas. And that stripped hospitals of that expertise and that knowledge.

I will give you an example just to illustrate how important this is.

We had somebody who had Covid who was admitted to hospital and she was unable to tolerate a face mask, so she was unable to be given oxygen, an oxygen mask. And as you can imagine, she was non-verbal, she had strangers wearing face masks who were trying to putting something on her face and it was very, very scary and she just wouldn't allow it. And the hospital tried and in the end they contacted the family and said that they were going to discharge her with palliative care because there was nothing they could do for her.

Actually, we managed to get on -- the family contacted us immediately and we managed to get on to a learning disability nurse from another hospital who was able to give some advice.

What she said was actually this is very common, that what could be used in its place was a simple oxygen hood or an oxygen tent. And an oxygen tent looks a little like one of those things that people put over child buggies when it rains, so it is a very simple

piece of plastic, basically, that goes over somebody. And that's in fact what happened. We managed to get this person saved.

The following day she went home, she was discharged, she was having a cup of tea in her garden with her family. She is still alive today, still parties and still is a lovely woman, and she would not have survived had it not been for the intervention of a learning disability nurse from another trust.

So that's a -- just to give you a flavour of the example of how important that knowledge and understanding is.

- 13 Q. Is it right that a number of learning disability nurses
 14 were redeployed to various different parts of the
 15 healthcare system during the relevant period?
- 16 A. Yes, it is. Yes.

- 17 Q. Did you have particular concerns about the decision to18 redeploy these nurses?
- **A.** Yes, absolutely. And we made those known. And I think
 20 it is fair to say that the nurses themselves had that
 21 concern. Some of the survey work that we did during
 22 that period of time that fed into a report we published
 23 at the end of 2020 said that only one in five had any
 24 confidence that reasonable adjustments were being made
 25 in their hospital during that time. And we were really

What were your particular concerns about the use of remote services for people with learning disabilities?

A. Well, they are harder to access. So, not everyone with a learning disability is IT literate, not everyone is able to use the technology. And then there is the issue of diagnostic overshadowing and GPs not being able to pick up on the signals that are coming from patients if they are seeing them in real life. And that's especially the case of people with a learning disability. So you've got an additional barrier -- communication is sometimes more difficult and then you have the additional barrier of the technology and the remote nature of the conversation.

And I think it probably led to a lot of people not getting in touch. There was general anxiety and fear, particularly around health and doctors, and I think there were probably lots of people that should have consulted their GPs during that time and who didn't, partly because they felt they shouldn't, partly because -- and I know that was an issue for the general public as well, but actually for people with a learning disability because they actually couldn't.

Q. One of the significant changes that was brought in was
 increased use of the 111 service?
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1 concerned about the loss of expertise, the loss of 2 someone to advocate as well, for patients.

Q. Do you think then there is a link between the fact that
learning disability nurses were redeployed and perhaps
a lower level of care being provided to patients with
learning disabilities?

A. Yes, absolutely. Absolutely. Because they were the
 ones that could actually put in place simple reasonable
 adjustments that could make a huge -- as in the case
 with this woman -- that could make the difference
 between life and death.

And I must say that post pandemic the numbers of learning disability nurses has been dropping since then as well. And that is of major concern to us because they play a vital role.

- Q. Do you consider that were there to be a future pandemic
 the specialist care provision of learning disability
 nurses should be protected and redeployment of those
 nurses be avoided?
- A. Absolutely, absolutely. And I also think that we need
 to increase the numbers as well, so that every hospital
 has access to a learning disability nurse.
- Q. Turning to an area that is linked to the changes that
 were made during the relevant period. The increased use
 of remote services.

1 A. Yes.

Q. Did Mencap have, again particular issues that they tookwith the way in which that service was being run?

A. Yes, yes we did. So, again, it's more difficult for people to use. It's also more difficult for people to articulate their symptoms in a way that is then interpreted by nurses remotely and on the phone, and we did have lots of cases as well of where family members had done this on behalf of patients, and actually the 111 people wouldn't listen to the fact that they had a learning disability and wouldn't make reasonable adjustments.

So well into the pandemic we had situations where -- you know, I remember one case a family contacted us on a Saturday night and they were trying to get antiviral drugs and the person on the end of the line wouldn't -- you know, they had a daughter with Down's syndrome, the person on the other end of the line couldn't make that happen, but they were told to go and collect them, which would have meant leaving the daughter on her own and they couldn't do that because of her learning disability. So there were lots of areas where there was less understanding of the situations people were in, and the things that the people with the learning disability needed, by staff there.

1	Q.	Do you know whether or not the algorithm which was used
2		by these 111 services accounted for or asked questions
3		about whether an individual had a learning disability?

4 A. I don't, I'm afraid.

Q. Finally, then, bearing in mind, of course, what we have already spoken about, and as we have gone along you have made several points that are potential recommendations for her Ladyship to consider, are there any other points that you would like to draw out for the Inquiry to consider?

A. Yes, absolutely. So I think there are three things that
 we could do that would make a massive difference in the
 future.

The first is around the learning disability register. There are only a third of adults with a learning disability on that register. If we got everybody on it we could then use it to collect data to make reasonable adjustments to passport, things like vaccines, and to really analyse what was going on and the impact on people with a learning disability.

So that would be my first recommendation.

The second one is around clarity and communications, particularly around the clinical frailty scales, ceilings of care, do not treat, do not resuscitate notices where there is and still is quite

the quality of somebody's life who perhaps has a learning disability, perhaps is non-verbal, perhaps is a wheelchair user, perhaps doesn't have a job, and I think those values cloud some of the decisions that have been made, and really we need to really focus on everybody with a learning disability has the right to a happy and healthy life, just like you and I do, we should all have the same rights.

And also that people with a learning disability do make really positive contributions to society and to everyday lives. People live really good lives.

Somebody non-verbal could come in this room and light it up and have everyone laughing, and I don't think that is recognised and really understood. So something around the attitudes and values that particularly healthcare professionals place on people's lives would be good.

17 MR FIREMAN: Thank you very much.

My Lady, that's all I ask.

19 LADY HALLETT: Thank you, Mr Fireman.

Mr Weatherby.

Questions from MR WEATHERBY KC

MR WEATHERBY: Ms O'Sullivan, I'm going to ask you just
 a few questions on behalf of the Covid Bereaved Families
 for Justice UK. There are just three short topics.
 I will start, if I may, just picking up a point

I will start, if I may, just picking up a point 91

a lot of confusion, the BMJ article that we submitted shows that there is still confusion on those areas, even after the pandemic. And also that article shows that resources are becoming factors in people's decision-making.

So some clarity in communication so that everyone is really clear.

And the other area is around understanding and attitudes towards people with a learning disability. So I think there is general lack of understanding around what a learning disability is in some spaces. We saw that during vaccination where people were told that they couldn't have a vaccine because they didn't have cerebral palsy and cerebral palsy was the only learning disability. So there is some general lack of understanding around that. But a lot of it is actually around the attitudes of people towards people with a learning disability.

So with the DNACPRs, the interpretation of them and the decision not to treat people is taken by clinicians based on value judgments according to their abilities and qualities of life. And if you think about it, doctors are university educated, they have really good jobs, they have a really clear contribution to society and they are then making a value judgment about

about DNACPRs, and you have given a fair amount of evidence about that already.

You are familiar with the NHS Learning Disability

You are familiar with the NHS Learning DisMortality Review?

A. Yes.

Q. And we asked for the 2019 one to be added to the documents so I think you may have had a chance to look at that. I can put it on the screen but I don't think I'll have to. It is just one discrete point.

Now, these are -- just to remind us, these are annual reports, NHS reports and they are designed to review cases and learn lessons and improve the quality of care for people with learning disabilities; that's right, isn't it?

15 A. Yes, it is, yes.

16 Q. The only point I want to pull out of that is that, and
17 I will give you the reference just for the record. It's
18 INQ000474362, and it's page 26.

So this is the 2019 Learning Disability Mortality Review and it's annex 3 which is a table of findings and consequent remedial action. Just this, and this is a quote:

"19 reviews reported that the term learning disabilities or Down's syndrome was given as the rationale for a DNACPR order."

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- 1 A. Yes.
- 2 Q. And that's quite a shocking finding, isn't it?
- 3 A. It is. It really is.
- 4 Q. And just to complete the picture, the action was to send
 5 a letter out to NHS Trust chief executives and others.

So bearing in mind that was a May 2019 document
would you agree that the placing of entirely
inappropriate DNACPRs on those bases in relation to
people with learning disabilities or Down's syndrome has
been a somewhat persistent issue prior to the pandemic
and a known issue?

- 12 A. Yes, it is. It was known before and it still is
- 13 afterwards and we also see learning disability being
- 14 listed as a cause of death on death certificates as
- 15 well
- 16 Q. Yes, indeed, which again is inappropriate?
- 17 A. Yes, it is to say if somebody put "woman" on my death18 certificate.
- 19 Q. Yes, indeed.

This is an issue, bearing in mind this is the 2019
review and it is an important review document, this is
an issue that decision-makers should have had well in
mind at the beginning of the pandemic when they were
looking at pandemic-specific guidance as well?

25 A. Yes. Yes.

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- Q. Was that a surprise and a concern that that hadn't beendone before that point?
- 3 A. It was certainly a concern that it hadn't been done
- 4 before, given that there had been several bits of data
- 5 that had come through that suggested that people with
- 6 a learning disability, not specifically people with
- 7 Down's syndrome but people with a learning disability
 - were at higher risk, and I would have expected some
- 9 further study to have gone on really to assess whether
- 10 it was the type of learning disability that someone had
- 11 or other factors.
- 12 Q. Yes.

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- 13 A. So, yes, it was. And it made it all the more shocking
- 14 as well, given that welter of evidence that when
- 15 vaccines came around we had to campaign to get people
- 16 onto the priority list for a vaccine, it wasn't
- 17 automatic.
- 18 Q. Yes. And people with learning disabilities, butspecifically people with Down's --
- 20 A. Specifically people with -- I think people with
- 21 Down's syndrome were included by that point because they
- 22 were on the clinically extremely vulnerable list.
- 23 Q. When the -- when people with Down's were added to the
- 24 CEV list, is it correct that Mencap was consulted by the
- 25 DHSC, Department of Health and Social Care, in planning 95

1 Q. So when we are looking at guidance, for example the

guidance that you have discussed before, the NICE

- 3 guidance from 20 March, is it a particular
- 4 disappointment that this issue wasn't highlighted then
- 5 so that it wouldn't happen again?
- 6 A. Yes, it really is, and I think what you have highlighted
 - also shows that there are some people in NHS England, in
- 8 the Department of Health who knew this and understood it
- 9 and probably were advocating for it as strongly as
- 10 I was --
- 11 Q. Yes.
- 12 A. -- but they weren't being listened to either.
- 13 Q. Yes, and I think the point you made earlier was that,
- 14 having been in the initial Covid guidance it then -- it
- 15 was too late to put the genie back in the bottle?
- 16 A. Yes, and it fed existing perceptions and attitudes.
- 17 $\,$ Q. So there was certainly the potential for it to carry on
- 18 later into the pandemic?
- 19 A. Yes.
- 20 Q. Second topic, and briefly, the inclusion of people with
- 21 Down syndrome on the clinically extremely vulnerable
- 22 list. It is correct, I think, in late autumn of 2020 it
- 23 was announced that people with Down's syndrome had been
- 24 added to the clinically extremely vulnerable list.
- 25 **A.** Yes.

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- 1 out the communications rollout about it?
- 2 $\,$ A. Yes, it was. Yes, and we were given advance warning
- 3 that it was going to happen.
- 4 Q. Yes. And it was initially intended to be through GPs by
- 5 the use of easy to read leaflets and letters?
- 6 A. Yes
- 7 **Q.** However, did it later become known to Mencap that the
- 8 communication plan hadn't been implemented effectively
- 9 and many GPs were in fact unaware of the responsibility
- 10 that had been placed on them, or were struggling to find
- 11 the materials?
- 12 A. Yes, I believe so.
- 13 Q. And as a result of that a different strategy had to be
- put in place with individuals being directed to contact
 - 15 their GPs?
- 16 **A.** Yes, yes.
- 17 **Q.** And was Mencap involved in all that process to make it
- 18 happen?
- 19 A. Yes, we were. I mean, this was our role almost
- 20 throughout the pandemic was trying to communicate with
- 21 our communities and empower them to ask for their rights
- 22 as well as working with government to try and get the
- 23 cascade working the other way around, yes.
- 24 $\,$ Q. So it was good that Mencap was being involved but in
- 25 fact really you were filling in the gaps --

1 **A.** Yes.

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20 **Q**.

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2 Q. -- that really ought not to have been there.

And did the overall result in this failure of the rollout of the communication and the problems with it, did that in fact then delay some people receiving shielding letters, for example, until January 2021 at least?

- 7 8 A. For sure, yes, some of the letters were delayed and 9 I think some of the other consequence of it is that 10 people were actually taking matters into their own hands. So we knew there were lots of people who perhaps 11 12 didn't need to but who were shielding because they 13 didn't know what to think and they just wanted to keep 14 their loved one safe. So it was placing intense 15 pressure on families who might have other children who 16 were in and out of school. There were tales of parents 17 having to live in two bits of the house and not speaking 18 to each other while one looked after the child with the 19 learning disability and one looked after the other kids.
- Final topic, and again it's a brief one, and it is the impact of rapidly changing guidance on people with autism.

The Inquiry has a statement from Dr Lade Smith of the Royal College of Psychiatrists and she reports

A. -- and I can see absolutely how that can make people
 very upset indeed.

Q. And is it right then that insufficient consideration was
 given to for example people with autism in terms of the
 frequency of changes and the specific measures --

6 A. Yes.

7 Q. -- that should have been applied and weren't to assist8 them?

9 A. So in the frequency but also the specific measures. So it took a while for people to be allowed to not have to 10 11 use a face mask. It took a while for some of the rules 12 to be changed so that people could go and exercise with 13 a support worker because either the previous rule said, 14 you know, you had to be alone. So it took a while for 15 things to be acted upon, which actually a bit of 16 consultation would have made all the difference and 17 perhaps reduced the number of changes.

18 **MR WEATHERBY:** Indeed.

Thank you very much. Those are my questions.
LADY HALLETT: Thank you very much Mr Weatherby.
Mr Wolfe.

Questions from MR WOLFE KC

MR WOLFE: Good afternoon, Ms O'Sullivan, I ask questions on
 behalf of the Patients Association, Care Rights UK and
 John's Campaign. I just have two brief topics, if

hearing from an autistic patient representative that 1 2 frequent government rule changes were confusing and 3 upsetting for people living with autism and the patient representative felt that communication of the rules 4 allowed for different interpretations and that was 5 6 difficult for people to pass and understand that 7 guidance personally and that knock-on effect was on 8 public safety --

9 A. Yes.

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10 Q. -- for people. Is that something that Mencap was awareof or became aware of?

A. Yes. I mean, just the rules changing constantly but also the way they were communicated out. So we would read something in the newspaper at the weekend, then maybe mid-week it would be part of one of the press conferences, then the guidance would come out a few days later. It was all very bitty and confusing and that really made people anxious.

And I think, you know, if you are told that you are vulnerable, and if you are told that there are various rules in place in order to keep vulnerable people safe, and then you see people in society breaking those rules, that's basically telling you that those people don't value you and your life --

25 **Q.** Yes.

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I may.

The first relates to escalation pathways for people with a learning disability. You say in paragraph 51 of your witness statement that:

"There should be a clear and effective escalation pathway for access to care issues for people with a learning disability in times of emergency."

What would that involve?

disability register could be really helpful, that actually if it is known that a patient has a learning disability the pathway could involve, say, consultation with a learning disability nurse, it could involve ensuring that communication preferences that -- were met, it could involve extra stringency around the use of things like DNACPRs. So there are various measures that could be put in place. Specifically if it is known that a patient has a learning disability, that doctors are aware that they might need to communicate differently, they might need to take account of the fact that they

they might need to take account of the fact that they
might be aware of diagnostic overshadowing or particular
issues, and that they might need expert support from

23 a learning disability nurse.

24 Q. And they might also need to involve family care?

25 A. Absolutely, yes. Absolutely. The role of families is

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absolutely vital, and we saw that absolutely through the pandemic where families weren't listened to.

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And we have seen that dating back quite a long way. I mean, this is -- the origins of the Oliver McGowan Mandatory Training stem exactly from a family not being listened to and that their son tragically dying.

Q. You have taken me naturally into my second topic, which is the involvement of family carers being listened to in the pandemic, and you have explained how your view was that they were not sufficiently listened to.

How did that impact on the process of informed consent for treatment for people with learning disabilities?

A. Well, it meant that there was no one there to advocate for the patient, that in some instances we know do not attempt resuscitation notices were applied without family consent or with very limited family consultation. So, you know, an example I think I might have used earlier where, you know, one family member was asked about it in relation to her sister, she said she needed to go and consult other family members, notably her mother, and by the time she came back the patient had been refused treatment and then died subsequently as a result of that and there was an indication that she

1 people with learning disabilities?

2 A. Well, absolutely -- and in fact, that specific example, 3 it was the sister of the person concerned that came to 4 us, because she would not give up on her sister. She 5 was not willing to leave her in a situation where she 6 was just going to get palliative care and die. And she 7 came to us and we managed quite swiftly to reach out, 8 through our networks of learning disability nurses, get 9 her some expert advice, which she then took back to the 10 hospital and advocated really strongly for the 11 treatment. And it was entirely successful. And rapidly 12 successful. So that's a really good example of how 13 family intervention can really make a difference.

MR WOLFE: Thank you, my Lady.

15 LADY HALLETT: Thank you very much, Mr Wolfe.

I think that completes all the questions that we have of you. Thank you very much, indeed, for your help. I'm sorry we had to ask you to come back this afternoon but it has been very interesting and very helpful, thank you.

(Witness withdrew)

22 MR SCOTT: My Lady, may we call Professor Philip Banfield.

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PROFESSOR PHILIP BANFIELD (affirmed)

Questions from COUNSEL TO THE INQUIRY

LADY HALLETT: Thank you for coming back to help,

had given consent when she is really clear that she hadn't.

So this was happening a lot where families were either not consulted or where they were their views were being ignored.

Q. Thank you. So one of the particular concerns that my
 clients have is about the way family members who were
 involved in healthcare, including in communications, as
 you describe, were often treated as mere visitors and
 subject to conventional visiting policies rather than
 being treated as part of the healthcare team. Do you

12 have an observation on that?

A. Yes, absolutely. And I think that's -- that led to them
being denied access to hospitals and visiting
arrangements, which, as I described earlier, it is not
a nice-to-have, this is -- it's really vital for someone
with a learning disability to have someone there who
knows them really well.

Q. Final thought, you gave a very helpful example, indeed
 you have given a couple, how learning disability nurses
 were instrumental in providing support. You gave the
 example of a person who was resistant to an oxygen mask
 and the learning disability nurse assisted with that.
 Do you by any chance have any examples similar that you
 can illustrate the role of family carers in supporting

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1 Professor Banfield.

2 MR SCOTT: Good afternoon, Professor.

If I just briefly set out your background. So you are the chair of the BMA's UK council and have been since July 2022; is that correct?

6 A. That's correct.

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Q. And you are a consultant obstetrician and gynaecologist
 based in North Wales and honorary professor in the
 Cardiff University's School of Medicine. Before being
 appointed as chair of council, you spent several years
 as a representative of BMA Cymru Wales and have sat on
 the UK council since 2012?

13 A. I have indeed, yes.

14 Q. We've heard a significant amount of evidence and the
 15 BMA's written evidence sets out a lot of the impact upon
 doctors, patients and healthcare workers.

17 Could you briefly just give us an idea of the 18 human impact that the pandemic had on doctors?

A. Well, doctors went into the pandemic already with
 significant pressures in work, large instances of
 burn-out and quite a high attrition rate of the
 profession, number of people leaving the profession.
 What the pandemic did, initially, strangely enough, was
 to increase morale, as people felt that they were

25 needing to pull together in this national crisis. But

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very rapidly, and across the course of the pandemic, we
 saw a worsening of both physical and mental health of
 the medical profession.

4 Q. How did that manifest itself, how were people on the ground impacted?

6 A. Well, we saw physically that because doctors were 7 exposed to Covid so readily and so much more than the 8 general public that there was a sixfold increase in the 9 chance of a healthcare worker getting Covid. So they 10 were off. Sadly we know of at least 50 doctors who died from the pandemic and we know of many hundreds who have 11 12 still got Long Covid. Those physical disabilities have 13 affected the mental health -- especially at the point at 14 which the services on the frontline did feel overwhelmed 15 and people were frightened of what was about to come and 16 then frightened about being put in situations that they 17 were unfamiliar with, untrained for, and might put them 18 at risk.

19 Q. Was that the same for doctors across the entirety of the20 United Kingdom?

21 A. Yes, it was.

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Q. Was that the same for doctors of all differentspecialities and seniority?

A. Well, there were different pressures on different age
 groups, so the older consultants, as it became apparent
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any health service that has to change the way it practices. So obviously in maternity we suddenly were in a very strange situation of pregnant women's partners not being allowed in for scans or at the point at which they were receiving bad news. But of course if you stop elective care and you are not then able to provide care to patients that have been under you for some time, if you are stopped from operating, then the stress and distress that that causes is huge. And of course that then has a knock-on effect to our colleagues in general practice because they effectively then took over the care of people on waiting lists that secondary care had effectively stopped working on.

14 Q. Was the medical profession as a whole overwhelmed, bothpersonally and professionally?

A. The medical profession is used to working under pressure. The feedback that we have had is that many people did feel overwhelmed, the sickness rates went up, and that sense of burn-outlasts to this day. And we have seen, certainly, a large number of people leave the service early because of the effects of that.

Q. In the event of a future pandemic, how would you preventthat happening again?

A. That's a difficult one because it doesn't feel as if
 much has changed at this point in time. But valuing the
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that Covid disproportionately affected those in older age groups, were a huge issue. It didn't affect doctors equally. We saw our black, African and minority ethnic colleagues affected. And then we saw the resident doctors, the doctors in training and local employed doctors, were more likely to be redeployed, having a lot of stresses because they were suddenly being put at short notice into strange environments.

9 Q. We will come back and look at that a little bit later10 on.

Dr Kevin Fong gave evidence to the Inquiry in the first period of hearings and he talked about the detail and the dedication and the ability to provide everything that could be provided to provide the best care for a patient who is critically unwell in intensive care.

And he said:

"If your definition of overwhelmed is your ability to provide that, then at many times and in many places the units were overwhelmed."

Now, Dr Fong was talking there about intensive care.

Would you say that other parts of the NHS and HSE across the United Kingdom were overwhelmed during the pandemic?

25 **A.** I think that happened everywhere. And, by definition, 106

staff and enabling them to get on with the job that they are there to do would be helpful.

We went into the pandemic with no capacity to expand, and at the same time, now, we are being expected to address the large backlog. And it would seem sensible to invest quite heavily in expanding that capacity now that could then be utilised for a future pandemic.

9 Q. Is it just capacity or is it flexibility of staff,systems and that capacity?

A. Well, I mean, it is all of those things. It is being
 able to match demand to capacity overall. There are
 mechanisms in place to discuss with the workforce how to
 work and how to optimise treating the largest number of
 patients in the most effective time.

16 Q. You mentioned GPs earlier on. Going to slightly take
 17 you through almost, like, a patient journey. So, in
 18 terms of GP appointments, does the BMA recognise that
 19 the public felt frustration that it was difficult to get
 20 an appointment with their GP during the pandemic?

A. We recognise it because that what was reported.

Of course very early on in the pandemic there was
a specific instruction from the NHS to GPs to switch to
remote working, which GPs did remarkably efficiently and
in very short timescale.

The GPs' surgeries were not geared to separate patients out. The duty of care on GP partners, as an employer, meant that one had to protect their staff as well, and because there are often smaller numbers of GPs you only had to have one, two or three GPs either ill or isolating and the entire service would collapse.

Q. Let me slightly unpick this. So if there was
 a difficulty in getting access to GPs appointments - firstly, do you think that there was difficulty for
 people to be able to access their GP?

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A. There is no evidence at all that GPs stopped seeing
 patients face to face. And in fact, actually, you know,
 the nearest percentage of face-to-face contacts was 52%.
 So -- and that was in England. So all the way through
 the pandemic more than half of the appointments were
 maintained as being face to face.

What GPs did was that they undertook total triage, where they talked to patients first to ascertain whether it was a problem that could be sorted out remotely, or whether they needed to be seen face to face. And they tended to concentrate on people with mental health, the elderly and those with long-term conditions.

- Q. Did primary care generally have the capacity, the
 physical infrastructure, the capability, to deal with
 the number of remote consultations that ended up taking
- ways in which people with varying disabilities are
 continually disadvantaged.
- Q. Can you think of any specific recommendations in thisarea that the Chair may wish to consider?
- A. The most obvious is about having suitable PPE. It took
 quite a long time for example --
- 7 Q. Sorry, just in terms of the remote consultations.
- 8 A. So in terms of the remote consultations, it is being
 9 able to ask or communicate with patients to ask what is
 10 their optimal way of dealing with their interaction with
 11 the GP.
- Q. Do you think that there was a loss of patient confidence
 in GPs because people felt they weren't able to get
 appointments?
- A. Well, I think a lot of the loss of confidence was driven
 by the Department of Health and NHS England appearing to
 blame GPs for the lack of contact, and I think that got
 picked up in the media. I would not blame GPs for
 a lack of ability to contact. We know that general
 practice is under-resourced for the work that it has
 been asked to do.
- Q. What do you think could be done to improve thatsituation?
- A. Well, I mean, significant investment in
 GP infrastructure and GP estates would help enormously.

1 place?

- A. Well, there was a significant investment in IT and that
 is one of the successes of the pandemic, was a rapid
 expansion of the number of laptops and the remote
 working facilities.
- Q. Is it right then that it was only after that expansion
 that there was that sufficient capability but initially
 there wasn't?
- 9 A. Yes. So it wasn't initially capacity.
- Q. And so at what point in time? Because I think you set
 out in your statement that over 50% of primary care
 respondents were limited by hardware, infrastructure,
 software, mobile devices, speed. Were all of those
- issues solved or is there more work to be done in orderto make sure there is sufficient remote capabilities?
- A. No, that work is still ongoing, but it is progressing
 more rapidly in general practice than it is in secondary
 care.
- Q. And do you think that there was sufficient preparation,
 planning or consideration given to those, like Dr Powell
 we heard from this morning, who was -- communicates
 primarily through BSL. Do you think there was
 consideration given to inequalities that might be caused
 by remote consultations?
 A. No. I think that the pandemic has exposed all sorts of

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Would that provide social distancing, what -- broader

- rooms -- how would that assist?
 A. It will help in any future pandemic by making sure that
 you can be proactive with your patients in assessing
 what their needs would be at any particular time if you
 needed to change the way that care was given.
- 7 Q. Okay.

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Finally, if we can look now at shielding. What was the difficulties that GPs faced in contacting those who were advised to shield?

- A. Well, originally they were being told that they would receive the lists of clinically extremely vulnerable patients. They came off several national datasets and they had to cross-reference them with their own patient records and they were finding that there were a lot of errors in those datasets. They then had lists from secondary care and subsequently lists of patients who self identified as clinically extremely vulnerable. So there was a lot of cross-checking that was needed and quite a short period of time in which to do that.
- Q. Do you think it was appropriate for GPs to beresponsible for contacting those who had to shield?
- 23 A. Do I think it was --
- Q. Well, was it the best way of doing it? Let's phrase ita different way.

- 1 $\,$ A. The GPs know the patients best, that's why general
- 2 practice is so successful, they are the most likely to
- 3 know whether the condition is still ongoing or not, but
- 4 if you are going to ask GPs to do that, you need to give
- 5 them the resources to do it.
- Q. And I presume by that answer it meant they didn't have
 the resources to do that, is that --
- 8 **A.** No -- well, no, but they actually -- they get on with the job and they delivered.
- 10 Q. And was there clear communication of the criteria for11 who should shield and if not, how should that have been
- dealt with differently?
- 13 A. Well, there weren't clear instructions and in fact the
- 14 criteria changed several times across the pandemic which
- 15 added to the confusion.
- 16 Q. Can you offer any recommendations, this is a question we
- 17 have been asked to ask, any recommendations to improve
- 18 the ability of healthcare -- doctors, nurses, GPs, to
- 19 safeguard clinically vulnerable and clinically extremely
- vulnerable people in the event of another pandemic?
- 21 A. It is being able to contact people quickly and
- 22 accurately but it is having central advice as to what
- 23 help and support would be available to them.
- 24 **Q.** And that central advice should come from government
- 25 rather than from their own GPs?

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- to be predominantly droplet spread -- I'm not sure that I agree with that, I think there is evidence to the contrary -- but because it is droplet spread that therefore an FFP3 mask is not needed.
 - Now, I would argue that a precautionary approach is advisable, and if I was an employer my duty is to protect my employees. So if there is any chance that the infection can be caught by aerosol spread I have a duty of care to protect against that.
- 10 Q. It is more we have heard people giving evidence who havesaid if you explain the reasons why certain decisions
- have been taken, that doctors, healthcare workers would
- nave been taken, that doctors, healthcare workers would
- have been able to get on and cope with it -- we heard
- 14 that in the initial impact video. I'm asking whether
- 15 there was any explanation to the BMA or to doctors as to
 - why the guidance was as it was rather than what you felt
- 17 it should have been?
- 18 A. No, there was no explanation given. We all felt, and
- 19 I think that was widespread across the profession, that
- 20 the advice was given to match the availability of PPE
- 21 rather than based on evidence.
- 22 **Q.** What do you think about any suggestion that doctors
- 23 wouldn't want to wear FFP3s because of any discomfort
- that may cause in the middle of a pandemic?
- 25 **A.** Well, none of us enjoy wearing protective equipment. If 115

A. Yes

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Q. I want to ask now about infection prevention control.

The Inquiry has heard a lot of evidence about the protection offered by FFP3s compared to FRSMs. On the whole -- obviously, you can't speak for every doctor, on the whole did doctors think that FFP3s provided them with more protection against a pathogen such as Covid-19 compared to FRSMs?

- 9 A. I can say that overwhelmingly the majority of people
 10 feel let down, felt let down at the time and still feel
 11 let down by the observation that fluid-resistant
- surgical masks are not protective against airborneinfections.
- 14 Q. So doctors were asking for FFP3 masks, is that --
- 15 **A.** Well, they were asking for appropriate respiratory
- 16 protection because the surgical masks are not
- 17 respiratory protection.
- 18 Q. Was there ever any explanation as to why -- coming from
- the IPC cell or anybody else who provided the guidance,
- as to why the guidance was being written as it was, as
- 21 to why the view had been taken that FFP3s were only
- 22 required for AGPs?
- 23 $\,$ **A.** I mean, ultimately you are going to have to ask them but
- 24 it was put to us that their view, and there are some --
- 25 still some predominant views that because Covid is felt

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- you've got to put an extra gown on, if you have an apron on, it is enormously uncomfortable but we do it because
- 3 it protects us and therefore protects our patients
- 4 because we know that you could catch Covid from
- healthcare workers and, you know, there was nosocomial
 spread within hospitals so it is not just about
- 7 yourself, it is about everyone else as well.
 - So there are different versions of FFP3 masks available. They come from very simple to very complex and ultimately you can have an air filtering hood as well so, you know, it is up to you and your employer to find the PPE that allows you to do your job across those shifts.
- 14 $\,$ **Q.** Moving now to a concern that had been raised about FFP3s
- and expiration dates. I believe there were concerns
- that have been raised by doctors and other healthcare
- 17 workers that they were being asked to wear FFP3s that
- 18 had come in boxes where the expiration date had expired
- and then there were stickers that had been placed over
- the top of them. That's a concern that you recognise;
- 21 is that fair?
- 22 A. Yes.

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- Q. There has been evidence that suggests that FFP3s werequality-controlled even if they had been expired and if
- 25 they passed that quality control they were then put back

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into circulation for use. Was anything like that ever explained to the medical profession, that actually this was making use of the -- what they thought was sufficiently good-quality PPE that was available at that time?

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A. No, those suggestions were not held with the BMA. It felt as if it was being used as an excuse for not having PPE available. Now, we had gone into the pandemic as a profession thinking that we might be overwhelmed and that we might not have sufficient equipment or beds, so it was within our own minds as to, well, how could we take single-use PPE and perhaps have to reuse it later, you know, you build for those contingencies.

Now, we know subsequently that some of the expired stock was quality tested and was still fit for purpose, and therefore it is not unreasonable to use that in those circumstances.

- Q. Do you think if there'd been better communication or dialogue from those who were writing the IPC guidance or those who were providing that PPE with doctors and healthcare workers, do you think the doctors would have felt more protected than they actually did?
- A. Yes. It would have been much more helpful to have
 discussed it with the BMA so we could have explained it
 to our members. It would have also been, because we

just ask you for a practical example about what you feel should have been done better by the HSE?

- 3 A. We feel that they should have inspected and enforced4 more in the workplace.
- Q. What recommendations would you wish to make, just
 briefly outline them, please, in relation to what more
 should be done in order to make doctors feel safer with
 the PPE that they are using in the event of a pandemic?
 - A. Well, the immediate one would be to recognise that infections like Covid-19 are possibly aerosol-transmitted and therefore that appropriate respiratory protection should be available to them because we still have Covid in our hospitals, we still have clinically extremely vulnerable patients who are frightened about engaging with the health service because we don't routinely wear masks around hospitals anymore so we are not protecting them.

But the medical profession as a whole still feels that its worries about infection control and respiratory protection, ventilation in the hospital estates, is still unheeded and therefore we are unready for the next pandemic.

Q. Did the BMA take any steps to try and ensure that any
 ethnic minority healthcare worker specifically who
 I think as the evidence shows, had a greatly likelihood
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the data and evidence of that testing. But this was at
a time in which people were feeling that there was
a lack of aprons, gowns, visors, you know, GPs were
buying their FFP3 masks from DIY stores and Amazon, and
so there was a kind of element of feeling that we were
so underprepared, you know, what else was being bent as
a rule?

like data and evidence, if they had actually shown us

9 Q. You set out in your statement that doctors didn't feel
 10 protected by the Health and Safety Executive. What more
 should HSE have done in the opinion of the BMA?

12 Well, there were two important things arising from A. 13 health and safety law. The first was a duty to assess 14 the hazard and then to mitigate against that hazard and 15 we feel that the Health and Safety Executive didn't 16 really do either adequately. So, for example, they --17 there was quite a long lag between getting risk 18 assessments for patients and then getting the right kind 19 of respiratory protection for staff and if you have 20 a situation in which the Health and Safety Executive is 21 aware that there are deficiencies in the advice about 22 fluid-resistant surgical masks, for example, because it 23 was their research in 2008 that showed that aerosols can 24 get behind these masks.

25 **Q.** Sorry, to cut across you, Professor Banfield, if I could 118

of being redeployed than other ethnic groups, that they had equitable access to PPE?

3 Yes, we flagged it on many occasions with both 4 government and the NHS in all four nations. The 5 difficulty for people of black, Asian and minority 6 ethnic origin is that are much more reticent, we know, 7 in raising concerns, they were much more readily 8 deployed, they were less likely to protest about having 9 inadequate protections because we know that systemically 10 there are issues with systemic racism in the NHS.

Q. I'm going to move on to a different topic.

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In terms of the provision of guidance or prioritisation protocols, you set out in your statement that there was no government guidance or prioritisation protocols that were issued about criteria or policies about which patients were being admitted into intensive care in the event that demand outstripped already limited resources or services were overwhelmed.

Fundamentally, do you believe that's a question for politicians to provide or clinicians to provide that kind of guidance in the event that it was required?

A. Well, it is a bit of both, isn't it, it is where it
 overlaps because if you are going into a pandemic under
 resourced and under prepared, the state of the NHS at
 that point has arisen because of government policies

1 then if you are going to -- if you are going to at that 2 point -- sorry, I've lost my train of thought.

3 LADY HALLETT: I think the question was were protocols for politicians and clinicians and I think you suggested 4 5 both. But I'm going to challenge you that really the 6 protocols -- I take your point about funding being for 7 politicians and making decisions about where the money 8 went in that kind of prioritisation, but not the 9 protocols

10 A. So we were not -- the point and the issue that we had was not necessarily with the frontline decision-making 12 on a day-to-day basis which doctors take every day. 13 You know, we have to decide we have got four people all 14 needing major surgery but there is one intensive care 15

16 MR SCOTT: Can I just ask for my own clarity, is this in 17 a non-pandemic time or in a pandemic time?

18 A. In a non-pandemic time.

19 Q. Right.

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20 A. When you get to a stage where you are then getting 21 a large number of people who may need a limited amount 22 of services then you need a framework of what are the 23 ethical and moral considerations and that's what we were 24 asking for because, to a certain extent, that has 25 a societal discussion to it as well.

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1 So I'm going to challenge you, if I may, do we 2 want politicians involved in clinical decisions? 3

A. I'm going to say that it is political how we have ended up with the number of staff and the number of beds --

LADY HALLETT: That I follow. I think that's a separate argument.

A. And therefore the point at which there is choice about what you still do and what you don't do. So for example, it is a political decision or it was 10 a political decision to stop cancer screening or some 11 cancer screening during the pandemic in order to create 12 extra capacity. So there are circumstances in which you 13 need all of this joined up, because really what you are 14 talking about is a situation in which rationing has to 15 take place, and we saw that quite considerably during 16 the pandemic. And that is not a clinical decision 17 alone. That is, you know, as I say, a wider societal 18 political decision as to what is funded or not funded 19 and what is continued and not continued.

20 LADY HALLETT: Thank you.

21 MR SCOTT: Because your statement then goes on to continue 22 in terms of what practically happened in the pandemic, 23 that:

> "A lack of guidance in circumstances of extreme uncertainty created anxiety amongst doctors and other 123

Q. Yes, although I think the chair's question is: is that 1 2 a matter for government to provide you or is that 3 a matter for clinicians to provide for themselves?

4 A. Well, it is getting consistency. That's the -- and 5 therefore having some form of national lead or 6 national -- and, of course, MEAG did at one point 7 commission a report to look at what the ethical 8 framework of being -- in the event of services being 9 overrun, how do you then decide to get the most care for 10 the most people, and what then happens, if you have got 11 people who are being treated but are not getting better, 12 what are the ethical considerations in saying, well, 13 that patient is not getting better, we must deescalate 14 or stop care.

15 LADY HALLETT: I'm still going to challenge you, if I may, 16 on an ethical consideration, a clinical decision. 17 I don't see that that should come anywhere near 18 a politician. No disrespect to politicians but it seems 19 to me that they are for doctors. I don't know if you 20 heard the evidence of Jeremy Hunt when he was health 21 secretary and he was involved in, I can't remember which 22 exercise -- was it Nimbus, I can't remember, and he said 23 he had been asked to take what he decided was a clinical 24 decision about who should be discharged from hospital, 25 treated, and he said, "No, it is not for a politician."

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healthcare professionals."

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And then:

"As a result of the UK Government's decision not to issue guidance or any protocols for prioritising care, the BMA issued its own guidance for the profession ... as did a number of other organisations."

So why was it that the BMA filled that gap? A. Because if you are in that situation as a group of clinicians or a single doctor, having to make such profound decisions about what does and doesn't get done, who do you admit to hospital, who do you give the bed that's available to? And we saw, for example, a large number of people who normally would have been admitted to hospital with respiratory symptoms not admitted to hospital because there were not the beds for them so they were kept at home and managed at home and, you know, having that sense that there are other people outlining and understanding that there are moral and ethical dilemmas and sharing those and getting consistency. So we issued guidance, a number of other colleges offered guidance as well. It would have been

better if there was one set because it would have been 23 something that everyone then could have said: we have 24 made the decisions as fairly and ethically as we can, we

have tried to treat everyone with respect and equally.

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1	Q.	How is a doctor who is faced with that situation meant
2		to apply multiple versions of guidance from different
3		organisations?

- 4 A. Well, that's why I would argue that it would have been 5 more helpful for there to be a single guidance on this.
- 6 Q. And did, to your knowledge, your members feel better 7 because there was that guidance had been put in place 8 once the BMA had published it?
- 9 A. Yes, they did, they felt better protected. I was on UK 10 council at the time that we were discussing how 11 necessary this was and when you are facing a situation 12 where you know people are going to die because you can't 13 help them or you can't help them as best you can, or you 14 are going to give care that is not up to your normal 15 standard, you need to feel that there are other people 16 with you as you take these decisions.
- 17 Q. Can I just take you, please, to INQ00011773.

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This is the "COVID-19 - ethical issues. A guidance note", dated March 2020. I think this is the guidance we have been talking about; is that correct? Α. Yes, it is.

22 And if we just go to page 5, please. Thank you very 23 much. It's that bottom paragraph.

> There is the example that's given there about clinicians reviewing and documenting the appropriateness 125

that and we were advocating much more for advanced care discussions. So, for example, you know, my mother was elderly at the point at which the pandemic started and we had the conversation very early in the pandemic, and we have been encouraging families to have those conversations with their loved ones more and more, because it then avoids the confusion and it avoids the surprise.

Q. I just want to touch very briefly on one topic in terms of the deaths of healthcare workers. What is your view on the fact that not all departments and other public bodies across the United Kingdom recorded specific data about the death of healthcare workers? Do you think that there should have been recording of the deaths of all healthcare workers?

16 A. Well, I do, because we've ended up this end of the 17 pandemic with really no idea how many healthcare workers 18 have died from the pandemic, as far as I know. It's 19 been very difficult to ascertain. And even throughout 20 the pandemic we were getting data from individual 21 doctors, people were finding out who had died from press 22 releases rather than being any central data.

23 Q. Did it make you feel valued as doctors, the fact that 24 this wasn't being recorded?

25 Doctors felt very undervalued during the pandemic and in Α. 127

of cardiopulmonary resuscitation for all patients.

I think it is fair to say that you are not suggesting that this guidance, the threshold for implementing this guidance, was ever reached, are you?

No, this is guidance for if the service is completely overwhelmed. I mean, of course, we do have discussions with patients all of the time in hospital about what they wish for the future of their care and we do discuss with them what happens if there is deterioration in 10 their condition. That has been part of routine 11 practice. We had -- there was guidance in 2001 and 2016 12 on this.

13 Q. Do you think, though, that if you published guidance of 14 this type, which is talking about CPR, that there is 15 a risk that doctors in the middle of a pandemic may see 16 this guidance and may potentially apply it in situations 17 where it wasn't intended to be implied?

I would hope that that is not the case. And the reason 18 19 I would hope that that was not the case is because these 20 are conversations that the profession had already 21 started to have prior to the pandemic.

> You know, we went -- way before the pandemic, the issue of doctors or other clinical staff unilaterally deciding who should have a DNACPR were a matter of public debate and we had started to work our way through

1 fact many times in our calls for evidence we have had 2 comments back about how doctors felt as if they were 3 kind of disposable commodities. 4 Q. Do you think there would have been a beneficial impact

5 about having an understanding of the types of doctors, 6 the areas they were working in, gender, BAME groupings, 7 if there had been this record about healthcare workers 8 and doctors who had died?

A. Well, we would have picked it up much quicker and it

10 would have been much more valid as an argument then for 11 taking precautions and more precautions earlier. If we 12 had known, for example, that healthcare workers --

13 I mean, if you have a look at the first 100 or so

14 healthcare worker deaths as were reported in the Health 15 Services Journal, what was striking was there were no

16 deaths recorded from anaesthetists or intensive care, 17 but there were from the wards. And of course people 18

on -- using -- anaesthetists and intensive care had FFP3 19 respiratory protection.

> And what we were witnessing was that -- you know, I, as, you know, a clinical school teacher, our medical students wanted to help straight away. As soon as the pandemic, they said: what can we do to help? They went out onto the wards with fluid-resistant surgical masks and they all caught Covid. Straight off.

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Now, if that had been tracked and if the deaths
had been tracked earlier, we would have known. Less
doctors, less healthcare workers would have caught
Covid, fewer would have died, and, you know, fewer
people would have caught Covid within the hospital and
care setting.

- Just two more questions if I may. The first is, do you think there was adequate support for doctors' and healthcare workers' mental and physical needs while they 10 were working during the pandemic?
- A. No. I mean, we went into the pandemic with very poor 11 12 occupational health services, very under-resourced 13 mental health services. What we did see in the early 14 stages, as other services were closed down, many of the 15 psychological services were redirected to providing 16 support for health and well-being. We saw in the BMA 17 across 2019 to 2021 a 343% increase in people contacting 18 our well-being services.
- 19 Q. Where was that, was that across the UK?
- 20 A. That's across the UK, yes.

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- 21 Q. And then finally, what more do you think should be done to protect doctors and healthcare workers in the event 22 23 of a future pandemic?
- 24 Α. Well, the immediate ones are to take a precautionary 25 approach because, you know, if there is any -- any --129

doubt about how someone can catch an infection, then the duty of care is with the employer, and doctors still do not feel protected in that workplace. We still have inadequate ventilation, for example. We are still unable to separate out patients.

And -- you know, that was very distressing for doctors to be told: you have to put a patient with Covid in a room with patients without Covid. This was a really difficult space for doctors to be in. And that ability to plan proactively and ahead to do that spacing out. What is going to stop if we don't have that capacity at the time?

But if we stopped doctors leaving, if we stop that exodus of doctors, then at least you are retaining your part of your workforce that is there for the future.

16 MR SCOTT: My Lady, those are all the questions I have. 17 LADY HALLETT: There are quite a few questions from core 18 participants for you, Professor Banfield, so, if you'll 19 forgive me, we will take a break now and then come back 20 at 3.30, but I promise you we will finish you this 21 evening or this afternoon. Thank you.

22 (3.15 pm)

(A short break)

24 (3.30 pm)

LADY HALLETT: Mr Weatherby.

Questions from MR WEATHERBY KC

MR WEATHERBY: Thank you.

Professor, as I think you know I'm going to ask you some questions on behalf of the Covid Bereaved Families for Justice UK group. I think all of the points that I'm going to ask you about are quite short and they've been touched upon so that hopefully will allow to us go a bit swifter than otherwise.

Can I start with the point that my Lady was particularly concerned about with the idea of the central guidance about triage or decision-making for resource allocation and it won't surprise you to know that the family members that we represent are very concerned about this area, many of them believe that their loved ones were -- interventions were not taken, care that would have otherwise been given wasn't provided due to rationing. So it is a point that's very dear to their hearts.

Your statement identifies how towards the middle and end of March the government was in fact looking at issuing guidance on this subject and then decided that they felt that the resources would not be exhausted, that's your paragraph 127.

And you go on to mention that identifying the lack of certainty was an important issue and to emphasise 131

that the BMA was aware that there were at times rationing of important resources such as oxygen.

So, is that really where the need for central guidance was, that there are issues of resourcing, there is issues of resource management, and there is also issues of clinical decisions, and all of those need to 7 be considered together in terms of when there is a possibility of the system or part of it being overwhelmed, and is that why there is a need for some 10 centralised guidance?

11 A. There is need for centralised guidance because there 12 needs to be a recognition at what point care is being 13 rationed.

14 Q. Yes

15 A. Care was rationed.

16 Q. Yes

17 We stopped elective procedures, we stopped screening for 18 certain cancers, so although the term "the service was not overwhelmed" has been used, in fact that was only 19 20 because we rationed and left out other things.

> The ethical decisions that we are faced on the frontline, actually we are used to making every day because we sometimes get more than one patient needing care at the same time and what you do is you try to make the fairest and best judgment and you try not to

prejudge your decision but make it on the clinical facts in front of you.

There is a stage though in between that where you have a large number of people and therefore having some form of framework as to who is going to make those decisions and how is, you know, incredibly useful.

- 6 7 Q. So on the individual level, the clinician is plainly the 8 person who should be making the decisions about the 9 priority of treatment or whether treatment is 10 appropriate. But the clinician doesn't necessarily know 11 the amount of resources available or what's coming down 12 the track in terms of resources, so there needs to be 13 an overarching departmental guidance about this as well.
- 14 A. Yes, and you need to know where your next bit of15 resources is coming from.
- 16 Q. Yes. Okay, that's all I ask on that.

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So can I just return to FFP3s briefly. Between paragraphs 266 and on from that, you talk about the fact that the PPE guidance was downgraded in March 2020 and that's when the requirement for FFP3 masks for healthcare workers was removed and you have indicated earlier that many doctors thought that was matching what was available rather than the actual requirement for protection for doctors.

And is that what the BMA thought at the time?

- fact that FRSMs were not sufficient for aerosol,potentially aerosol viruses?
- A. Well, I think the evidence as a BMA that aerosol transmission was a significant part of the problem, probably developed in the latter half of 2020 and 2021.

 The point at which it became unequivocal to us that this was a significant mode of transmission, we went both to government and then to our members as well, to raise

publicly that we thought this was an issue.

10 Q. Yes. That's very helpful.

Now, on the same theme, I don't know whether you followed it but Professor Susan Hopkins recently gave evidence to this Inquiry that there was weak evidence that FFP3 masks offered greater protection than surgical masks in practical healthcare settings, as opposed to a laboratory environment. Is that a statement that you would agree with?

- 18 A. No, I wouldn't.
- 19 Q. And why is that?
- 20 A. Well, it was interesting because at one point
- 21 Addenbrooke's decided to implement wholesale use of FFP3
- 22 masks instead fluid-resistant surgical masks and found
- 23 the infection rate plummeted. So that was practical use
- 24 of FFP3 masks.
- 25 **Q.** Yes, so you would say there is evidence that FFP3 masks 135

- 1 A. The BMA was involved in discussing the evidence. There
- 2 were a lot of internal discussions about the science --
- 3 Q. Yes.
- 4 $\,$ A. -- at that time, and probably the biggest discussion
- 5 that we had was that if the science was uncertain --
- 6 Q. Yes.
- 7 A. -- that as a protective measure you should take
- 8 a precautionary approach.
- 9 Q. Absolutely.
- 10 A. So we had a large number of our members in the workplace
- 11 make decisions about that they would continue to use
- 12 FFP3 masks even in situations with non-aerosol --
- 13 Q. Right. That's where I was headed. So did the BMA give
- 14 guidance at that stage to say that even though the
- 15 requirement had been removed, that doctors should still
- 16 wear FFP3 masks?
- 17 A. It did not give official guidance. It was trying to
- align itself as much as it could with the government and
- 19 the IPC guidance. What we did was we tried to push back
- 20 to the CMOs --
- 21 **Q.** Yes.
- 22 A. -- and government to have the IPC guidance changed.
- 23 Q. Yes, but to your members were you indicating that there
- ought to be a precautionary approach? I mean, why
- 25 didn't the BMA give guidance to its members about the 134
- 1 are more effective in clinical practice?
- 2 A. Yes, I -- I mean, FFP3 masks are a form of respiratory
- 3 protection. Surgical masks are not.
- 4 Q. Yes. If there is a disparity between the laboratory
- 5 evidence and the real-life setting, well, first of all,
- 6 it wouldn't be surprising if there was a difference
- 7 between those two, would it?
- 8 A. Well, no, and nor would it be surprising if some of that
- 9 difference didn't appear to be founded because the use
- of FFP3 masks is heavily dependent on you having them
- 11 correctly fit tested.
- 12 Q. Yes.
- 13 A. So if you wear an FFP3 mask wrongly then it does limit
- 14 your protection.
- 15 Q. Yes, and also perhaps in common rooms and corridors and
- 16 things like that?
- 17 A. That's true in terms of passing between healthcare
- workers, but predominantly most of the transmission is
- on wards working in areas of large numbers of
- 20 Covid-positive patients.
- 21 Q. Yes, sure. If there is a disparity between the
- 22 laboratory evidence and what happens in real life, is
- the answer to abandon FFP3 and just use FRSM or
- 24 a consideration of how to use FFP3s as efficiently as
- 25 possible in real life?

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- A. Well, I would go for the latter and I still recommend 1 2
- 3 Q. Moving on. The HSE, you have given evidence a little
- 4 earlier about this but I just want to clarify exactly
- 5 the position what you are saying about the role of the
- 6 HSE. Again, your paragraph 287, just for the record,
- 7 you say that in November 2021 the BMA, together with
- 8 other groups, raised concerns with the HSE, calling for
- 9 a review of IPC guidance, greater scrutiny of NHS
- 10 practices relating to the supply of RPE (respiratory
- 11 protective equipment) and asked the HSE to give specific
- 12 additional guidance to complement or correct, as
- 13 appropriate, IPC measures in effect at that time, but
- 14 the HSE declined to do that, saying that the guidance
- 15 from the department and UKHSA and the devolved
- 16 administrations was what they regarded as "competent
- 17 bodies". Is that right in your view? Was it right that
- 18 HSE should simply defer to the department and the other
- 19 bodies I've just referred to?
- 20 A. It felt to us and it felt to doctors on the frontline
- 21 that this was a bit of cop out of responsibility,
- 22 because it created a circular argument. The HSE was
- 23 responsible for insuring that hazards are identified and
- 24 that risks are mitigated, and then to use what we would
- 25 say was flawed logic from other party doesn't get rid of
- 1 running out of time. Ethnic minorities. In your
 - statement paragraph 67 you refer to the rapid review in
- 3 May 2020 into the disproportionate impact of Covid on
- 4 ethnic minorities and the concerns about that from
- 5 the BMA. The Inquiry has heard quite a bit of evidence
- 6 in an earlier module, as you know, about that, but can
- 7 I just cut to the chase here. What were the 8
 - recommendations that you, the BMA, considered that ought
- 9 to have been included in that report that weren't?
- A. Well, what was very important was to make sure that the 10
- 11 risk assessments for ethnic minority doctors were
- 12 undertaken, but not just that but the recommendations of
- 13 those risk assessments were implemented, because they
- 14 often were not and doctors from ethnic minorities were
- 15 more likely to be redeployed or put in areas of high
- 16 risk, really because they were not in a position to feel
- 17 empowered

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- Q. Yes. That brings me on to my next point, at 18
- 19 paragraph 318 in your statement. The BMA's survey found
- 20 that twice as many ethnic minority doctors as white
- 21 doctors felt pressure to work in high-risk settings
- 22 without adequate PPE, and you described the NHS as
- 23 having a significant degree of institutional racism.
- 24 Can you expand on that and what you mean by that?
- We know that doctors from ethnic minorities are less 25 Α. 139

- your responsibility as the regulator. 1
- 2 Q. Yes, you refer, and I quote, to an "abrogation of their
- 3 responsibility as the workplace health and safety
 - regulator", and is that largely driven by a factor you
- referred to earlier, which is the 2008 report that you 5
- 6 knew that the HSE had knowledge of, in terms of aerosols
- 7 and the fact that they knew that aerosols wouldn't be
- 8 stopped by FRSMs?
- 9 A. So, I mean, that's -- that is part of why the profession
 - has a sense that it was -- that it was being sold out,
- 11 because this wasn't common knowledge to us at the start
 - of the pandemic and it has become apparent since then
- 13 that people who should have been in a position to
- 14 protect directors and healthcare workers knew that there
- 15 was a possibility that optimal protection was not being
- 16 employed.
- 17 Q. Yes.
- 18 A. And that then translated into a real life experience,
- 19 which was, you know, if you were using appropriate PPE
- 20 and RPE you were relatively protected.
- 21 Q. Yes
- 22 If you were not using that, you caught Covid, you got
- 23 Long Covid, and some of you died.
- 24 Q. Yes

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- Final topic I will deal with briefly as I know I'm 138
- 1 likely to progress in their careers. They are less
- 2 likely to be successful in job appointments. We know
- 3 that they are more likely to be subject to bullying and
- 4 harassment. That is endemic within our NHS. It is well
- 5 recognised and it is one of the things that we are
- 6 desperately trying to correct. But the pandemic really
- 7 exposed it like, you know, no other situation.
- 8 Q. So, going forward, that institutional racism really
- 9 needs to be combated, and that would mean that in
- 10 a similar situation in the future there would be less
- 11 pressure, a disproportionate pressure, on ethnic
- 12 minority doctors and healthcare workers if that was
- 13 tackled?
- 14 A. Yes, I mean, that's true, but of course there are other
- 15 groups as well, like female doctors and those with
- 16 disabilities, that also encounter discrimination in the
- 17 workplace.

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- MS WEATHERBY: I think I'm out of time, my Lady. 18
- LADY HALLETT: Thank you very much, I'm very grateful. 19
- 20 Mr Wolfe.
 - Questions from MR WOLFE KC
- 22 MR WOLFE: Good afternoon, Professor Banfield.
- At paragraphs 241 to 243 of your statement -- you 24 don't need to turn them up -- you talk about the
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 - long-term impact of Long Covid on doctors and in

paragraph 243 you talk about the way in which family members are providing support and to some extent healthcare support for their doctor family members.

Presumably you would also agree that family members can provide valuable support including healthcare input for patients generally, it's not just doctors who can receive that and benefit from that support, it's patients generally?

- 9 A. Oh, a huge number amount of care in this country is10 given by families and relatives.
- 11 Q. And particular examples of that during the pandemic, how
 12 were doctors able to be confident that family members
 13 returning home, where they did, would continue to
 14 receive the necessary support and treatment if they
 15 hadn't had the family member involved in the hospital
 16 stage of the treatment?
- 17 A. I'm not following -- I'm not sure I follow your18 question.
- Q. Let me put it the other way round. If you had had
 a situation where a person was in hospital being treated
 and the doctors in ordinary times would have expected
 the family members to be present and providing support
 but in the pandemic they weren't for whatever reason,
 how could those same doctors be confident during the
 pandemic that whatever support was needed at home would

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- an important role, indeed are consultees, should be consultees in that process, shouldn't they?
- 3 A. We would encourage all, you know, anyone having that4 discussion to discuss it with their families.
- Q. Yes. So in the context of the pandemic where family
 members were not present in the hospitals there would
 have been a potential gap in all of those areas,
 wouldn't there?
- A. It depends whether the patient themselves had capacity
 to consent or not.
- 11 **Q.** Yes.

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- A. I mean, a number of patients who are severely ill do not
 want their relatives -- to have their care discussed
 with relatives because they are trying to protect their
 relatives.
- Q. But in the instances where somebody had a communication need, a language need, whatever it may be, whether it was a DNACPR-type situation or a consent situation, the absence of their family member was a potential impediment, wasn't it?
- A. It is a potential impediment if you cannot speak the
 language and the NHS tries to engage people in their own
 languages, so we engage with various language lines or
 interpreters to assist with that.
- 25 **Q.** You are not saying that that all was hunky-dory, worked 143

- 1 then continue, or was there a gap there?
- A. I think there most certainly was a gap. I mean, I think
 that a large number of patients during the pandemic were
 abandoned once they were out in the community.
- Q. And then similarly in relation to doctors securing
 consent, making sure they had consent for treatment.
 Again, presumably family members could have a very
- 8 significant role in supporting the consent-giving9 process particularly of people with communication
- 10 difficulties, language issues and so on?
- 11 A. Yes, it is only the patient that can give consent.
 12 There are mechanisms to -- well-defined mechanisms for
- gaining consent in people that can't give consent and
- then of course we have a duty of care where there is
- 15 a lack of capacity to act in the patient's best
- 16 interests.
- 17 Q. But in those cases where the patient has consented they18 may have other reasons why they struggle to communicate.
- They may have a communication difficulty, they may have
- a language issue, they may have all sorts of things, and
- in that case family members can provide communication support, can't they?
- 23 **A.** Yes, but we obviously try and make it as independent as we can.
- 25 **Q.** Similarly, DNACPR, again, family members can have 142
- fine in the pandemic during a period when family members were not routinely around, are you?
- A. No. So much didn't work in the pandemic but, as I say,
 in terms of capacity to consent and consent, it is only
 the patient that can give that consent.
- Q. My focus is on the impact that not having the family
 members around had on the process. I think we are
 agreeing that it had a detrimental impact.
- 9 A. I'm not agreeing that it did, I'm not disagreeing that
 10 it might have, and that is because if a patient is happy
 11 to have a discussion about consent then they are happy
 12 to have that and actually it isn't in that case anything
 13 to do with the relative, it is the patient's decision.
- 14 LADY HALLETT: Mr Wolfe, if it helps, I take your point.
- 15 MR WOLFE: I'm grateful, my Lady.

16 Let's not argue about the extent of the
17 impediment, there was an issue -- I think we're
18 agreeing, let's not fall out about the extent of it -19 of patients' communication and so on and the support
20 that came around that being impacted by lack of family
21 members. I want to understand why we think that
22 happened during the pandemic. Do you have any sense of

- why that came about, why were patient family members not
- able to be sufficiently involved?
- 25 **A.** Well, in the hospital environment a decision was taken

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reported.

1 to minimise (a) the exposure of the general public to 2 Covid by putting restrictions on visiting, and (b) to 3 concentrate on trying to treat as many patients with 4 very limited resources. That led to situations that 5 were far from ideal. So I think to explore I hope where 6 you want to be with this, you would normally have 7 conversations that are difficult conversations with 8 patients with relatives present unless the patient 9 themselves says, "No, I do not want the patient --10 a relative here, I want to discuss this just with you", which the patient has the prerogative to do. 11

12 LADY HALLETT: I think we have to leave it there, Mr Wolfe, 13 I'm really sorry. We have a lot more to get through

14 this evening, I'm sorry.

MR WOLFE: My Lady. 15

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16 LADY HALLETT: Ms Peacock.

Questions from MS PEACOCK

MS PEACOCK: Good afternoon, Professor. I ask questions on behalf of the Trades Union Congress. If you could just ensure, although I'm behind you, that your answers go into the microphones. They just need to be picked up.

My questions relate to the reporting of Covid-19 infections in healthcare workers to the Health and Safety Executive.

> You refer in your statement to the fact that many 145

1 you know, you have your hard hat in case a brick is 2 going to come, not because you expect it is going to 3 come. But if you find that even if you've got your hard 4 hat on and it is not saving you, sooner or later you 5 need someone to say: actually there is a problem here, 6 isn't there? And that wasn't a sense that we got during 7 the pandemic.

8 Q. So, in essence, the regulator doesn't have the necessary 9 broad insights about what is or may be happening in the 10 sector to accurately direct its investigations; is that fair? 11

12 A. Yes. I mean, and it's -- you know, whereas it, you 13 know, passes quite detailed comment about asbestosis, 14 for example, I would have expected it to do the same in 15 the health environment.

Q. You have referred to the threshold there slightly but, 16 17 in your view, was underreporting a problem of the 18 threshold set by the HSE or was it a problem of the 19 threshold not being properly applied by employers? Or perhaps both, of course.

20 21 A. Well, of course, we as the BMA wrote to both, so we 22 reminded employers of their duties to report and to HSE 23 for their duty to investigate. Neither of those 24 appeared to happen and we had a large number of 25 members -- we did a survey of over 600 people with

employers failed to report Covid-19 infections of staff by RIDDOR, despite it being a legal requirement for employers to report instances of workplace-acquired Covid-19 infections. And that's at paragraph 289.

My question is, why is it a problem if

occupationally-acquired Covid-19 infections in

healthcare workers are not leading to RIDDOR reports? Why is underreporting a concern for the BMA? A. Well, I mean, the biggest and most obvious consequence to that is an enormous number of healthcare workers who really can only have caught Covid -- and are now disabled and unable to work or earn a living, are having to undertake individual litigation to get their work-acquired Covid recognised. And it is difficult for us because, you know, the RIDDOR reporting is supposed to be based on if there was a reasonable chance, and that -- that -- the goalposts seem to move during the pandemic to a balance of probabilities, and then, "Well, you don't need to report it if someone was using the IPC relevant PPE at the time". Well, of course, if the IPC guidance is incorrect, as we would say, then, you know, you are not getting the right number of things

I mean, it's a bit like, I don't know, someone going onto a building site with a hard hat on and, 146

Long Covid and a large proportion of them said that they had asked for their Covid to be reported under the RIDDOR's reporting mechanism and it had been declined. Q. Thank you.

The HSE produced an interim report in January 2021 titled "The impact of Covid-19 in the workplace", and the report stated, in relation to the duty to report occupational exposure under RIDDOR:

[as read] "There may have been criticisms of the HSE in how this has been interpreted, alleging that an exclusive rather than an inclusive approach will significantly underestimate the true toll of Covid-19-related effects, thereby missing opportunities to learn lessons."

And this really is the focus of my question. It goes on to say there is an implied view that -- in the criticisms that HSE would be able to follow up every

In your witness statement, however, you explain that reporting is crucial to understanding infections at the health service level, how infection spreads within healthcare settings and how to better protect staff and patients. That's at paragraph 290.

Can you help on this point? Is the expectation that the HSE will follow up individually on each RIDDOR 148

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report, or do you criticise the threshold adopted by the HSE during the pandemic for a different reason? A. I'm going to answer this as someone on the frontline, and that is that I would expect the system to protect me. And therefore if there wasn't and should have been an opportunity to highlight that harm was coming sooner, then we would have recognised that more needed to be done and we could quite possibly have saved many of the lives that were lost.

10 Q. This is my final area of questioning.

In oral evidence, Mr Brunt said of RIDDOR:

"It's not intended to track the total number of cases that are happening."

However, the Chair suggested to Mr Brunt -- and, my Lady, I'm afraid I'm paraphrasing -- that, given the large number of cases and the obvious difficulties in investigating all individual cases, a solution could have been to say that all NHS trusts and boards have to report every Covid-19 infection in a healthcare worker so that the HSE can analyse whether there appears to be a systemic problem.

Focusing on the next pandemic and thinking creatively, if you will, so ignoring the legal requirements as they currently stand, would it in fact make sense for the HSE to have access, whether by RIDDOR 149

1 a Covid-19 infection in a healthcare worker?

A. In terms of -- because we are in a situation where we have no idea what has happened, that is not an unreasonable suggestion for Covid-19 until we are in a position to clarify exactly what has happened and what it means for the future.

7 MS PEACOCK: I'm grateful.

Those are my questions, my Lady.

9 LADY HALLETT: Thank you very much, Ms Peacock. Very10 helpful.

Ms Woodward.

There we are. Around the pillar, Professor.

Questions from MS WOODWARD

MS WOODWARD: Thank you, Professor. I ask questions on behalf of Covid Bereaved Families for Justice Cymru and there is a few topics I'd like to ask you about this afternoon but the first of those is on IPC guidance, and in response to a question raised by the UK Covid Bereaved Families a few moments ago you said that one of the things the BMA were trying to do was to push back to have IPC guidance changed and that you went to government to raise this.

We know that BMA Cymru made several communication s to the Welsh Government asking them to strengthen IPC guidance on masks, and to increase protection for

or perhaps another process, to data on all infections and deaths taking place amongst healthcare workers, so that it would be possible for them to identify hot spots or outbreaks and to investigate accordingly?

A. It doesn't actually matter who does it, but someone needs to do it. Someone need to know whether harm is happening to the workforce. So, you know, whether it is HSE or whether it is Public Health England or government, but someone has to do it. And that absence, sadly, has led to harm and it gives us no confidence that that has been rectified for either now or the future.

You know, if you had a circumstance, for example, in which Covid-19 was a recognised industrial disease, then you wouldn't be in the situation of now not knowing exactly what has happened to these workers -- who went into this and gave up their lives to serve other people.

Q. And I guess the essence of my question really is, there is been a lot of discussion about the threshold for the report and what it should be and how difficult it can be for employers to interpret it and decide which instances to report. My question really, in this context of a widespread pandemic that's highly infectious, would it be helpful for the removal of that potentially complex threshold and to simply report on every instance of

healthcare workers.

My question is: does the BMA consider that the Welsh Government acted sufficiently robustly to form its own view on the adequacy of IPC guidance in order to provide clear leadership to health organisations in Wales?

A. Ultimately I think you are going to have to ask them that question as to, you know, because they had a need or, as it was put to us, to be in consensus with the other nations because a lot of the PPE was being sourced communally.

I can answer the discussions that we had at clinician level because I had weekly meetings with consultants across the whole of Wales and we had quite a lot of discussion about the pushback that was coming against IPC guidance and we effectively came to an agreement that we would advise in Wales our doctors to use FFP3 masks if they felt that was appropriate to their situation, and especially with Covid-19-positive patients.

21 Q. Thank you, that's helpful.

My next question is on a different topic and that's in relation to testing, both of patients and of healthcare staff. And in your witness statement you discuss the importance of protecting staff and patients

through regular testing and that was something that the BMA called strongly for. And again we know that BMA Cymru wrote to the Welsh Government as early as July 2020 calling for a robust testing system for patients and the regular testing of asymptomatic staff.

My question arising is: do you consider that there was sufficient engagement between the Welsh Government and relevant stakeholders such as the BMA or BMA Cymru on the issues of testing?

- A. Was there adequate engagement? Yes, there was. There was quite a lot of toing and froing. Did it happen quickly enough? No, it didn't but it didn't happen quickly enough around the UK. Once we got into a situation where it was possible to test with lateral flow tests for example it made much more sense. The difficulty was the point at which it was recognised that transmission could be by, you know, asymptomatic spread because at that point you didn't really know who had and who hadn't got Covid and who was able to pass it on.
- Q. Just so I can clarify, when you say that it didn't
 happen quickly enough, do you mean the engagement with
 the BMA or the testing programme in Wales or perhaps
 both?
- A. Mainly the testing programme. It didn't become
 available quickly enough for us to either test staff in

were simply not the beds.

My question arising from that, especially given the evidence we have heard this morning from Age UK about difficulties across the nations in relation to the care for older persons, is: would you agree that it is likely that the elderly were disproportionately advantaged by those alterations in decision-making during the pandemic?

A. I'm not sure that I have enough data to say that it was specific to any particular group of patients. The discussion that GPs have with patients every day, even outside of Covid, is the state of the health service and quite often -- I'm married to a GP and she has conversations with elderly patients about going into hospital and long waits on trolleys in corridors and they quite often say to her, do you know what, I would rather not go into hospital I would rather, you know, spend my last days at home.

Do I think that the criteria necessarily changed?

No. But I do think that what happened was that people who would have gone into hospital for care were managed and nursed at home who in times when there are perhaps beds available they would have been admitted for that care.

Q. And do you think those problems also persisted once

1 a meaningful way or patients.

Q. And what do you think the impact of those delays on both
 patient and staff testing was on both patient and staff
 safety, particularly in the context of nosocomial
 infections?

- A. Well, there is no doubt in our minds that that increased
 the rate of infection and therefore the harm that arose
 as a result of that.
- Q. And is the BMA aware of whether there were any
 operational difficulties in implementing the
 Welsh Government's testing guidance and what those
 issues were?
- A. Well, I mean, they had the same issue over the
 availability of testing and scaling up testing as the
 rest of the four nations.
- 16 Q. But nothing specific over and above that that you wereaware of in Wales?
- **A.** No.

Q. My next topic is on escalation of care and what you have
 spoken about today in your evidence as care rationing
 which I suppose is the flip side of that. And earlier
 today you said that during the pandemic there were
 a large number of people with respiratory symptoms, for
 example, who would have been admitted to hospital in
 other circumstances who were not admitted because there

people were in hospital, so for example with admissions into critical care, were patients not being admitted to critical care from the wards whereas in other circumstances they might have been? A. I think it goes back to what we were talking about individual decisions about who is going to benefit from care. I mean, if you have a look at cardiopulmonary resuscitation the number of people who survive CPR is

- relatively small and you can predict who may or may not do well from that, so having those discussions with people is something that we do on a regular basis. I've got no direct evidence of that kind of rationing. I do not believe that we got to the stage of having two patients for one intensive care bed with the same kind of possible outcome and then having someone who was older being selected as not having care. I think it was always done on who was most likely to benefit in the
- Q. My next topic is regards to advanced care planning and
 DNACPRs. My first question is, has the Welsh Government
 ever consulted, to your knowledge, with BMA Cymru on
 issues of DNACPRs or advance care planning either prior

quickest and most effective manner.

- to, during or since the pandemic?
- A. There have been ongoing discussions, as we were talking
 about earlier, about the need to have advanced care

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decision-making discussions because it is really important for people to maintain their dignity and to have those discussions while they are well so that they don't need to come as a surprise when they become ill. So there has been, you know, before the pandemic, a push to start those discussions between families and their loved ones

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So I would say that the way it works in Wales, the NHS Wales, the Chief Medical Officer, so Welsh Government, and the service would be used to the idea that in general this is a discussion that we want to have round Wales.

- 13 Q. And you will be aware, I'm sure, of the introduction of 14 the ReSPECT process in England and that there are no 15 such plans to roll out the ReSPECT process in Wales. 16 Are there any, in your opinion, downsides of the 17 proposed Welsh approach, which is the all-Wales national 18 DNACPR policy and treatment escalation plan, as compared 19 to the ReSPECT process in England?
- 20 A. Well, I think that a lot of GPs in Wales know their 21 patients very well and are having those conversations 22 already, regardless of what process may or may not be in 23 place.
- 24 Q. And perhaps a very similar question but in a slightly 25 different form. Do the BMA, or BMA Cymru in particular, 157
- 1 to a certain extent that continues to today. The GPs 2 have always seen clinically extremely vulnerable 3 patients face to face and are geared still to do that.
- 4 Q. Second, Professor, was patient safety put at risk by 5 that confusion? And if so, can you expand on how.
- 6 Α. Well, those who are clinically extremely vulnerable and 7 with long-term conditions have higher rates of morbidity 8 and mortality anyway and therefore they have or 9 certainly they did stay away from engaging with services 10 and have continued to do so, is the evidence. And the 11 effect of that is that they are not optimising their 12 treatment, and many of them are suffering in silence at 13
- 14 Q. Thank you. And thirdly, Professor, the shielding 15 programme came to an official end on 15 September 2021, 16 but you have said in your statement that questions and 17 anxieties remain to this day amongst the formerly 18 shielding, and I think you have touched on this in your 19 last answer, but can you explain the nature of those 20 questions and anxiety that remain from the BMA's 21 observations?
- 22 A. Yes, I mean, we are currently in a society that is 23 running as if Covid-19 doesn't exist anymore and yet 24 clearly Covid infections are still a source of hospital 25 admissions. Because we now no longer wear masks in 159

consider that perhaps still there would be any benefit 1 2 in Wales adopting a nationally standardised process so 3 it was in line with the other nations in the UK in the 4 form of ReSPECT? 5

A. My Lady, I don't know enough about that to comment.

6 MS WOODWARD: Thank you very much, Professor.

7 LADY HALLETT: Thank you Ms Woodward. Very grateful.

Ms Polaschek.

9 Over that way.

Questions from MS POLASCHEK

11 MS POLASCHEK: Good afternoon, Professor. I ask questions 12 on behalf of Clinically Vulnerable Families and we have 13 just three, hopefully brief, clarifying questions around 14 shielding, all of which refer back to specific 15 paragraphs in your witness statement.

> First of all, you describe at paragraph 447 of your statement that when shielding advice was relaxed in the summer of 2020 the BMA considered that the poor communication of that advice had caused confusion and you give an example about a lack of clarity over whether shielding people should visit GP surgeries for routine medical treatment or not. What was the effect of that confusion on patients?

24 Α. Well. I mean, the effect at the time was to create doubt 25 in their minds where safety existed and didn't exist and 158

1 hospitals we have got a situation in which the carers 2 are walking around as if Covid doesn't exist and the 3 clinically extremely vulnerable for whom Covid could 4 still be an issue either from a mortality or from 5 a Long Covid issue are wondering what's going on, and 6 they are feeling very anxious and there is, you know, 7 evidence that they are not engaging with either society 8 or with medical services. And that is something that we 9 have to address.

10 MS POLASCHEK: Thank you, Professor.

11 My Lady, those are my questions.

LADY HALLETT: Thank you very much. 12

Mr Simblet.

Questions from MR SIMBLET KC

15 MR SIMBLET: Thank you, my Lady.

16 Professor, some of my questions have been asked. 17 I'm asking questions on behalf of the Covid-19 Airborne 18 Transmission Alliance.

Now, you have mentioned various examples of medical -- medical students getting Covid on the wards and people working in intensive care not getting Covid. What sort of equipment are you talking about in your recommendation in your statement that there should be more routine use of RPE in healthcare settings?

25 A. Yes, can I just be clear that it's not absolute because 160

1 there are people --1 you consider that the list of aerosol-generating 2 2 Q. Yes, of course. procedures was too restrictive? 3 A. -- who subsequently did catch Covid in those 3 A. Yes, we did, and we wrote with the RCN and the 4 4 Resuscitation Council to have CPR added to that list of environments. There are various forms of respiratory 5 protection from the FFP3 masks to, you know, much bigger aerosol-generating procedures. The whole idea of AGPs 5 6 masks that are incredibly uncomfortable to wear and that 6 preceded the pandemic and, clearly, when one is talking 7 fit almost like a fireman's visor and then there are 7 about aerosols, there are significant aerosols generated 8 8 by other normal activities, like coughing or singing. almost self-ventilating hoods as well, and so it is 9 9 Q. I was about to say, it is right, isn't it, that a cough getting the right equipment that provides your safety as is a cough? 10 judged by fit testing because you are objectively then 10 11 measuring whether that is appropriate for you. 11 A. Well, that's right. And even if you have got 12 And is there anything more precise that you can say on 12 a predominantly explosive droplet output, there are Q. 13 what sort of equipment or is it that you would want to 13 aerosols generated at the same time. 14 leave your answer in the territory of what is 14 Q. Did you consider that the AGP list was too restrictive appropriate? 15 15 because there were concerns about managing the supply 16 A. Yes, what's appropriate and what fits and suits you for 16 of, in particular, FFP3 masks? 17 the job at hand. 17 A. No, I don't think that that was part of our thinking at 18 that time. 18 Q. Was it the BMA's position that all healthcare workers 19 should have been provided with respiratory protective 19 Q. What about subsequently? 20 equipment during the pandemic? 20 A. No, I think that once we got into understanding more 21 21 A. Yes. about the previous evidence and then the emerging 22 22 Q. Thank you. Now, as you know, and it is described in evidence of airborne transmission, our concerns went 23 your statement and so on, a list was drawn up of 23 away from AGPs to everything. 24 24 aerosol-generating procedures, or AGPs, that had Q. Everything, yes? 25 an impact on how protective equipment was deployed. Did 25 A. Everything. If you have got someone who has Covid then 1 you should provide the appropriate respiratory equipment 1 Well, no, I have absolutely no idea. As a frontline 2 for anyone caring for them. 2 clinician I find it unbelievable. 3 Q. Thank you. I'm going to move to something else. It is 3 Q. And both as a frontline clinician and as 4 something you have been asked about already but I've got 4 an authoritative figure from the BMA, did the BMA take 5 5 a couple of different questions to ask about in relation any steps to fill in the gap in recording and what could 6 to the Reporting of Injuries, Diseases and Dangerous 6 you and did you do, if anything? 7 7 Occurrences Regulations, or RIDDOR. You have described A. Well, I mean, it was very difficult. In our tracker 8 in some detail the problems for doctors when there is 8 surveys that we did, we were getting a lot of data back 9 an underreporting or a misreporting, or however you want 9 about the harm that was happening in terms of Long Covid 10 to use it in relation to the application of RIDDOR, but 10 and we have tried to push on that front ever since. MR SIMBLET: Thank you. 11 what do you see as being the public health value of 11 12 12 Those are the questions I wanted -- I'm just going accurately recording the incidents of infection of 13 healthcare workers from the perspective of patients? 13 to swap with Mr Thomas. 14 A. Any recording or tracking of nosocomial infections is 14 LADY HALLETT: The last questioner is Mr Leslie Thomas KC, 15 highly relevant to anyone within the healthcare setting, 15 who is in a similar position, Professor. Oh, he's going 16 as a patient. I mean, it just beggars belief that we 16 to move. Well done. 17 report MRSA infections when you have a cluster of three 17 Questions from PROFESSOR THOMAS KC 18 or four and yet here we had clusters of hundreds of PROFESSOR THOMAS: Good afternoon, Professor Banfield, let 18 19 Covid infections and we are not taking those into 19 me introduce myself. I'm representing FEMHO, the 20 account and it was relevant to patients then. It 20 Federation of Ethnic Minority Healthcare [workers] 21 certainly should be relevant to patients now and it will 21 Organisations. 22 be relevant to any future pandemic. 22 My first question is this, I want to look at data 23 23 Q. Why do you think RIDDOR reporting appeared to have been sufficiency and the early action on the mortality

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disparities. Okay?

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suspended or downgraded in the way that you have

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described during the pandemic?

At paragraph 214 of your statement you discussed

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the disparity and high mortality rates amongst black and Asian groups. We know that by 9 April 2020 Dr Nagpaul of the UK council called on the NHS England to investigate the disproportionate impact of Covid-19 on black and Asian minority healthcare workers.

Question: at that time, do you believe there was sufficient data or evidence for public health bodies to take action on the heightened mortality risks faced by ethnic minority healthcare workers?

- A. I don't think at that time the quality of the data was known. It was sufficient for us to say: you need to know more. I mean, our actual data collection about, you know, ethnic origin is poor overall, so I think it was essential at that point to push. And, you know, Chaand Nagpaul, as chair of UK council, pushed repeatedly even to get the review and then to get the reports -- and then still is pushing for the action that needs to take place, because it has not taken place.
- needs to take place, because it has not taken place.
 Q. Let me follow on from that and ask you this. So, given what you just said about the state of the data and the need to know more, in your view what would have been the most appropriate action for public health bodies to take based on the available evidence?
- A. Well, I think at that point, in a sense, to the theme
 throughout, it would have been eminently preferable to
- 1 ourselves.

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- Q. So, again, that leads me on to this question. What
 action, if any, did the BMA take to address these
 disparities in the mortality rates?
- 5 A. Well, in terms of our advice to our own members and --6 we started to look very proactively at pushing for risk 7 assessments that took other factors, such as ethnicity, 8 into account, and we in the end created risk assessment 9 tools both within England, that Professor David Strain 10 had started to organise, and in Wales separately, that had ethnicity as one of the risk factors that had to be 11 12 mitigated.
 - Q. Let me move on. At paragraph 318 of your statement you address the ongoing issue of institutional racism within the NHS and you talked very powerfully about that this morning -- sorry, earlier on this afternoon.

Could you expand, please, on how this institutional racism manifested itself before and during the pandemic, particularly in relation to the experiences of ethnic minority BMA members?

Before the pandemic we already knew that there was, you know, a disparity in opportunity, what was happening to you in the workplace, disproportionate referral to

to you in the workplace, disproportionate referral to
the GMC, you were less likely to have been -- correctly
had an induction at work, and therefore you were always

have taken a precautionary approach. And at that point to have made sure that we were absolute in our support and making sure that people from ethnic minority backgrounds were protected and facilitated in making sure they were getting their risk assessments and that those -- whatever the risk assessment was was being enacted, and that they were not being pressurised to work in unsafe environments.

9 Q. Let me move on.

Before Dr Nagpaul's letter, FEMHO is aware of other organisations, such as the British Association of Physicians of Indian Origin, for example, that had raised concerns about mortality disparities amongst ethnic minority healthcare workers.

Question: were there indications of these concerns prior to April 2020, and how did the BMA respond to them?

- A. Well, I mean, Chaand Nagpaul is a member of BAPIO and,
 you know, BMA works closely with BAPIO, so the point at
 which -- you know, it was obvious very, very early on,
 the first ten deaths of doctors were all black or --
- 22 Q. People of colour?
- A. -- South Asian. Yeah. And at that point it is the why.
 And what do we do, what do we not know? So that was
 escalated. At the same time we started looking for data
- 1 on the back foot about being able to practice in a safe environment.
- 3 Q. Mm.
- 4 $\,$ A. And we went into the pandemic, you know, in that state.
- The BMA was already aware of that and has been busily trying to support doctors in the workplace, which is why
- we worked with the diaspora organisations like BAPIO andMANSAG.
- Q. I want to be forward thinking and look at this not just
 from a negative point of view, so my next question
 is: what actions or reforms do you believe are necessary
 to address these long-standing issues of institutional
- 13 racism within the NHS?
- 14 A. I think we've got to accept it and acknowledge it and
 then actively do something about it, rather than
- passively. So, you know, at the moment we don't have
- 17 very good data. We need to create the space in which
- 18 people can speak up and feel safe about doing that.
- 19 We've got to create allyships where we, you know,
- 20 observe the micro aggressions and the cultural
- insensitivities, and being able to speak up and speak
- out and feel safe about doing that. All right? That's
- 23 about our attitude and our culture.
- Q. The BMA's concern with Public Health England's review on
 Covid impact, you mention at paragraph 67 of the BMA
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4		aniana anno manadina Dublia Haalib Englandla	4		and managetive in madeinar arms that there for a set and
1		serious concerns regarding Public Health England's	1		we are proactive in making sure that they feel safe and
2		May 2020 review on the disproportionate impact of Covid	2		are safe and are treated in an equal manner. All of
3		on ethnic minority groups. Could you elaborate on the	3		those recommendations have not really had concrete: yes,
4		specific issues that the BMA identified with the content	4	_	but what has actually happened now.
5		of this report? What were some specifics?	5	Q.	Two more questions and then I'm finished. My
6	Α.	So the first report came out and appeared to be missing	6		penultimate question is this. At paragraph 436 of your
7		the recommendations and then we had some feedback saying	7		statement you discuss shielding of high-risk
8		that 60-odd pages had been removed from the report and	8		populations. Were ethnic minority healthcare workers
9		that sparked off an exchange between the BMA and Public	9		adequately informed and supported regarding shielding
10		Health England over what was happening and also the	10		protocols considering the higher risk of severe Covid
11		minister for inequalities.	11		outcomes?
12	Q.	Yes.	12	A.	That's an interesting question because I'm not sure that
13	Α.	A few weeks later a part 2 appeared with recommendations	13		anyone who was shielding was adequately informed about
14		in it. Those recommendations still have not been rolled	14		what it actually meant. In terms of people from ethnic
15		out.	15		minorities as healthcare workers, we knew that they were
16	Q.	You pre-empted my next question which is: what	16		more vulnerable, we knew that they were under more
17		recommendations, if any, did the BMA make to improve the	17		pressure to work, less likely to say, "Do you know what,
18		report and to what extent were those recommendations	18		I am vulnerable, I shouldn't be working in this
19		adopted?	19		environment", and that's for many reasons not least
20	A.	So, you know, I can't say the explanation that was	20		because there were fear amongst a number of
21		given to us was that there was always intention for it	21		international medical graduates for their visa status.
22		to be a two-part report. I cannot comment on whether	22	Q.	Sure.
23		that is factually correct or not. But that bit about	23	A.	So, you know, they ended up with all sorts of reasons
24		making sure that people who are from an ethnic	24		doing the wrong thing but actually the right thing
25		background are in a safe space and listened to and that 169	25		because they put their lives on the line for us. 170
1	Q.	Well, we were all clapping for them, weren't we?	1	THI	E WITNESS: Thank you.
1 2	Q. A.	Well, we were all clapping for them, weren't we? Yes.	1 2		E WITNESS: Thank you. DY HALLETT: And it is 10 o'clock tomorrow. Thank you.
				LA	
2	A.	Yes.	2	LA	DY HALLETT: And it is 10 o'clock tomorrow. Thank you.
2	A.	Yes. Let me come to the very last question. Reflecting on	2	LA	DY HALLETT: And it is 10 o'clock tomorrow. Thank you.
2 3 4	A.	Yes. Let me come to the very last question. Reflecting on paragraphs 500 and 501 of your statement where you	2 3 4	LA	DY HALLETT: And it is 10 o'clock tomorrow. Thank you. 36 pm) (The hearing adjourned until 10.00 am
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