1 **Tuesday, 29 October 2024**
2 **(10.00 am)**
3 **LADY HALLETT:** Mr Scott.
4 **MR SCOTT:** Good morning, my Lady. May we please call
5 Julia Jones.
6 **MS JULIA JONES (sworn)**
7 **Questions from COUNSEL TO THE INQUIRY**
8 **MR SCOTT:** Good morning, Mrs Jones. You're here today to
9 give evidence on behalf of John's Campaign; is that
10 correct?
11 **A.** Yes, indeed, and I'm part of a core participant group
12 which includes The Patients Association and Care Rights
13 UK.
14 **Q.** Thank you. And we have a joint statement which is
15 signed by yourself, and then two senior members of Care
16 Rights UK and The Patients Association.
17 Can I just get a little bit of background just
18 about your organisation because I believe you are the
19 co-founder of John's Campaign, is that right?
20 **A.** Yes, I am indeed.
21 **Q.** And John's Campaign came about as a result of
22 an individual who -- you phrase it as:
23 "... the observed deterioration and death of ...
24 a man living with dementia, when he was separated from
25 his family support due to infection control measures

1 taken in hospital."
2 Is that correct?
3 **A.** It was almost like a microcosm of what's happened now,
4 yes.
5 **Q.** And the point of John's Campaign is about supporting
6 vulnerable people and their families, where a person in
7 need of support is being accommodated in any of the
8 institutions of the UK, and in particular there's
9 a campaign for a legal right to a personal care
10 supporter in respect of each individual rather than in
11 respect of any health or social care institution. Is
12 that right?
13 **A.** Yes.
14 **Q.** And John's Campaign, do you hear just from patients or
15 do you hear from healthcare workers as well?
16 **A.** John's Campaign wouldn't function if it weren't for the
17 goodwill and the understanding of people working in
18 health and care settings, so yes, of course we lobby
19 particularly for people living with dementia, that's
20 where we started, and for their family carers, but
21 John's Campaign has no organisation apart from the
22 goodwill of people working in hospitals, mental health
23 units, care homes, any of the health and social care
24 institutions.
25 **Q.** When was John's Campaign founded?

1 **A.** Ten years ago.
2 **Q.** And just in terms of The Patients Association as well,
3 I think a fair summary is that The Patients Association
4 seeks to provide the patient's voice in relation to the
5 treatment that they receive in healthcare; is that
6 right?
7 **A.** Yes. And I know that the CEO of The Patients
8 Association is with us today and she feels passionately
9 about the patient's voice but also about patient
10 partnership.
11 **Q.** I think we'll come back to the patient partnership. But
12 if I can, please, take you to I think what is the
13 central element of your statement.
14 If we can have up on screen INQ000283957, and it's
15 page 18, paragraph 41, it sets out there:
16 "As a Core Participant group, we have been and
17 continue to be particularly concerned about the
18 intense focus on infection control at the expense of
19 many other (healthcare) issues faced by individuals we
20 represent."
21 You said it:
22 "... had a huge impact on the quality of the
23 overall experience of care ... for those who
24 required it. It ... significantly impacted the
25 quality of ... end of life period and death ..."

1 Can you please expand a little bit about what you
2 mean by that paragraph in terms of where the balance
3 lies between infection control in a pandemic and the
4 other aspects of healthcare that you believe there
5 should have been more prominence put on?
6 **A.** When I said that our experience with Dr Gerrard, after
7 whom John's Campaign is named, was like a microcosm of
8 what's happened between 2020 and 2022, it was because he
9 was a man living with dementia, living well with
10 dementia, who was taken into hospital for a fairly minor
11 procedure. But there was a norovirus outbreak in the
12 ward and the default mode, then, of infection control
13 was separation and isolation. No visitors, slam the
14 ward door.
15 And my co-founder Nicci Gerrard's family had no
16 idea what this would do to her father. He simply lost
17 all his -- he lost his body weight, his power of speech,
18 his continence, his mobility, because he'd been sundered
19 from that framework that had been enabling him to live
20 well with his condition. And we've learnt since then,
21 and I know others of your witnesses have said, this
22 doesn't just apply to people who are living with
23 dementia, it applies to so many people who need that
24 additional carer support.
25 If the main method of infection control is

separation and isolation, the damage and the danger is far greater than -- dementia is incurable. You can survive Covid. You don't survive dementia. And that was a known fact and we were deeply shocked that that wasn't considered when the infection control guidance was set up.

Eventually there were some exceptions to the guidance and they were very welcome, but it made us wonder whether the infection prevention and control cell, as it were, had actually consulted with people outside of that cell, whether they had actually consulted with patients.

One of your witnesses, I think it was Professor Gould, said that she felt that patients and their families should have been part of the infection prevention and control guidance because they're the ones who are going to have it done to them, I think is the way she put it.

So, it made us wonder whether people issuing that sort of guidance are sort of aware of the diversity of people and the diversity of needs and whether they're obliged to take that into account when they're drawing up these sorts of guidance.

Q. Can I just -- just to clarify, you're not saying infection prevention control measures are bad per se?

A. Of course not.

Q. You're just saying that the balance in certain situations was wrongly drawn; is that a fair summary?

A. It's one of those situations where the prevention can be worse than the disease for some people. My co-founder, Nicci Gerrard, went on television on March 13, 2020, and said, for people living with dementia, separation and isolation will be a worse risk than Covid. And that has proved to be true.

Q. Do you think that there should be a different approach taken in pandemic times compared to non-pandemic times in relation to --

A. Yes. Yes, yes, of course. And that's where one need to look at the difference between visiting and caring. So I think one would of course want to reduce footfall in health and social care institutions. And people themselves would wish this to be the case, people don't want to go bringing infection into hospitals or indeed acquiring infections in hospitals. But if you know that the outcome for the person who you care about, who you support, is going to be dire without you, that's where there needs to be flexibility -- well, yes, flexibility and conversations.

Infection prevention and control needed to be much more complex and nuanced and appropriate for individual

need in our view.

Q. What would that have looked like? How would that flexibility have presented itself in a way that you thought would have been worthy -- appropriate balance had been drawn? And I appreciate it's very difficult to generalise at different stages of the pandemic, in different settings, but if you're able as far as possible to give examples of how you think things could be done better?

A. Well, in the very early stages there was a complete visiting ban, but immediately there were exceptions to the ban made for parents of children, for people who were dying, and for women who were giving birth, and in Scotland, very quickly, people living with dementia, learning disability or other cognitive impairment where separation causes distress, there was an exception made for them.

In England, that did come, it came on April 8th, from NHS England. Unfortunately, by that time the very negative message had gone out.

Q. Could you just tell us what that negative message is?

A. Yes. The negative message was: shut your doors.

And of course I also think that as the pandemic continued -- and what I'm talking about is also relevant to Northern Ireland and to Wales, it's not just England.

As the pandemic continued there were sort of fluctuations and changes to guidance which unfortunately got people quite confused, and so I think there was a lack of psychological insight, in that when you sent out such a very negative message to start with, and where people are very frightened and where you're looking at death statistics every night, so many people took no notice of all the nuances and the iterations of guidance, particularly, particularly when it became locally -- you could make your own minds up locally which should have been a good idea but actually wasn't.

Q. Picking up that thread then. Why wasn't it a good idea? Was it because of confusion that it caused? Was it because of difficulties in applying that? What do you think was the problem with that kind of set up?

A. Well, we became very aware of variability between the, particularly the English trusts but actually I think when you were speaking to Professor McArdle it was very obvious there was variability between the Northern Ireland boards as well, but some hospitals would listen and take the guidance and have an overall flexible attitude, that if the patient needed somebody and it was essential to their health then the essential person would be welcomed, whereas other hospitals would say no. And it could go down to a really micro level.

1 I had a very distressing incident in one of the
2 hospitals I would have thought was one of our best
3 John's Campaign hospitals, one of the hospitals who had
4 really taken on the idea of patient-centred visiting,
5 but there was a gentleman, and he was non-English
6 speaking, elderly and he'd had a bad -- living with
7 dementia, being cared for by his son and
8 daughter-in-law, was taken into a hospital with no
9 provision made for the fact that he didn't speak
10 English, and he got to the end-of-life state and they
11 were now no -- no contact, no support at all. He was
12 moved then into a different ward in the same hospital
13 for his end-of-life care, and the nurse said: but we're
14 a John's Campaign hospital, he has dementia, you could
15 have been coming in all through this time.
16 Think how those people felt. And of course in
17 that case he did revive, he did start to eat, which he
18 hadn't been able to eat before, but sadly it was too
19 late and they kept him better for a week or so and then
20 he died.
21 **Q.** Where do you think the flexibility in guidance should be
22 built in? And it could be at more than one level.
23 Should it be those who are creating the guidance?
24 Should it be at regional level, Trust level, board level
25 or ward level? Where do you think is the best place for

1 that flexibility to be built in given your experiences
2 of assisting people?
3 **A.** We, actually, I'm not sure flexibility is entirely the
4 right word because what I actually think is that we have
5 very good laws in this country, such as the
6 Equality Act, such as the Mental Capacity Act and indeed
7 such as the human rights legislation and I think if
8 those pieces of legislation, particularly the
9 Equality Act had been better observed then I think
10 legislation -- sorry -- guidance would have been drawn
11 up that was in accordance with legislation, and yes,
12 flexibility then does come in, as Ms O'Sullivan was
13 saying yesterday, people with learning disability for
14 instance who should have reasonable adjustments made for
15 them under the Equality Act not just because somebody is
16 feeling kind, but because that is their legal right,
17 then those people would have been better catered for.
18 **Q.** And do you think that those who are, so sisters, other
19 people who are working on wards, do you think they would
20 have been assisted by a better rights-based guidance
21 being given to them about when people could visit and
22 the circumstances to which visiting should be allowed?
23 **A.** I do. I do. And I think there's -- I mean, obviously
24 it's also a communication issue. I think there's a huge
25 amount that could have been done to reassure and support

1 ward sisters, ward managers, or the managers of mental
2 health units or anywhere in the health and care system
3 that actually it was okay to say, say yes carefully, say
4 yes in consultation, but otherwise it felt that the
5 default option was just say no, just say no, and that
6 wasn't best for patients.
7 **Q.** Do you think there was a sufficient -- this may be
8 a question also for The Patients Association's view
9 on -- do you think there was sufficient patients' voice
10 being put into the creation and the changing of guidance
11 as it went along?
12 **A.** No, I don't and I think that The Patients Association
13 would, I think as I've already said, recommended that
14 the patient voice should have been there in the drafting
15 of guidance, but I also think if you look within
16 hospital trusts, for instance, they have patient
17 experience departments and I ask myself: were those
18 patient experience departments well used during the
19 pandemic? And I think, as with so many things, the
20 answer will be in some cases yes, but in other cases no.
21 **Q.** How do you think they were best used?
22 **A.** I think they would have been very well used as a clear
23 point of communication, that if somebody was anxious
24 about -- if they felt that their relative needed this
25 additional support, and they felt -- perhaps they were

1 aware of the guidance, perhaps they knew they should be
2 entitled to it, it's very hard when you're a person in
3 the community looking at a big institution like
4 a hospital. You don't know who to ask.
5 So if the patient experience departments were
6 there, it would be a very good point of contact for
7 families to say: I really think that my mother needs me
8 in hospital or we're really distressed that we've been
9 told that our sister is on an end-of-life pathway but
10 we're not being allowed in to see her.
11 So in fact what very often happened was if they
12 were savvy enough to know about John's Campaign they
13 might ring me up and I might find I did know somebody in
14 the hospital and I could ring them, perhaps a lead
15 dementia nurse, or perhaps I would need to go to
16 safeguarding or the director of nursing and I would go
17 to somebody in authority, I'd say, "Look, this is
18 happening in your hospital", and they would say, "Oh
19 dear. No, no, that's not our policy at all." And so
20 then they would go to ward level and say, "Actually, you
21 should let this person in, it's part of our policy."
22 There was a huge gap between what happened at the
23 top and what was written down in guidance but what was
24 actually happening among very frightened people under
25 stress and taking large and scary responsibilities.

1 Q. It sounds like you had a number of those conversations.
2 Is that gap between the top and those applying the
3 guidance, was that a very common theme that you found?
4 A. Yes, and the sad thing is that of course only the people
5 who were assured enough to -- somebody told them about
6 John's Campaign or they found us in sort of desperation
7 trawling the internet or on social media, those people
8 could get through to me, or to Nicci, but people who
9 weren't confident and didn't go on social media and
10 didn't use the internet, there were so many people who
11 must just have taken their dismissal and they'll be
12 nursing the hurt until this day.
13 Q. And it shouldn't have been just because people made
14 contact with you, it should have been available to
15 everybody, I think you'd probably agree with that?
16 A. The experience of the pandemic changed us enormously.
17 We used to believe that you could get things done by
18 relying on people's goodness and their wish to do the
19 right thing, and in so many occasions that's absolutely
20 true, but we now feel that the power imbalance between
21 patients and their families and the institutions of
22 health and social care is so great that we now feel that
23 there should be a legal right lying with a patient that
24 if you're a patient or a service user or a resident, and
25 you need this personal support, you should have a legal

1 right to have it.
2 Q. Just a couple of things. You said "we" on a couple of
3 occasions; who do you mean by "we"?
4 A. Well, so firstly I meant Nicci and I who changed our
5 views. Then during the course of the pandemic we worked
6 with other organisations, principally to start with
7 other dementia organisations, but then we came closer to
8 Care Rights UK, and to many care organisations and
9 health organisations and I can now say -- possibly it's
10 out of the scope of this Inquiry -- that our statement
11 that what we feel now is that a care supporter's bill is
12 needed, has been signed by over 80 English
13 organisations, including, you know, people like Age UK.
14 I think you would have heard Caroline Abrahams use the
15 word "legal" in her evidence yesterday and that I think
16 is what she was referring to.
17 Q. So "we" is very broad when you use it?
18 A. It is. It is.
19 Q. Can I just ask, and this is one the things about patient
20 voices for The Patients Association. So The Patients
21 Association was part of the voluntary sector Covid-19
22 briefing group with DHSC which I think was intended to
23 be able to raise concerns from patients directly with
24 the briefing group. Have I got that correct?
25 A. Yes.

1 Q. Did The Patients Association feel like that group
2 achieved anything?
3 A. That's probably one for The Patients Association but
4 I think that they felt that they didn't feel that --
5 they might have been listened to but they might not have
6 been acted upon. I think in one or two of the other
7 groups that they were part of, for instance, the group
8 that advised on communication with people who were
9 waiting for procedures, I think they felt they had some
10 impact there but I think for a very clear answer
11 I'd have to refer you to The Patients Association, but
12 I don't think they would be saying the things that
13 they're saying now so strongly about patient partnership
14 if they felt it had worked through the pandemic.
15 Q. And then just finally in terms of points of contact.
16 You were describing earlier on when you were speaking to
17 people in hospitals, and I think you gave three
18 different examples of the type of people who you would
19 end up speaking to. When you spoke to hospitals, did
20 you tend to find that there was one person, one role,
21 one individual maybe who had that same level of
22 knowledge effectively asking it a different way, in each
23 trust board that you spoke to, did the decisions about
24 visiting and the application of guidance end up resting
25 with the same position within that trust or board or was

1 it just spread across different people in different
2 hospitals?
3 A. Hospital trusts vary so much. We function by a system
4 of pledges and we were able in 2018 to present pledges
5 from all the English Acute Trusts to the then Chief
6 Nursing Officer and say: look, these trusts have pledged
7 to welcome carers 24/7. It was a big pledge they made
8 but it was entirely voluntary and the way they would
9 implement it was up to them. And it's also true that
10 across Scotland, Wales and Northern Ireland almost all
11 trusts had made similar sort of undertakings but because
12 trusts are such complicated and big organisations
13 sometimes it would be that it was the dementia, lead
14 dementia nurse who had made this pledge, obviously in
15 consultation with a director of nursing.
16 Sometimes it would be the patient experience
17 department. Sometimes you would find it had come from
18 safeguarding because, you know, it was seen to have the
19 presence and support of a family carer is a safeguarding
20 measure. It can be proved to reduce the number of
21 falls, for instance, and pressure sores and
22 malnutrition, if you've got somebody there for
23 an individual patient.
24 So I had to think and sometimes I would strike
25 lucky and I'd realise we've got a John's Campaign

1 ambassador in that trust. Sometimes I would just have
2 to try and -- I'm afraid sometimes I just used Twitter
3 or something to get a response and then find who I could
4 talk to.
5 It was by no means ideal and that's what I mean
6 about that I think that every trust and institution
7 should have a clear point of contact for the public.
8 And, you know, I was acting as the public.
9 **Q.** You've given a lot of examples of the impact and what
10 could be done better. I think in your statement you've
11 also been keen to set out examples of things that worked
12 well. Can you give us examples in this kind of broad
13 area about what worked well, good practice, things that
14 should be adopted that happened during the pandemic?
15 **A.** I think even looking at your evidence from the spotlight
16 hospitals you can see that there are some who -- like,
17 I'm thinking of Altnagelvin Hospital in Londonderry, you
18 can see there's a hospital where the culture of
19 visiting, I'm using that word which -- I try not to say
20 "visiting" but that's the word we're all using, I'm
21 talking about therapeutic care, you can see that that's
22 taken seriously. So in some of the hospitals that
23 I know best, because John's Campaign has been working
24 for a while, the culture of valuing family care and
25 a sort of open visiting culture in non-pandemic times

1 has really taken root and that's true of some of the
2 health boards in Scotland as well.
3 So in those hospitals, because they believed in
4 it, and because they thought it was the right thing to
5 do, they would find ways to manage it. That's the
6 thing -- clearly in a pandemic you can't just go along
7 as normal and nobody would wish you to but you can find
8 positive ways round the regulations, you can find
9 positive and safe ways to balance the risk of not caring
10 for somebody in need and welcoming in a personal
11 supporter.
12 **Q.** Is this boiling down to what you were saying earlier on
13 about trying to find a way to say yes rather than the
14 default of saying no?
15 **A.** Yes, indeed.
16 **Q.** I'm going to move on to patient experience reports.
17 If we can please have the screen INQ000283957.
18 This is at page 21, paragraph 51.
19 I think The Patients Association provided or
20 conducted a series of surveys, is that correct, during
21 the pandemic --
22 **A.** Yes.
23 **Q.** -- about what patients find and their experiences. And
24 just to pick out a couple of the highlights of this
25 paragraph. So many people had treatments and other

1 support postponed or cancelled. Lack of information
2 about when services will restart. A risk of the voice
3 and experience of patients getting lost in the need to
4 get things done. Disabled people and people who are
5 chronically ill have been told they've been left behind.
6 And services for mental ill health have become even more
7 difficult to access under lockdown.
8 In relation to each of those, about each of those
9 points raised during the pandemic, do you have any ideas
10 about how any of those features could be improved in the
11 event of a future pandemic?
12 **A.** Yes. Some things could have been I think done quite
13 simply. One of the features that comes out from those
14 Patients Association surveys is the depression and
15 anxiety, and indeed, well, the people who feel that
16 they've been left behind, the people who felt that their
17 life and health wasn't of value. Those could have been
18 alleviated by quite simple human relatively cost-free
19 measures, making it important to ring somebody back, to
20 keep them in touch with what's going on, just normal
21 human positive interactions and I can't believe that if
22 one had thought of it that way that there couldn't have
23 been the man or woman power able to do that.
24 And I think communication, such an enormous
25 issue in every, every part of the pandemic, and could

1 have been handled so much more proactively and so much
2 more sensitively.
3 And while we're on -- The Patients Association
4 particularly heard from many people who'd been sent out
5 from hospital with inadequate follow-up, perhaps they'd
6 just had a heart operation or cancer treatment and they
7 were hurried out of hospital back home with inadequate
8 follow-up and very little idea who to contact, and
9 I feel I must say that we have to recognise who it was
10 picking up the pieces in that situation, and that was in
11 a vast number of cases it was the families of those
12 people who came home.
13 Carers UK have drawn up an estimate that four to
14 five million people found themselves needing to become
15 carers, and that means carers for health, people who
16 help somebody take their medication, help them do their
17 exercise, help their mood stay up, try to find if there
18 is a chance of them being referred onwards, those people
19 add up to 13.8 million people, and the CQC in their
20 State of Care report highlighted the strain on the
21 health and well-being of those people, and I really feel
22 that the contribution made by those people to the
23 continued functioning of health in our four countries
24 should be recognised, and I don't think it was
25 recognised.

1 Q. And those were people who were put in that position
2 because of decisions taken to discharge people earlier
3 than they otherwise would have been had it been
4 non-pandemic times, is that --
5 A. Yes, and people as the ambulance services said, who were
6 left at home sicker for longer.
7 Q. If I can just come back to the communication point and,
8 as you said, these basic human elements of communicating
9 with families or patients.
10 What do you put that lack of communication down
11 to? Is it a lack of time of those who are on a ward or
12 those who are treating other people? Is it a culture
13 within NHS, HSE of not prioritising communication?
14 Where do you think the fix fundamentally lies?
15 A. I think during the pandemic possibly everybody slipped
16 into what they call command and control mode of issuing
17 orders and indeed not encouraging alternative points of
18 view, discussion and communication. I think that has
19 an impact. I don't think people like being treated in
20 that way.
21 I think there are better ways to get the best out
22 of people and if a little bit more psychological insight
23 had been used, a little bit more sensitivity in the use
24 of language, that wouldn't have taken very much more
25 time, and it would have been very much more productive.

1 But I don't think the NHS is great on its
2 communication, and I think that's a great pity because
3 if you're separating people and you're leaving one set
4 of people in anxiety and ignorance and you're leaving
5 other people feeling frightened and abandoned by not
6 facilitating communication you're exacerbating that.
7 Q. Communication was a feature, I think, that flows
8 throughout the statement. You refer to communication in
9 the context of communication about shielding, about the
10 position in relation to DNACPRs, about people feeling
11 able to access services during the pandemic when they
12 otherwise may put it off.
13 Is that something that is at the heart of your
14 experience that difficulties with communications in
15 many, many different ways across the pandemic?
16 A. And also the sort of unspoken aspects of communication.
17 So we can tune in our televisions, and we can listen to,
18 you know, the people in suits telling us things, but
19 they're not really addressing our fears and they're not
20 giving reassurance and good communication handled better
21 could have given us more reassurance.
22 If you take something like the do not attempt
23 resuscitation issue which has been hugely covered, and
24 very well covered during this Inquiry, it's not only
25 people saying, "Well, of course it shouldn't have

1 happened like that", it's the thought if you're letting
2 somebody you love go into a hospital where you're not
3 going to have any contact with them, and you're not
4 going to have -- hear anything from them, you begin to
5 feel, you have imagination, you're human, you begin to
6 wonder what is going to happen to the person I love in
7 that institution? You're frightened, so the whole
8 feeling, and I'm afraid it was a true feeling that "do
9 not attempt resuscitation" could segue into "do not
10 treat" is extremely frightening and those sorts of fears
11 need to be tallied and real reassurance should be given.
12 Q. If I could, please, put on screen INQ000273424, page 5.
13 This is one of the reports from The Patients
14 Association's surveys and these are what appears to be
15 a similar thing, they're described as principles for
16 ensuring all patients, disabled people, carers, and
17 others are able to have the best possible experience.
18 Does that -- do those principles, do they
19 encapsulate what it is that you're trying to convey
20 about what you think were failings and what could be
21 improved in the pandemic?
22 A. I think that's a really excellent list and I feel fully
23 in support of it:
24 "Recognise from the outset that the impact of the
25 crisis will fall hardest on those who already face

1 discrimination and inequality ..."
2 And that's a lot of people. And as
3 Caroline Abrahams said yesterday, that includes older
4 people, it includes disabled people, it includes people
5 who are already socially disadvantaged, that's a big
6 thing.
7 Now, knowing that, surely the Equality Act, the
8 Human Rights Act, those laws that we already have should
9 swing into action and say: we're a democracy, we value
10 everybody, we're going to do something for these
11 individuals.
12 Q. Would you be able to provide a practical example of
13 how -- please feel free to choose any of those
14 principles, and more than one if you wish, about how
15 those principles should be brought in.
16 In terms of the fifth one down:
17 "Provide clear, concise and timely communication,
18 updated regularly, about the impact of the crisis on
19 support and services, what is available ... and how
20 services may begin to restart."
21 How do you think that should be done? Are you
22 talking broadly to the population, are you talking to
23 individuals using the services?
24 A. I think you're talking to the individuals and their
25 families using the services. I think what -- reverting

1 to yesterday and what Jackie O'Sullivan said about
2 involving people like Mencap or the Alzheimer's Society
3 or Age UK when you're drawing up guidance to make sure
4 it's going to relate to people's actual life
5 experiences, I think that's a sort of fundamental and
6 sort of structural thing.
7 I lost count of the number of times people said
8 "I'd been ringing all day and I got no answer". The
9 Patients Association have a horrible example, just one
10 of many, about a man who spent a whole weekend ringing
11 the hospital, his local hospital, to discover whether
12 his wife was still alive.
13 Let's just think of that. That was not necessary.
14 Somebody could have answered the phone in that hospital,
15 found the information and reassured that poor man. It's
16 not rocket science.
17 **Q.** Coming back to your points of communication. It sounds
18 like it's sort of about NHS and HSE and others
19 listening, not just broadcasting.
20 **A.** Yes.
21 **Q.** Do you think there was sufficient listening?
22 **A.** Putting themselves in the shoes of the patients who were
23 at the heart of their services. The services are there
24 for the patients. Family carers are sometimes a way of
25 articulating that.

1 We heard good recommendations yesterday about how
2 we should all do advance care planning. So somebody of
3 my age should be doing -- so I then appoint perhaps one
4 of my children to have power of attorney for me. And
5 that seems a good thing to do. Under the Mental
6 Capacity Act people would have guardianship. Under the
7 Mental Health Act there are people called the "nearest
8 relative". Now, all those people who had been appointed
9 by patients to -- in good times to undertake those
10 functions in bad times, far too many of them found
11 themselves just rejected, just not listened to, unable
12 to do these emergency functions which they'd accepted
13 the responsibility to do.
14 **Q.** Do you mean in care settings or in hospitals as well?
15 **A.** I mean in hospitals. And that's why I think Mr Wolfe
16 yesterday was trying to raise the issue of consent to
17 treatment, which I know your Ladyship heard. For people
18 who are not able to consent to treatment properly,
19 people -- I'm going to say people with dementia again,
20 but I'm also going to say people with learning
21 difficulty, people whose first language wasn't English,
22 when they're taken in and they're separated from the
23 people who have accepted responsibility for them, that's
24 not a situation that one should tolerate, because that's
25 them doing things to people without their consent, which

1 is fundamentally opposed to what the National Health
2 Service stands for. And it also inflicts great harm on
3 the people who have said "I will stick up for you in
4 your time of need, I will be your advocate", only to
5 find that they are not here. It shakes people's faith
6 in the system.
7 **Q.** Do you think that during the pandemic, whether
8 inadvertently or not, that there was a lack of
9 recognition as the individual circumstances of people
10 attending hospital?
11 **A.** Can I just say a straight yes?
12 But I -- no, I won't say it about every hospital,
13 because I do know that hospitals who had truly
14 understood the principles of patient support and carer
15 access did do their best, and I've heard from John's
16 Campaign ambassadors in hospitals of the way in which
17 they did facilitate access for people when they knew
18 that the risk of not doing so would be so damaging for
19 their patients.
20 And I think that, again, once a hospital is
21 working on a positive, ethical basis, that's a great
22 strength, because we've heard too much about the
23 distress caused to people working in hospitals and care
24 settings because they knew that they were doing things
25 they felt to be wrong.

1 So if one could do better in channeling the
2 positive principles, those hospitals, those patients
3 will, tangibly, do better.
4 **Q.** Just drawing all the threads together, apart from what
5 we've covered so far, are there any other
6 recommendations you'd like the Chair to consider when it
7 comes to writing the report?
8 **A.** I think you've allowed me to say them.
9 Firstly, that we play to our strengths and that
10 the good laws that we have and the good people -- you
11 know, the good institutions we have within our
12 institutions should be prioritised.
13 I would go further than that, and I know my
14 friends at Care Rights UK would want me to say this, we
15 feel that actually everybody working in health and
16 social care should, as part of their training, have
17 an understanding of the Equality Act and Human Rights
18 Act and the Mental Capacity Act. Those really
19 fundamental building blocks could be in training.
20 We understand that that's all quite complicated,
21 so that's why we would like the very simple right for
22 every patient to have this legal right to a care
23 supporter, a personal support, at the times that they
24 need it, and that should be a right with the patient.
25 And once you establish that, then the sorts of

1 things that went wrong with planning -- because
2 pre-pandemic planning didn't take any account of people
3 in hospital settings with confusion. It didn't take any
4 account of people with mental health issues in the
5 preplanning. It didn't take any account of visiting
6 issues in the preplanning. Now, once you know that your
7 patients and your residents and your service users have
8 this personal right, which comes in with them, and they
9 know they've got it and their families know they've got
10 it, then you're going to have to plan a little bit
11 differently, and better, and that would improve matters.
12 I know I must say about, you know, involvement in
13 patient planning. I must say that for The Patients
14 Association. And I must say for both The Patients
15 Association and Care Rights UK that access to healthcare
16 remains a fundamental equal right in our system and you
17 really shouldn't be saying to somebody, "I'm sorry
18 you're living in a care home, you can't see a doctor",
19 "I'm sorry, you've got -- you're old", or, "You're
20 disabled, this isn't going to be available to you."
21 I must say that very strongly for patients of the
22 future.
23 **MR SCOTT:** Thank you, Ms Jones. Those are all the questions
24 I have.
25 **LADY HALLETT:** Thank you very much, Mr Scott.

1 Mr Weatherby.
2 **Questions from MR WEATHERBY KC**
3 **MR WEATHERBY:** Ms Jones, I ask questions on behalf of the
4 Covid Bereaved Families for Justice UK group. Just
5 a few short points from me. I want to start with
6 shielding decisions and public health messaging and
7 mainly about The Patients Association surveys. So if
8 you can't help then obviously you'll say so but I think
9 you will be able to from the excellent statement that
10 you've put in to the Inquiry.
11 One of The Patients Association services covered
12 in that statement, and for the record it's
13 paragraph 138.1, found that two-thirds of respondents to
14 the survey who had shielded had not been advised to do
15 so by the NHS and that most people had shielded on their
16 own judgment. And it also showed that there had been
17 low levels of satisfaction with shielding guidance and
18 there'd been confusion about it because of a lack of
19 clarity.
20 If you're able to say, does this indicate
21 a problem with the reach of official advice about
22 shielding during the pandemic? Or does it show
23 a problem with public trust in that official guidance,
24 or both?
25 **A.** I think it shows people's caution and people's fear.

1 I think -- and also people's wish to protect others who
2 they love. I think that -- and there's probably
3 a confusion, and I probably shared it for a bit, between
4 voluntary self-isolation and shielding.
5 **Q.** Yes.
6 **A.** I think a lot of people, particularly those who felt
7 they had a vulnerable member of their family, did
8 voluntary self-isolation, and perhaps -- and also people
9 themselves who felt they had a health condition and they
10 were frightened chose to keep themselves out of society.
11 And I have often thought it was a great pity that
12 when people are looking at infection prevention and
13 control risk factors that somebody who had been
14 voluntarily shielding, or self-isolating or whatever we
15 want to call it, that wasn't taken into any sort of
16 account if they then wished to visit or care for the
17 person at their heart if that person was taken into
18 hospital.
19 It wasn't listened to, and I think that's a very
20 great waste and a pity.
21 **Q.** Yes. Okay, what are the lessons going forward here?
22 Are the lessons in terms of this issue of shielding
23 guidance identifying groups like yours or Patients
24 Association and to liaise with them about proper
25 guidance, what it actually means to shield or

1 self-isolate, and better planning generally? Are those
2 are the lessons?
3 **A.** Well, clearly there are people who should have been
4 consulted, and I wouldn't say it was us, because we're
5 just, you know, a little campaign movement, but there
6 are people, you know, with -- you've had, you know, some
7 wonderful witnesses representing clinically vulnerable
8 groups, so of course I think those specialist people --
9 **Q.** Yes.
10 **A.** -- you know, should have been involved.
11 But I think for many people the root anxiety, and
12 this came out in The Patients Association surveys, was
13 their feeling of disconnection from their GP. And
14 I worry enormously -- and I'm a bit digitally challenged
15 myself -- about how our relationships with our GPs are
16 going forward. And I listened to, you know, the
17 gentleman from the BMA saying: no, no, GPs know their
18 patients best --
19 **Q.** Yes.
20 **A.** -- these things should come through GPs. I'm not at all
21 sure that that continues to be the case.
22 I think it would be wonderful if everybody in our
23 four countries felt they had this personal relationship
24 with their local surgery but I'm worried about it.
25 **Q.** Partnership?

1 **A.** Partnership, yes.
2 **Q.** I'll come back to it, if I may, in my final question,
3 but before I get there a final point on shielding:
4 a respondent to The Patients Association survey
5 highlighted the issue of invisible disabilities --
6 again, for the record, paragraph 142 of your
7 statement -- and that included mental health
8 difficulties. And these invisible disabilities were
9 being overlooked in the public health messaging, the
10 shielding guidance.
11 Again, it's kind of the same question, but how
12 should these invisible disabilities have been better
13 accounted for and supported when advice was being
14 offered during the pandemic?
15 **A.** I think there could -- should and could have been a more
16 sophisticated understanding of the impact of isolation
17 on people, and I think that runs through everywhere,
18 everything that you're talking about, and the impact of
19 disconnection.
20 I think perhaps we've all learned quite a lot
21 through the pandemic about how people need each other
22 for their identity and how people need to feel valued.
23 If you're in the situation where people are either
24 voluntarily or on advice withdrawing from society,
25 I think it's extremely important to try to alleviate

1 that.
2 **Q.** Yes.
3 **A.** And people have mentioned some of the excellent
4 voluntary mutual aid initiatives that sprang up but
5 I'll bet you they only sprang up in certain areas.
6 **Q.** Okay.
7 **A.** I think those sorts of other ways of keeping contact,
8 particularly for people who don't have families to ring
9 them up, should have been prioritised.
10 **Q.** So the guidance shouldn't have missed invisible
11 disabilities in the first place but should have
12 addressed how local groups, for example, or support
13 networks could have been --
14 **A.** And there's potential for those difficulties being
15 exacerbated.
16 **Q.** Yes.
17 Final point, and it's rolling back to this idea of
18 partnership, we know and we asked to be added to your
19 document bundle, so I think you've probably seen it,
20 there was a letter from Rachel Power, the
21 chief executive of The Patients Association, sent to
22 Sajid Javid just on his appointment as health minister
23 in June 2021, so quite into the pandemic, and the whole
24 letter was about the absence of a role for patients --
25 **A.** Yes.

1 **Q.** -- within the pandemic proposals. And Ms Power was
2 explaining to the new health minister really the
3 importance of partnership. I'll just read one sentence
4 from it:
5 "The Patients Association exists to ensure that
6 everybody can access the health and care they need to
7 live well, and our priority is to secure equal
8 partnership between patients and those who deliver the
9 care they need."
10 Does that encapsulate what is at the heart of all
11 of these matters, that there is a need for a recognition
12 that healthcare must involve the patient as well as the
13 provider in this partnership? I mean --
14 **A.** I mean, I would make it a three-way partnership.
15 **Q.** Yes.
16 **A.** You knew I was going to say that. And Ms Power says it
17 in her letter. Because for some people, advocating for
18 themselves as patients, some people can do it, some
19 people can't. And that's why I really feel we need
20 recognition for the -- what I'm calling the invisible
21 army.
22 **Q.** Yes. And this letter and things like this letter, does
23 this illustrate really that there was a lack of an equal
24 partnership or a three-way partnership, as you put it,
25 during the pandemic when it came to healthcare

1 provision?
2 **A.** I think there always is. I think, as I was saying
3 before, it's the sick individual and the people who are
4 worried about them and the big institutions, and
5 anything we can do to break down that -- and remember
6 that the patient is the whole purpose of the
7 institution. The institution -- we weren't there to
8 Protect the NHS, we were there to help to save
9 individual lives, to protect individual people.
10 **MR WEATHERBY:** Thank you very much. That's very helpful.
11 **LADY HALLETT:** Thank you, Mr Weatherby.
12 Mr Wolfe, I think (unclear) might say you
13 (unclear).
14 **Questions from MR WOLFE KC**
15 **MR WOLFE:** My Lady, I seem to have disappeared behind
16 a screen, but I think I can just see you.
17 Mrs Jones, I just want to give you an opportunity,
18 if you want it, to come back to a couple of topics and
19 say a bit more if you want to.
20 The first relates to people with dementia in
21 hospital during the pandemic and their particular
22 experience. You've touched on the position of people
23 with dementia generally.
24 What were the particular difficulties faced by
25 people with dementia in hospital during the pandemic?

1 A. I think if you'd designed a system to make dementia
2 worse you would have pretty well done what happened in
3 the pandemic. And when you think how serious an illness
4 dementia is -- I was looking up some stats the other
5 day, and from the period from 2019 to 2022, 2023, for
6 women dementia was the biggest killer in all those
7 years, dementia remained the biggest killer and very
8 often it's the biggest killer for the whole of society.
9 So dementia really matters. There is nothing you
10 can do to cure dementia. You can only make it steady or
11 you can make it worse. And all those things that
12 happened to people with dementia in hospitals were --
13 the move from ward to ward, the people dressed in masks,
14 the emotional temperature of the hospital, people with
15 dementia may not be able to express themselves very
16 clearly, but they can feel very acutely and they can
17 feel very aware and very frightened but there's nothing
18 they can do about it, and they're out of their comfort
19 zone and they're away from the people who are relied
20 upon to care for them and they don't understand why.
21 How much more can one say?
22 Q. What, in simple terms, should have been done, could have
23 been done to address those things, or perhaps was done
24 in the best places but wasn't done everywhere?
25 A. Yes, yes, thank you. It was recognised by NHS England,

1 was recognised at the top levels in Wales, these are
2 people with additional needs, was recognised in the
3 guidance, but it wasn't implemented. And why didn't
4 people check that it wasn't being implemented? That's
5 what I don't understand. It's not that we just had
6 a terrifying first month, we had two years, as
7 Mr Weatherby has just said, there were two years of the
8 pandemic to make these things better, and in the good
9 hospitals people caring for people with dementia or
10 learning difficulty were very often welcomed back in, in
11 a careful way, to the benefit of the patients, and also
12 to the benefit of the staff, because we realise how
13 stressed and how exhausted all staff were. So if you've
14 got somebody who says, okay, I'm going to help with this
15 person, that's a plus.
16 In our witness statement we mention the case of
17 Claire who was caring for her husband -- father, sorry,
18 Bruce, who had Parkinson's dementia and had had a heavy
19 fall and so had to go into hospital, and she had
20 recently had Covid, the risk to her was negligible,
21 she'd had the jabs, all that, and so when she was able
22 to care for Bruce, Bruce was recovering. Then,
23 unfortunately, while he was in hospital he caught Covid
24 and was then moved into a Covid area, at which point the
25 ward door clanged shut, Claire was not allowed in,

1 despite the fact that the risk to her, she'd been
2 shielding, she'd had the vaccines, she'd had Covid, she
3 was actually a medical aid worker. She was okay. She
4 wanted to go in but she wasn't allowed.
5 By the time her father was eventually allowed out
6 again, and there was a lot of muddle about infection
7 areas and non-infection areas, it was too late for him.
8 His Parkinson's treatment had stopped, because that's
9 very specific treatment and it hadn't happened, his body
10 weight had dropped, he'd deconditioned. Older people in
11 hospital without stimulation decondition and you don't
12 get it back again. And so he just came out to die. And
13 that was unnecessary.
14 Q. And had he been properly supported, including by his
15 daughter, how would that have helped the staff?
16 A. Well, one would like to think that the overstretched
17 staff doing their best in those circumstances would have
18 welcomed the assistance.
19 With Parkinson's, for instance, you must have your
20 medication absolutely at the right time. Now, you've
21 got a whole ward to manage and a lot of demands upon
22 you. If you've got somebody looking at her watch and
23 saying, "Ah, time for Dad to have his Parkinson
24 medication", that surely is a help? The trouble is
25 I think that the exclusion and the saying "no" sort of

1 became institutionalised, and care did suffer and ward
2 staff were aware that their care was not to the standard
3 that they wanted it to be, and in those situations
4 perhaps you don't want outsiders coming in because,
5 you know, it's just a little bit of psychology. If
6 you're not doing very well, you don't want necessarily
7 a loving daughter coming in and, "Oh, what have you done
8 to my dad?" In fact you should say, "Oh please, come
9 in, help us with your dad." But it doesn't always work
10 like that.
11 Q. Could I ask you about a different topic, visitor
12 guidance. So Dr Warne in his evidence to the Inquiry,
13 described visitor guidance as an under-studied area,
14 a misunderstood area. I'd imagine you agree with that.
15 How could visitor guidance improve in terms of the
16 things about which you're concerned?
17 A. I think by differentiating between the social and the
18 therapeutic aspects. So -- and I'm not saying that it's
19 not great to have visitors if you're in hospital,
20 you know, the grape bearers, the chocolate bringers,
21 they are lovely and they make you feel valued and they
22 cheer you up and that's all good and well-being matters,
23 so all those things matter, but I think we're talking
24 about something very much more fundamental here and that
25 is what I would call therapeutic visiting and that comes

1 from the person who makes your life worth living.
2 Because in hospital you might become very discouraged,
3 you're in pain, you wonder is it worth carrying on, and
4 for many people there is somebody or some people who
5 make life worth living and that's why in your heart you
6 carry on.
7 So I think -- sorry, a bit of a non-answer. On
8 a good hospital website you will see differentiated
9 guidance for visitors and for carers. The Department of
10 Health has just upgraded their visitor guidance to make
11 visiting part of the fundamental standard, but what
12 NHS England is trying to do is establish care partner
13 guidance and make it much more obvious why staff should
14 welcome this person if they're willing to come, it's
15 a voluntary role, and if the person wants them. Nobody
16 has to have anybody they don't want.
17 **Q.** Final topic if I may. Different sort of guidance. The
18 end-of-life guidance.
19 So Professor McArdle described the way in which
20 the end-of-life guidance changed over time including in
21 particular acute periods of Covid pandemic, limiting
22 visits in extreme circumstances as they were called. Do
23 you think that concept of extreme circumstances were
24 sufficiently understood at the time?
25 **A.** I think it's the single most horrifying and distressing

1 aspect of the pandemic. The whole -- all the edifice of
2 guidance and infection control was because we are all
3 terrified of death and we want to avoid death, and then
4 to say, "And by the way if you are dying you're not
5 necessarily going to have the person you love with you"
6 or for the person outside "You're not necessarily going
7 to be with the person who is dying", that should be
8 an absolute right. Somebody who is dying, if it's
9 possible, and I mean possible because their family are
10 willing to come in to possibly an infectious area, that
11 should be an absolute right.
12 There shouldn't be -- and if it's known to be
13 an absolute right then you have to work out in practical
14 terms how to facilitate it. And people are very good,
15 if they know they've got to do something, they're very
16 good at finding ways to do it, and that's what the good
17 hospitals do, but it was just unacceptable -- and the
18 legacy of grief, guilt, anger, and mistrust that's left
19 behind it is massive and so if one could do just one
20 single thing, it would be to say, if you are dying you
21 have the right to have somebody with you and we will
22 facilitate that and that is our legal duty.
23 **MR WOLFE:** Thank you, Ms Jones.
24 Thank you, Chair.
25 **LADY HALLETT:** Thank you very much, Mr Wolfe.

1 Ms Jones, you may have called yourself, I think --
2 was it a little campaign group? -- but you obviously do
3 excellent work for people often in dire need of support,
4 so please take my thanks to you and to Nicci Gerrard for
5 all that you're doing, and if I may say, so you're also
6 an excellent advocate of the cause. You've been
7 extremely helpful, articulate and constructive, and I'm
8 very grateful to you and all the other people who have
9 joined in your group for the work that you are doing.
10 **THE WITNESS:** Thank you for giving us the chance because you
11 didn't have to, and thank you very much.
12 **LADY HALLETT:** Thank you. I just hope that it's a similar
13 feeling to, I suspect, the Long Covid groups. It's --
14 participating in this Inquiry may get some recognition
15 for the causes that you're advocating.
16 **THE WITNESS:** Thank you.
17 **LADY HALLETT:** Thank you very much. I shall break now and
18 return at 11.25.
19 **(Witness withdrew)**
20 **(11.09 pm)**
21 **(A short break)**
22 **(11.25 am)**
23 **LADY HALLETT:** Mr Mills.
24 **MR MILLS:** My Lady, I call Ms Ritchie, who will affirm.
25 **LADY HALLETT:** Can you hear us, Ms Ritchie? Are you hearing

1 us? Maybe we need to get a message to the techies.
2 **MR MILLS:** I can see things are happening, my Lady.
3 **(Pause)**.
4 I'm speaking to test whether we now have sound to
5 Ms Ritchie.
6 **LADY HALLETT:** Can you hear us?
7 **THE WITNESS:** Yes, I can.
8 **LADY HALLETT:** Oh, you poor thing. You've been sitting
9 there with us talking to you. I'm so sorry but we had,
10 as you probably gathered, a technical hitch. If you
11 could now just listen to the usher, please, to affirm or
12 take the oath.
13 **MS NICOLA RITCHIE (affirmed)**
14 **Questions from COUNSEL TO THE INQUIRY**
15 **MR MILLS:** Your full name, please.
16 **A.** Ms Nicola Ritchie.
17 **Q.** Ms Ritchie, you have provided a statement to the
18 inquiry. The reference is INQ000492258.
19 You are a mental health physiotherapist and
20 a member of Long Covid Physio, is that right?
21 **A.** That's correct, yes.
22 **Q.** And you are here today to assist the Inquiry by
23 providing evidence of your experience of developing
24 Long Covid in the course of your work as a healthcare
25 professional, and your subsequent efforts to secure

1 a diagnosis and treatment.
2 Can I begin by asking you to describe your
3 physical health before you developed Long Covid?
4 A. My physical health before, I was incredibly fit, I think
5 I was actually the fittest I've ever been in my life.
6 I swam a mile twice -- two or three times a week in the
7 mornings before I went to work, I would walk my dogs
8 an hour and a half every day, I went to exercise
9 classes, I went to the gym, I went hill walking,
10 anything I could just to be fit and active. I loved to
11 exercise and that is something that I really miss doing
12 now.
13 Q. And again, before Long Covid, what was a typical working
14 day like for you?
15 A. A typical working day, I cover the whole hospital for --
16 around about 12 wards or so and the wards cover
17 in-patients covering from older adults to younger adults
18 to brain injuries, to enduring mental health in forensic
19 patients. I would be treating them for multiple
20 traumas, orthopaedic fractures, sore backs, mobility
21 issues, anything and everything really. I would also
22 see some outpatients as well.
23 We had a number of exercise classes during the
24 week as well, so I would be taking part in them and
25 leading them as well.

1 Q. Can you take us, please, back to April 2020 and share
2 with the Inquiry how you contracted Covid-19?
3 A. I contracted Covid-19 in the workplace. I firmly
4 believe that I contracted it from a patient that was
5 within the hospital. The patient was seen as being
6 positive for Covid but untransmissible. I don't really
7 understand why that was the case but that was what the
8 medical staff had told us in the hospital. He had been
9 positive for around about 14 days or so, but we had to
10 see him for a multiple of different reasons and it was
11 myself and one of my colleagues that went to go and see
12 this patient and we both developed symptoms about a week
13 and a half later but we developed the symptoms on the
14 same day and that was the only patient we had seen
15 together.
16 I feel the PPE that we were given was inadequate
17 to be seeing patients that had Covid. It was generally
18 the fluid-resistant face mask, gloves and a sleeveless
19 gown is what we were wearing to go and see patients at
20 the time. I had been face fit tested for more
21 appropriate masks, but because I was not carrying out
22 aerosol-generated procedures, I was told that I was not
23 to wear them and that was the guidance at the time.
24 Q. Had you expressed any concern about seeing a patient
25 presenting with Covid-19 with only the PPE that you have

1 described?
2 A. Of course. I felt that we should have been wearing more
3 appropriate PPE regardless of who we were seeing. At
4 the time Covid was so unknown, it was quite a scary time
5 to be working because nobody knew what to expect and
6 nobody knew what was going to happen and there were so
7 many people dying all over the world. That was not
8 something that I wanted to be exposing myself to.
9 Q. Can you describe the symptoms you began to experience?
10 A. I started off with a cough, but the cough didn't last
11 particularly long. It was only over a couple of days
12 I had the cough, but I experienced temperatures, the
13 temperature lasted possibly a week or so, but it was
14 mainly the fatigue. I was extremely fatigued. I was
15 sleeping pretty much the majority of the day, only awake
16 for maybe an hour or two in the day. I tried to do
17 anything at all, get up, get washed, even put a load of
18 washing on and I was completely and utterly exhausted
19 from it.
20 I had very bad shortness of breath from doing
21 anything at all and I had a lot of pain. I had never
22 experienced back pain in my life, but for some reason my
23 back had become very painful and I couldn't understand
24 why.
25 Q. Were you self-isolating during this time?

1 A. Yes.
2 Q. How long did you self-isolate for?
3 A. I isolated for two weeks. That was the recommended time
4 to take off at the time so I isolated for the two weeks.
5 Q. And during the two weeks did your symptoms improve or
6 did they become worse?
7 A. They became worse and then better, so worse over, like,
8 the few days that I first contracted it and then
9 gradually better, but I wouldn't say better to the point
10 that I was functioning. I felt after the end of the
11 two weeks that I had never really taken time off work so
12 being off was really alien to me. I felt that if
13 I pushed myself to get back then I would get better
14 faster. But that was -- in hindsight that's a very
15 silly thing to do but I feel like if I did push myself
16 I would be able to get back into a routine, get back to
17 normal a little bit faster but it took me quite a number
18 of months then to be able to do anything that I would
19 have done normally.
20 Q. We'll come in a moment to look at the extent to which
21 you're able to carry out your regular duties when you
22 returned to work, but can I ask this before we move on.
23 During the two weeks you were self-isolating, were you
24 able to access a test for Covid-19?
25 A. No. There was an online application system within the

1 NHS trust that I worked for, and I applied for a test at
2 the time but I never actually heard anything back from
3 it. At the time I was told, word of mouth, that there
4 were maybe possibly 20 tests being carried out every day
5 at that point, so I imagine, yeah, there would have been
6 hundreds of tests needed to be carried out every day.
7 **Q.** When you returned to work and you've told us about the
8 routine of your working day before this time, to what
9 extent were you able to carry out those regular duties?
10 **A.** I was back to working my full-time days but I was very
11 much unable to carry out my full duties. Because of the
12 fatigue and the shortness of breath and the discomfort,
13 the pain that I was in, I really struggled to carry out
14 any exercise as such or cart -- like, any of the moving
15 and handling, any of the more difficult moving and
16 handling that I would have to do. I had to -- basically
17 I had to do a lot of online learning, I had to do a lot
18 of lighter duties. I couldn't do all of my duties at
19 that point.
20 **Q.** You say in your statement, and I'm at paragraph 29, that
21 the muscle pain you had during the acute stage developed
22 into severe back pain?
23 **A.** Yeah. And as a physiotherapist, I thought: I know how
24 to treat this, I'll use all of the tools in my toolkit
25 that I've been teaching everyone all of these years.

1 And no matter what I did, it only got worse.
2 Basically I did an assessment on myself, I carried
3 that out. I thought: these are the exercises that would
4 generally help back pain like this. And literally
5 everything I did made it worse. The only thing that
6 actually helped was when I had a bug, like a very bad
7 bug, a few weeks down the line, and I was basically
8 bedbound for another couple of days, and that helped to
9 ease my pain. Which goes against everything we would
10 ever say as a physio: don't go to bed and rest because
11 that's not going to help your back. That was the only
12 thing that helped me.
13 **Q.** Moving, please, to September 2020. You describe in your
14 statement, and these are your words, suffering a "severe
15 'crash'" in September 2020.
16 Can you explain, please, what happened to you, and
17 perhaps also what you mean by that term "crash"?
18 **A.** Well, I would say that between April 2020 and
19 September 2020 I'd pushed myself as much as I possibly
20 could within my limits to get back to fitness, to get
21 back to what I would normally be doing. In hindsight
22 again, after hearing many other people's stories of
23 similar experiences, it's probably the last thing
24 I should have been doing, but all I wanted to do was get
25 back to some sort of normality.

1 For maybe four to six weeks over the summer I was
2 able to do a little bit more of my normal kind of
3 exercise. I went hill walking again, I was enjoying
4 walking the dogs. Then September came and all of the
5 original symptoms of Covid came back.
6 I thought I was positive again, but on testing
7 I wasn't. I think it's because I pushed myself too much
8 and my body then responded very negatively. And I have
9 never recovered since. That's why I call it my crash,
10 because I crashed and I've never recovered from it.
11 I -- sorry.
12 **Q.** Take a breath, Ms Ritchie.
13 **A.** Yeah. Sorry, I'll just take a drink.
14 My original symptoms that I had carried on. The
15 breathlessness, the pain -- the pain came back just as
16 bad as it had done the first time around -- the lack of
17 ability to exercise. For example, if I was -- well,
18 sorry, I took two weeks off work as usual. I thought:
19 right, I'll get back to work as normal. But when I got
20 back even basic things like very, very gentle exercise,
21 if I was doing anything, like, say, a push up against
22 the wall, I would be sore for a week. All of the
23 muscles that were involved in that exercise would give
24 me pain for a week and I would be struggling to move.
25 That has basically led to me not being able to

1 exercise. If I do any kind of exercise now that is the
2 kind of thing that will happen to me.
3 I went back to work and was on even lighter duties
4 than I had been the first time around.
5 **Q.** Around this time did you become aware of the term
6 "Long Covid"?
7 **A.** I think it would have been around about the December
8 I heard about it in the news. And I did a little bit of
9 research into it and so many of the symptoms resonated
10 with what I'd been experiencing. I didn't have a clue
11 what it was but I've been on quite a learning experience
12 since.
13 **Q.** Can I ask this. Did you discuss the possibility of you
14 having Long Covid with your GP?
15 **A.** I did. I phoned the GP, I think it was in the December,
16 and I said I feel like I may have Long Covid. They
17 asked me why, I explained the symptoms I'd been
18 experiencing, and it was never questioned. No
19 differential diagnosis was ever chased, no testing was
20 carried out, they just took my word for it that I had
21 Long Covid.
22 **Q.** At your paragraph 33 you say this:
23 "I spoke to my GP. My GP responded that there
24 was nothing they could do, and I should look online
25 for resources."

1 A. This is something that I have heard continually from my
2 GP basically since. I have had multiple contacts with
3 the GP, to the point that I've stopped contacting them
4 because every time I did it was a case of "There are
5 online resources, there's nothing that we can do".
6 Yeah. "Go and have a look online. It's for self
7 management only."
8 Q. I think around this time, in December 2020, you also
9 found out you are were pregnant?
10 A. Yes.
11 Q. Can I ask this, did being pregnant have a noticeable
12 effect on the Long Covid symptoms you were experiencing?
13 A. Massively so. Basically from day one of being pregnant
14 I couldn't understand why I was suffering from
15 debilitating fatigue, like I'd never experienced
16 anything like it in my life.
17 I had gone in to work and I tried to push through
18 it, but after maybe a week or so of trying to really
19 push myself through that I had to basically end up going
20 off sick because I struggling so much. I was going home
21 and not functioning. I wasn't able to do anything on
22 my days off, I just -- it was just -- it was so
23 challenging.
24 Q. As we move into the new year, in January 2021 I think
25 you joined Long Covid Physio, is that right?

1 A. Yes.
2 Q. Can you tell us a little bit about how you found out
3 about that organisation and what help being a part of it
4 has offered you?
5 A. I think I heard about it -- it was a webinar on
6 Long Covid that one of the main people within
7 Long Covid Physio had been providing, to give a little
8 bit of education for people. So I had a look online and
9 found out that it would be quite a fantastic thing for
10 myself. It was mainly -- I joined it for peer support;
11 at the time there were only a few of us that were
12 members of Long Covid Physio.
13 And what was fantastic about it was we could ask
14 all of the bizarre symptoms. There are so many symptoms
15 that Long Covid has but none of it made sense at the
16 beginning and we couldn't figure out what was going on.
17 So we kept almost like a back and forth with each other
18 just to find out: are you experiencing the same as this?
19 What does this mean? And we all kind of figured it out
20 together, it was fantastic.
21 Q. You say in your statement that the more people that
22 joined the group, the more information there was?
23 A. Yes. And that was key because, well, the more people,
24 the more knowledge. And it was just -- it was
25 eye-opening for me because so many people had so many

1 good hints and tips of different things that you could
2 try to try to help yourself to get better, and I was
3 willing to try anything.
4 Q. At your paragraph 39 you say:
5 "In July 2021 I was finally provided with
6 a diagnosis of Long Covid from a consultant at my local
7 hospital."
8 How did that diagnosis come about?
9 A. I basically went to my doctor and said, "If you can't
10 help me, please send somewhere that can". So they sent
11 me to -- it was just, like, a general department within
12 the local hospital.
13 I had been asking my GP for a number of months to
14 put Long Covid or something Covid related on my fit
15 notes for work, because I wasn't going to be getting any
16 sick pay for being off from the six-month mark, I would
17 have been down to half pay or no pay, but with that
18 Covid diagnosis on my fit note, I would have been able
19 to get Covid special pay, which was quite important at
20 the time.
21 So I basically had to go to that department to get
22 a diagnosis.
23 Q. Having first contracted Covid-19 in April 2020, then
24 suffered your crash in September 2020, how did you feel
25 in July 2021 when you received your diagnosis of

1 Long Covid?
2 A. At the point it was a means to an end. I knew I had
3 Long Covid. It was a case of a bit of validation that
4 somebody actually believes me, but at the same time they
5 turned round and said to me: what are you actually
6 expecting from being here, because there's nothing we
7 can do?
8 So it was a good thing that I had the diagnosis,
9 but on the other hand there was nothing that they could
10 do, to offer me, to help. So I was still left in limbo.
11 Q. In September 2021 you gave birth to your daughter and
12 I think within a month or so you had contracted Covid-19
13 again, is that right?
14 A. Yes.
15 Q. On that occasion were you admitted to hospital?
16 A. Yes.
17 Q. How long were you in hospital for?
18 A. I was in for four nights.
19 Q. Can you describe the symptoms you experienced during
20 that infection and the treatment you received, please.
21 A. During that infection it was mainly the debilitating
22 headaches that I struggled with more than anything.
23 I had the fatigue, I had the fever, all of the usual
24 things but it was the headaches. I had incredibly bad
25 light sensitivity so I was basically sitting in the dark

1 for days in the house.
2 I was unable to eat because of nausea, I was
3 unable to drink because of the nausea, so I was admitted
4 basically because I was so dehydrated my oxygen
5 saturation levels were low so I required supplementary
6 oxygen when I went into hospital. I had to be put on
7 a drip because I was so dehydrated.
8 Yeah, it was -- it was not a fun time.
9 Q. Can I ask you now, please, about the treatment that you
10 have been able to obtain for Long Covid.
11 In your statement, from your paragraph 43, you set
12 out the private treatment that you have sought. Can you
13 tell us a little bit about that, please.
14 A. In March 2023 I had basically had enough. I had been
15 fighting, trying to get some form of treatment from the
16 NHS since probably from the December 2020 and I kept
17 getting knocked back every time but I was researching
18 everything that I possibly could to help myself.
19 I eventually found out there was a private GP seeing
20 patients with Long Covid so I thought: I've got nothing
21 to lose, I will go on the waiting list.
22 At the time it was a video call that I had,
23 thankfully, because the clinic was in Stirling, which
24 was quite, quite a long way away but this was the clinic
25 that pretty much most Scottish people with Long Covid

1 have gone to at some point.
2 It was one of the most validating experiences
3 I think I've ever had. She believed everything I said,
4 I didn't have to fight to get my point across. I told
5 her the symptoms I was experiencing and she diagnosed me
6 and offered medications to try and help my symptoms. It
7 was a massive relief to be heard.
8 Q. Did the medications help?
9 A. They have to an extent in terms of I have managed to
10 stabilise my symptoms so I don't have bad crashes as
11 much any more, my headaches have been helped massively,
12 things like that, but I still am operating at a very low
13 level.
14 My fatigue, my brain fog, everything like that is
15 still at a very low level that I struggle to function
16 day to day, but I don't experience the ups and downs
17 that I did before which was -- which is a massive
18 improvement for me.
19 Q. You have also attended a Long Covid practitioner
20 service?
21 A. Yes.
22 Q. What did that service offer you?
23 A. It's mainly run by other allied health professionals
24 which is fantastic for anyone that's in the initial
25 stages of recovery because they can teach all of the

1 pacing advice and lots of the educational things to
2 self-manage in the initial stages, but because I'd been
3 going through it for almost four years by that point
4 I had followed all of that advice and I had managed to
5 get my pacing down incredibly well.
6 This is the sort of thing that I teach to patients
7 on a day-to-day basis in my work so if I don't follow it
8 I'm kind of a hypocrite really. So I knew exactly what
9 I should be doing and everything that they went through
10 with me was just reinforcing that I was doing the
11 correct things.
12 I did ask for a medication review because I had
13 been on the medications that the private GP had
14 prescribed to me for about a year and I said that
15 I think it's about time we had a review just to see if
16 there's anything that needs to be changed with them, or
17 anything along that lines. So I had an appointment with
18 the consultant within the practitioner service and I was
19 told that basically all of the medications that I had
20 been prescribed, there was no evidence behind them so
21 I shouldn't be on them, so I was a bit deflated with
22 that. It was quite difficult.
23 Q. Can I move to our final topic, please. The impact of
24 Long Covid on both your physical and mental health.
25 You have throughout your evidence described the

1 symptoms you have suffered through 2020, 2021. Can
2 I ask you, please, for you to describe your current
3 persistent Long Covid symptoms?
4 A. At the moment I have symptoms of PoTS or orthostatic
5 intolerance, so basically when I stand up, when I go
6 from lying to standing or sitting to standing, my heart
7 rate elevates quite significantly. If I do any kind of
8 exercise as in maybe 20 or 30 seconds' worth of very
9 basic exercise with patients, my whole body feels like
10 a lead weight and I can feel palpitations, my heart is
11 incredibly fast. I get short of breath very, very
12 easily. And I still experience incredibly debilitating
13 fatigue.
14 Throughout the conversation today I have obviously
15 been struggling with a lot of brain fog. Word finding
16 difficulty is one of my big ones, even just basic easy
17 words. It took me about 12 hours to think of one word
18 yesterday. I was texting a friend to try and find out
19 this one word but I could not think of it for the life
20 of me. I had about five different ways to explain one
21 simple word but I could not think of that one word. But
22 that's just day-to-day for me now.
23 I'm trying to think of other symptoms that
24 I experience. Basically I have to use a mobility
25 scooter because I can't walk any distance at all. If

1 I try and walk any kind of distance I really struggle.
2 The post-exertional malaise is awful. I think I have
3 around about a 2,000-step limit every day and that
4 includes walking around the house, like going back and
5 forth to different rooms and things like that. So that
6 is my maximum really. I normally try and stay around
7 about the 1,000 limit and that's kind of more
8 comfortable for me but anything over 2,000, I know I'm
9 going to struggle the next day or later on that day.
10 **Q.** In your statement you used the term "energy spoons".
11 Can you describe to us how that helps you manage your
12 energy?
13 **A.** Every day I have to pace to within an inch of my life.
14 So everything I do is planned. I can do one thing a day
15 whether that is going to an appointment, taking my
16 daughter to a 30-minute swimming lesson or meeting
17 a friend for a coffee. I have to basically think of
18 everything I have to do within that day and I have
19 an infinite -- well, I have a certain amount of energy
20 for that day that I can use and I have to pace it
21 through that day.
22 I think of things almost like if I get up, if
23 I have a shower, that's one spoon for the day. I have,
24 say, maybe ten spoons for the entire day. Washing is
25 one spoon. Having breakfast is another. Drying my

1 hair, that generally takes two spoons because it doesn't
2 happen that often because it is so exhausting. Things
3 like that.
4 If I have to do anything within the day that has
5 to be allotted to a certain length, like a certain
6 amount of energy and I have to make sure that I don't go
7 over that, that allocation of energy spoons.
8 **Q.** What has been the impact of developing Long Covid on
9 your career?
10 **A.** It has been massive. I feel like I am at risk of losing
11 my career. I have been fighting since I got back to
12 work to try and stay within my career because it's
13 something that I am passionate about, it's a job that
14 I love, I love treating people, I love helping people.
15 But because of what has happened to me with Long Covid
16 and the symptoms that I struggle with every day, since
17 I've been back I've had to reduce my hours even more.
18 So I was previously full-time, now I'm down to 18 hours
19 a week. But even that is still a struggle.
20 I'm on restricted duties -- well, not restricted
21 duties. I've got reasonable adjustments. So I have
22 a mobility scooter to get between wards. I -- at the
23 moment, I don't have to participate in the exercise
24 classes because of the impact that they have on me.
25 It's quite scary really because I don't want to lose my

1 career, although being in the workplace for me at the
2 moment is still a terrifying place, because of the risk
3 of contracting Covid, I still want to be there, I still
4 want to help people, I still want to be able to fulfil
5 my role. It is something that I am really passionate
6 about and something that I still want to continue to do,
7 but I can only do that if the reasonable adjustments are
8 continued longer term.
9 **Q.** Finally this, please. Can you help the Inquiry
10 understand how Long Covid has affected the way you are
11 able to interact with your daughter?
12 **A.** It has been very challenging. She is my only daughter
13 and since she was born I have really struggled with such
14 fatigue. When she was born I couldn't stand up and hold
15 her because of the effort involved. I couldn't walk
16 around the room with her. I still can't carry her and
17 walk because I become so incredibly breathless and
18 fatigued straight away.
19 If I go to the park, someone else has to be with
20 me because I can't run after her. If we do anything
21 along that lines basically someone else has to be there
22 because, yeah, she is full of energy and I can't match
23 that and it's so difficult. We spend quite a lot of
24 time doing things in the house, like different toys and
25 games and things likes that in the house because it

1 saves my energy which is so incredibly difficult because
2 all I want to do is run around the park and play with
3 her. But I have to make sure that I can do as much as
4 I can with her for the rest of the day and if I do too
5 much at one point of the day I'm gonna be useless the
6 rest of the day and not be able to care for her.
7 **MR MILLS:** Ms Ritchie, thank you.
8 My Lady, that's all I ask.
9 **LADY HALLETT:** Ms Ritchie, thank you very much indeed. I'm
10 really grateful to you for your help. I can't imagine
11 how difficult it is to manage the symptoms you describe
12 and a three-year-old. Is she a bit of a terror?
13 **THE WITNESS:** She very much is.
14 **LADY HALLETT:** That doesn't surprise me, having had
15 grandchildren recently at that age. But thank you so
16 much. I do hope your symptoms improve. I hope your
17 career does thrive when they do improve and I hope the
18 relationships within the family get much better as you
19 get better. So thank you for all your help.
20 **THE WITNESS:** Thank you.
21 **(Witness withdrew)**
22 **MR MILLS:** My Lady, may I next call
23 Professor Chris Brightling and Dr Rachael Evans, who
24 will both affirm.
25 **LADY HALLETT:** Thank you.

1 **PROFESSOR CHRIS BRIGHTLING (affirmed)**
2 **DR RACHAEL EVANS (affirmed)**
3 **Questions from COUNSEL TO THE INQUIRY**
4 **LADY HALLETT:** I hope you haven't been waiting for too long.
5 I think you did arrive quite early so I'm sorry if we've
6 kept you waiting.
7 **MR MILLS:** Your full names, please, perhaps starting with
8 you, Professor.
9 **PROFESSOR BRIGHTLING:** Professor Christopher Brightling.
10 **PROFESSOR EVANS:** Professor Rachael Evans.
11 **MR MILLS:** I'm so sorry, Professor Evans, I introduced you
12 as Dr Evans.
13 **PROFESSOR EVANS:** That's fine.
14 **LADY HALLETT:** I think you introduced both of them as
15 "Doctor", actually.
16 **MR MILLS:** Did I?
17 **LADY HALLETT:** There's nothing wrong with that.
18 **MR MILLS:** You have, Professors, both provided a report to
19 this module of the Inquiry. For reference, that is
20 INQ000421758 and it's right, isn't it, you also prepared
21 a report and gave evidence to Module 2?
22 **PROFESSOR EVANS:** That's correct.
23 **Q.** Can I begin with a very brief summary of your
24 experience.
25 Professor Brightling, you are a professor of

1 respiratory medicine at the University of Leicester and
2 you have been a treating consultant physician since
3 2004?
4 **PROFESSOR BRIGHTLING:** That's correct.
5 **Q.** Professor Evans, you are an Associate Professor at the
6 University of Leicester and an honorary respiratory
7 consultant physician at the Glenfield Hospital which is
8 part of the university hospitals of Leicester NHS Trust?
9 **PROFESSOR EVANS:** Correct.
10 **Q.** Since 2020 both of you have been involved in studying
11 Long Covid and treating those with it.
12 **PROFESSOR EVANS:** That's correct.
13 **Q.** Now, I know that you have divided areas of the report
14 between the two of you. We'll adopt the same format as
15 when you last gave evidence with whoever took the lead
16 on a particular issue providing the answer.
17 Can we begin, please, by setting out the central
18 pillars of our current understanding of Long Covid.
19 First, the definition.
20 Please can we go to INQ000238545.
21 This is an extract from NICE's managing the
22 long-term effects of Covid-19 and we have here under
23 "Post-COVID-19 syndrome" this:
24 "Signs and symptoms that develop during or after
25 an infection consistent with COVID-19, continue for

1 more than 12 weeks and are not explained by
2 an alternative diagnosis. It usually presents with
3 clusters of symptoms, often overlapping, which can
4 fluctuate and change over time and can affect any
5 system in the body. Post-COVID-19 syndrome may be
6 considered before 12 weeks while the possibility of
7 an alternative underlying disease is also being
8 assessed."
9 Is this the definition according to which
10 Long Covid is diagnosed?
11 **PROFESSOR EVANS:** Yes.
12 **Q.** Can you help, when did NICE establish this definition?
13 **PROFESSOR EVANS:** That was towards the end of 2020. But the
14 patient-derived "Long Covid" term happened much earlier.
15 **Q.** Quite. And we see here, don't we, "post-Covid-19
16 syndrome". Is that a term you use or do you use the
17 "Long Covid" term instead?
18 **PROFESSOR EVANS:** I and our clinic use the "Long Covid"
19 term.
20 **Q.** Can you help the Inquiry understand why that is.
21 **PROFESSOR EVANS:** Because it was developed for a reason. It
22 was developed by the people that were experiencing this
23 and they chose the language very carefully. They
24 describe in their report their concerns around the
25 post-Covid-19 syndrome and I think it's very helpful

1 that we all use the same language and that we are
2 a group together. We don't want language to become
3 divisive between patients and healthcare professionals
4 and researchers.
5 And there wasn't any new science that led to that
6 definition. I think that would be a different scenario.
7 But I think any terms going forward need to be jointly
8 agreed by all the stakeholders.
9 **Q.** If we can just return to the NICE page here. The
10 paragraph below the one we've just read together says
11 this:
12 "In addition to the clinical case definitions,
13 the term 'long COVID' is commonly used to describe
14 signs and symptoms that continue or develop after
15 acute COVID-19. It includes both ongoing symptomatic
16 COVID-19 (from 4 to 12 weeks) and post-COVID-19
17 syndrome (12 weeks or more)."
18 Do you find this use of the phrase or the term
19 "Long Covid" a helpful one or not?
20 **PROFESSOR EVANS:** I think so. I think it's the term that
21 most people understand and understand what is being
22 described, both patients and healthcare professionals --
23 and researchers and now the media.
24 **Q.** Next, please, this. The Inquiry has heard
25 Professor Whitty use the phrase "if you don't get Covid

1 you don't get Long Covid", but what, if anything, does
2 the severity of someone's acute Covid infection tell us
3 about (a) the likelihood they will develop Long Covid or
4 (b) if they do, how severe their Long Covid symptoms
5 will be?
6 **PROFESSOR EVANS:** Okay I'm going to answer that question in
7 two parts because it is quite nuanced.
8 If we're talking about cohorts of people, you
9 are -- there's a greater likelihood of getting
10 Long Covid if you have a more severe acute infection.
11 And in a cohort there would be more chance of
12 having severe ongoing sequelae Long Covid according to
13 how severe the infection is. However, it's really
14 important for everyone to understand that somebody can
15 have a very mild infection, in fact sometimes even be
16 asymptomatic, and (a) still get Long Covid and have very
17 severe Long Covid.
18 **Q.** You say it's really important for everyone to understand
19 that. Do you say that because there is evidence,
20 anecdotally perhaps or otherwise, that that for a time
21 was not understood?
22 **PROFESSOR EVANS:** I think that's correct in the first
23 few months of the pandemic and actually people with the
24 lived experience of not being hospitalised and
25 developing Long Covid very clearly articulate this

1 issue, that the post-Covid sequelae in Long Covid was
2 mainly, to begin with, studied and clinical care
3 directed towards the awful illness that people were
4 experiencing where they were hospitalised with severe
5 lung injury, and healthcare and focus was very
6 concentrated on that. As it should have been, but there
7 should have been more understanding research and
8 clinical care looking into those that were developing it
9 in the community.
10 **Q.** Next, can we think about someone's characteristics. Are
11 we able to identify the characteristics that increase
12 the chances of someone developing Long Covid?
13 **PROFESSOR EVANS:** Yes, absolutely.
14 The scientific evidence now is very strong, but
15 again I give the answer in two parts, that there are
16 risk factors for getting Long Covid. So we've already
17 discussed one: the severity of the acute illness. Being
18 around middle age, being female, having a higher body
19 mass index, somebody with pre-existing co-existing
20 conditions and those from lower socioeconomic status,
21 all have been shown consistently in many research
22 studies to have a higher likelihood of getting
23 Long Covid.
24 But I think there has been a new definition of
25 Long Covid this year that was published in one of the

1 very high-impact medical journals, and I think one of
2 the most helpful things that that statement made was
3 that anyone is at risk of getting Long Covid. And that
4 is absolutely true. From children to older adults,
5 across different sexes, gender, different geography,
6 different socioeconomic status, everybody is at risk if
7 you've had Covid.
8 **Q.** Do the same characteristics that you listed in your
9 answer increase the chances of someone developing a more
10 severe form of Long Covid as well?
11 **PROFESSOR EVANS:** Yes. And again this was shown early on
12 from the research studies, that, again, people of middle
13 age, females, higher body mass index and more
14 pre-existing long-term conditions were more likely to
15 get severe Long Covid.
16 **Q.** Is there evidence that healthcare workers as a cohort
17 were at a higher risk of developing Long Covid during
18 the pandemic?
19 **PROFESSOR EVANS:** In relation to the fact that they were at
20 higher risk of contracting Covid-19 during 2020, and
21 certainly during that lockdown period when everyone else
22 was isolated, they were much higher risk of developing
23 Covid-19 and therefore higher risk of developing
24 Long Covid.
25 And particularly in that time, just to take us all

1 back, we weren't -- there were no vaccinations. So for
2 most of 2020 if you were contracting Covid-19 it was the
3 wild-type virus and pre-vaccination, so a much higher
4 chance of developing Long Covid than now.
5 **Q.** Next, some figures, please. Approximately how many
6 people in the UK are currently suffering with
7 Long Covid?
8 **PROFESSOR EVANS:** The caveat to what I'm about to say, which
9 I know we're going to come on to at other points, is
10 around data and the diagnosis of Long Covid on
11 healthcare records.
12 Our best UK data comes from the Office of National
13 Statistics and they published another report earlier
14 this year showing an estimated 2 million people are
15 still living with Long Covid.
16 And some really important statistics -- that's the
17 same number as we had in 2023, so 2 million.
18 Some important statistics to highlight on that
19 would be at least a million of those have been living
20 with this, as we heard from Nicola, this very difficult
21 illness, for at least two years. So it's really showing
22 that for a large proportion of people it's not going
23 away.
24 There are some people that have recovered but
25 there are also at least -- I think it was half a million

1 that developed that since 2023, so there are new cases.
2 And a question that I'm often asked is: well, is
3 it just a problem from 2020 or are you still seeing new
4 cases in the clinic? And very tragically, we are still
5 seeing new cases in the clinic, and the ONS data
6 highlight that.
7 **Q.** To put those figures into perspective, are you able to
8 give examples of chronic illnesses that have a similar
9 prevalence?
10 **PROFESSOR EVANS:** Absolutely. So both Chris and I are in
11 clinical care, we're lung doctors, and we look after
12 people with chronic lung disease, and one chronic lung
13 disease called COPD, there's at least 1 million people
14 in the UK living with that condition and probably many
15 more where it's not been diagnosed.
16 Heart failure, very common long-term condition
17 where the heart is not working properly. At least
18 1 million of those.
19 So even just combining our commonest chronic or
20 long-term heart and lung conditions is very similar to
21 the prevalence that we're seeing of Long Covid.
22 **Q.** With that context, are you able to comment on the
23 scepticism that those suffering from Long Covid have
24 faced when seeking a diagnosis?
25 **PROFESSOR EVANS:** Yeah, it's heartbreaking to hear but you

1 heard from Nicola her experience, as a healthcare
2 professional, and the qualitative studies where people
3 living with this illness have been interviewed, and
4 there's been many of them now, so it's not just one or
5 two anecdotes, sadly, that people have faced scepticism
6 both in the public and through their healthcare
7 contacts.
8 And it's --
9 **LADY HALLETT:** Can I just -- sorry, finish your answer and
10 I'll ask a question.
11 **PROFESSOR EVANS:** I was going to add: and that's deeply
12 unscientific.
13 **LADY HALLETT:** That may lead into my question.
14 I think I've been told, maybe by you in the past,
15 that it's well-known for a virus to have sequelae, and
16 therefore why would medical health professionals not be
17 ready for Long Covid, if you see what I mean?
18 **PROFESSOR EVANS:** Yes, and I think it's a really important
19 question that actually this whole area has been
20 under-researched and underinvested for clinical care for
21 decades. But you're right, the post-viral syndromes are
22 well-known about and there are experts in that area.
23 **PROFESSOR BRIGHTLING:** If I may add to that, I mean, you're
24 absolutely right that people should have been prepared.
25 So one of the first things that we and other colleagues

1 did very early on in the pandemic is highlight that it
2 was quite likely that there would be consequences that
3 then were sustained after the acute infection and that
4 was very much the driver for us to then seek early
5 research funding. So I think it was clear but it didn't
6 seem to have the same priority early on, and the
7 scepticism that you were asking about is clearly
8 unfounded.
9 Not only have we heard testimony today and many
10 people in this room could also give similar stories, we
11 know from the epidemiology studies when you actually
12 look at people who were studied before the pandemic,
13 during and after acute infection, there was a step up in
14 symptoms in those who had Covid infection compared to
15 those who did not.
16 We know from imaging studies that there is organ
17 damage in a number of patients, this is done by
18 multi-organ magnetic resonance imaging, and we know from
19 a number of blood tests that there is evidence of
20 changes in the blood in particular around inflammation.
21 So there's overwhelming evidence that there's a change
22 in symptoms, organ damage and inflammation.
23 **MR MILLS:** Can I now ask you about symptoms. Approximately
24 how many symptoms of Long Covid have been identified?
25 **PROFESSOR EVANS:** Well over 200 is I think the largest

1 number I've seen but I expect it's even larger than that
2 and experienced in very many different ways and
3 wide-ranging which is extremely challenging for the
4 person experiencing it but does give a challenge to
5 healthcare professionals and healthcare symptoms
6 as well.
7 And although there are over 200 symptoms reported,
8 there are some that are particularly common, shall we
9 say, and fatigue, breathlessness, we heard from Nicola
10 about that back pain and pain that she'd never
11 experienced before, difficulty sleeping, there's a sort
12 of cluster of quite common symptoms and certainly as
13 a healthcare professional now, wherever somebody is
14 working they should absolutely be alert to those
15 symptoms and understand that that is really classic for
16 Long Covid, and whilst in those definitions it's really
17 important to exclude other conditions that may either be
18 contributing or causing the symptoms we can diagnose
19 Long Covid as what we would call a positive diagnosis,
20 ie a clinical diagnosis, because of the clinical
21 scenario that it's captured in, rather than -- we would
22 like to have a bio marker that tells us it is this
23 disease but at the moment clinicians can make a positive
24 diagnosis of Long Covid from the symptoms and the
25 context of the illness.

1 **Q.** What do we know about the persistence of those symptoms?
2 **PROFESSOR EVANS:** So for any individual it can be quite
3 different. For most people with Long Covid in that
4 first, maybe it's not most, but there are certainly
5 different groups of people within Long Covid.
6 So there is a group, thankfully, that do get the
7 symptoms that do seem to recover within that first year.
8 We see that clinically. The ONS data highlights it and
9 other studies have highlighted that. But then there is
10 this very large group where the symptoms, if they've
11 gone beyond a year, seem very persistent and certainly
12 Nicola described the after-effect of that.
13 And Nicola also described that it wasn't this sort
14 of linear trajectory. Now, that can be the case for
15 some people that they develop terrible symptoms at the
16 time of the illness and then over the years they seem to
17 improve a small amount. Other people really develop
18 this waxing and waning of symptoms and that's very
19 challenging to live with and, again, others here would
20 be able to describe that better than me but the
21 planning, that you don't know how you are going to be
22 one day to the next, is very difficult.
23 **Q.** Was the crash that Ms Ritchie described something you
24 recognised?
25 **PROFESSOR EVANS:** Yes. So we hear about this in clinical

1 care. Now, Nicola's was very obvious to her what had
2 happened but actually many people aren't quite so alert
3 or knowing what's happened so and that, where she
4 describes that sort of episode in September, wasn't it,
5 where everything just became awful again. Some people
6 will describe those crashes depending on what they've
7 done the day before or the day itself and they can
8 happen very frequently for some people and actually
9 probably for many people with Long Covid they develop
10 something that we term "post-exertional symptom
11 exacerbation" that occur sort of 12 to 24 hours and last
12 many, many days after a particular activity and that
13 activity doesn't have to just be a physical activity, it
14 could be concentration, it could be emotion.
15 **Q.** Professor Brightling, we may have already touched on
16 this but what can you tell us about the mechanisms of
17 Long Covid, that is the bodily processes by which
18 Long Covid physically causes the symptoms we have
19 discussed?
20 **PROFESSOR BRIGHTLING:** So we've learnt a lot over the first
21 few years since the beginning of the pandemic and no
22 doubt there's much more to learn.
23 We recognise that in some patients there's
24 evidence of viral persistence. We don't fully
25 understand how common it is. We can measure changes in

1 the immune system so we now know what type of cells are
2 activated, what pathways in the immune systems are
3 activated, and these all open up potential targets for
4 therapies.
5 We recognise that the lining of the blood vessels,
6 the endothelium is activated, and there's change in
7 organ damage in the brain and other organs.
8 We also know the nervous system that controls
9 blood pressure, temperature control, the autonomic
10 nervous system can also be disrupted, and we know, as
11 Rachael has already alluded to, that there are a number
12 of risk factors so those risk factors such as things
13 like changes in your metabolic profile, that may be
14 increased weight and obesity as an example, are things
15 that also amplify your risk of then having Long Covid
16 and can also be potential treatment targets.
17 **Q.** A new topic, please. Access to healthcare and treatment
18 for adults with Long Covid. Starting in England,
19 please, with the Your Covid Recovery website.
20 That website was perhaps, until it closed earlier
21 this year, the first port of call for many people
22 seeking help with Long Covid. In respect of the
23 information it provided about Long Covid, can you help
24 us with what the purpose of the website was and whether
25 in your view it achieved its aims?

1 **PROFESSOR EVANS:** So the website was developed early in the
2 pandemic, so it was started in May 2020, it was formally
3 released early July 2020 and the main purpose of the
4 website, Nicola talked about self-management, Nicola is
5 a physiotherapist and clearly very aware of what
6 self-management is, whereas a lot of people wouldn't
7 necessarily know how to support their own
8 self-management, and because the consequences of having
9 Covid-19 are very varied, the website was really
10 designed as a light-touch information-sharing platform
11 and really aimed at those probably at the milder end of
12 the Long Covid spectrum.
13 It was originally designed mainly to support
14 people post hospital so that they had some information
15 about the symptoms as they left hospital and continued
16 to recover, hence the name.
17 What it wasn't set up to do and what it never
18 could do was provide complex management advice for
19 somebody like Nicola that we heard where she had very
20 complex symptoms, very severe impact where you really
21 need healthcare professionals and to work with you one
22 to one.
23 **Q.** Next, Long Covid clinics.
24 An introduction to them, please, if you would.
25 How does someone access them and what do they offer to

1 an individual with Long Covid?
2 **PROFESSOR EVANS:** So the Long Covid clinics in England
3 started really through the post-hospital route and
4 originally were set up on the ground by respiratory lung
5 teams, trying to support the people that were coming out
6 of the hospital after having that lung injury. The --
7 NHS England came together to develop a task force in
8 October 2020, and quite a few of those clinics it had
9 already started were then part of the 70 clinics that
10 were funded from 2020.
11 As far as accessing them and what they should
12 provide, there is an NHS England service specification,
13 very much advocating a tiered approach, so depending on
14 the needs of the individual, the healthcare request
15 should match it. So for milder Long Covid, sometimes
16 self-management support, the use of a website, online
17 platforms may be appropriate.
18 For people with much more complex needs there
19 really should be available, people with -- healthcare
20 professionals with expertise in Long Covid,
21 a multi-disciplinary team meaning doctors, nurses,
22 occupational therapists, physiotherapists, that's not
23 all encompassing there are many different healthcare
24 professionals that we need, and also a key bit is it
25 needs to be interspeciality.

1 We heard that there are 200-plus symptoms. We
2 cannot and mustn't send poor individual people to 200
3 different specialists. For those symptoms that
4 I mentioned, if we think about pain you might need to
5 see a rheumatologist; problems with memory, problems
6 with concentration, you may need to see a neurologist.
7 Chest pain, you might get sent to a cardiologist,
8 breathlessness gets sent to a lung physician and it goes
9 on and on.
10 So these Long Covid clinics must have a meeting
11 where you've got the expertise of all these different
12 professionals. Certainly in our clinic and in some
13 others we do this with a virtual team meeting. So the
14 individual person with Long Covid comes to see
15 an individual clinician. That is the partnership. And
16 then you bring in that extra expertise that you need
17 through virtual meetings, and so that we're not sending
18 people for multiple appointments.
19 **Q.** The 70 clinics that were in place by I think you said
20 the end of 2020, is it possible to say how many of those
21 are operating now?
22 **PROFESSOR EVANS:** So the number increased to 100 at some
23 point. I think that was in 2021, the peak. I don't
24 know the exact number now because the Long Covid task
25 force has finished, but I do know that some have very

1 sadly stopped altogether, others have got embedded
2 within the integrated care systems, within care for
3 other long-term conditions, and there probably are few
4 that are really running as the NHS England service
5 specification suggests.
6 **Q.** Generally speaking, would someone be referred to
7 a Long Covid clinic by their GP?
8 **PROFESSOR EVANS:** Yes, which is the same route to specialist
9 care for any long-term condition and there usually are
10 multiple things that GPs and primary care can help with
11 and should help with first, and then refer on to the
12 specialist as needed.
13 **Q.** I wonder if we could have on screen, please,
14 INQ000492271.
15 These are the results of a survey conducted by the
16 Royal College of General Practitioners between August
17 and September 2020. In response to question 8, we find
18 that 51% were not very, and 14% not at all confident in
19 treating patients with Long Covid symptoms at that time.
20 Do these results to you suggest that in those
21 early stages of Long Covid clinics, the end of 2020,
22 there may have been a lack of uniformity in the approach
23 of GPs to making referrals to those clinics?
24 **PROFESSOR EVANS:** Yes, and I think we've heard that in the
25 experience of people living with this condition. And

1 I think it's very challenging for primary care,
2 you know, they have a huge amount that they're expected
3 to do. I think that 65% that were not feeling confident
4 we need to absolutely support and I think that's where
5 some of the issues that people have described, accessing
6 healthcare and sometimes hearing the scepticism about
7 what, you know -- what they actually have, if people are
8 not aware of Long Covid and not aware how to treat it
9 you can see how that will -- how that happens. And
10 then, absolutely, if you're not aware of a condition and
11 you're not aware of what support there is, then the
12 referrals, yeah, won't happen basically.
13 And there's also a responsibility of those working
14 in the Long Covid services to, you know, one of the key
15 things of why also you would want a Long Covid
16 specialist and clinic is so that you can outreach and
17 help and support primary care and make your service well
18 known.
19 **Q.** That certainly sounds like a recommendation for how
20 a more consistent approach to referrals might be
21 achieved.
22 Is there anything else you would like to see to
23 ensure a consistent approach to referrals?
24 **PROFESSOR EVANS:** I can't think off the top of my head,
25 sorry.

1 **Q.** Not at all.
2 Is patient self-referral an option to consider
3 here?
4 **PROFESSOR EVANS:** I think the healthcare service needs to
5 start thinking about this for all long-term conditions
6 but, as I said, primary care really do have a valuable
7 role and I suppose I would not want to see that missed,
8 because actually then other problems can happen because
9 there are things that primary care do really well that
10 specialists don't.
11 When you hear how difficult certain people have
12 found it to access healthcare you can understand -- and
13 specialist care -- why they are advocating, you know, if
14 I know I've got Long Covid and if primary care feel that
15 they can't do any more for me I want to be able to
16 access the specialist clinic, but I think we would have
17 to be, yeah, very careful on how that was implemented in
18 future. It needs a lot of thought and really working
19 closely with both people living with the condition,
20 healthcare professionals and the organisations.
21 **Q.** At your paragraph 78 you refer to NHS England providing
22 funding to primary care for the "Long Covid Enhanced
23 service". Could you tell us a little bit about that,
24 please.
25 **PROFESSOR EVANS:** Yes, it was supposed to really be to

1 develop Long Covid champions, to really do that role
2 I was discussing where you've got a link with
3 a Long Covid specialist service, but also then can
4 upscale and promote the Long Covid service within
5 primary care and also ensure that, on the ground, GPs
6 are trained in this new condition so that they know
7 about it and know how to refer.
8 **Q.** Are you able to comment on the extent to which that has
9 been a success?
10 **PROFESSOR EVANS:** I don't think we have that data to know
11 exactly what -- we know that -- whether GPs accessed it,
12 and there were a few criteria that they had to check,
13 but I don't think we really know the impact of that.
14 **MR MILLS:** My Lady, I'm about to move on to a new topic.
15 I wonder whether that might be lunch?
16 **LADY HALLETT:** Certainly.
17 You remember we have breaks; we certainly have
18 a lunch break, as you'd expect. So, I shall return
19 at 1.40.
20 **(12.38 pm)**
21 **(The short adjournment)**
22 **(1.40 pm)**
23 **LADY HALLETT:** Mr Mills.
24 **MR MILLS:** Professors, can we next look at the issue of
25 training. Is there specific training for healthcare

1 professionals working in Long Covid services?
2 **PROFESSOR EVANS:** There's been education fact packages
3 written for primary care from the Royal College of
4 General Practitioners. Most of us, as I was explaining,
5 sort of started off from the respiratory, the lung side
6 because of the follow-on from hospital admissions.
7 So at the moment there's no formal training,
8 you know, if you're going to medical school through to
9 junior doctors you won't do a section in post-viral
10 syndromes or Long Covid and we're not -- and
11 particularly if the Long Covid clinics are reducing,
12 actually we're going to have even less people with the
13 expertise in Long Covid to actually help support that
14 training.
15 **Q.** As well as that do we also see a variation in the type
16 of clinicians delivering these services?
17 **PROFESSOR EVANS:** Yes, there's a huge variety, from people
18 like myself as a lung physician to people from
19 infectious diseases, where they have looked after people
20 with post-viral syndromes before, to general
21 practitioners who specialise in fatigue. There are some
22 services where there aren't any physicians involved, so
23 that multi-disciplinary team is the allied health
24 professionals and the nurses without the medical
25 support.

1 **Q.** So if we take these points together, different training
2 potentially, and different clinicians, is this a recipe
3 for variations in approach?
4 **PROFESSOR EVANS:** There will be variations in approach.
5 I think I would be less concerned about the background
6 of the person delivering a service as long as they have
7 got the skill set to be able to deliver the service and
8 I think going forward we definitely need to think about
9 that more carefully and plan for that.
10 **Q.** At paragraph 35 of your report you describe that there
11 was initial consternation on the part of clinicians that
12 in October 2020, as we've discussed, Long Covid clinics
13 were set up but not rehabilitation services. Can you
14 help us with the reasons for that consternation?
15 **PROFESSOR EVANS:** Yes, so if you're -- and there is value
16 from meeting a healthcare professional, hearing about
17 what your symptoms might mean, validating those
18 symptoms, having an empathetic response. We've seen in
19 the qualitative evidence that that's very important, but
20 ultimately people want something that's going to help
21 them, and those non-pharmacological strategies including
22 rehabilitation are really important. So as somebody
23 leading a service if you didn't feel you had the
24 interventions to then support after your assessment you
25 definitely felt that that was going to be sub-optimal.

1 **Q.** And we'll come on later to think about some of the
2 rehabilitation services that we have.
3 Before I move on, can I ask you this finally about
4 referrals. At paragraph 37 of your report you record
5 that at the time of writing following approximately
6 125,000 referrals, 113,000 patients have been assessed
7 by a specialist Long Covid service. To what extent are
8 the two of you encouraged by these figures?
9 **PROFESSOR EVANS:** So I'm encouraged that people have been
10 seen and there are Long Covid clinics but I think -- and
11 I'm certainly not going to infer that all 2 million
12 people that are living with Long Covid need to see
13 a Long Covid specialist, but I would have thought that
14 the 100,000 that have is leaving a big gap of people
15 that are experiencing very difficult symptoms that are
16 impacting on every facet of their life and not getting
17 the support that they need.
18 **Q.** Professor Brightling, do you tend to agree?
19 **PROFESSOR BRIGHTLING:** I think it's a good start
20 an encouraging start and if we had confidence that the
21 clinical service was now beginning to expand and
22 accelerate then I'd be very pleased with those figures.
23 What you've already heard from Rachael is a number of
24 the services are already under threat. There's likely
25 to be a shrinking of the clinical service next year.

1 The service is not the same across the four nations from
2 the get-go and are very different now and this has
3 enormous impact then on training as you've alluded to
4 and also research which needs to be integrated into
5 clinical care. So the clinics have to be the foundation
6 of then actually being able to find solutions for people
7 with Long Covid.
8 **Q.** Can we move to Wales. Is it right, by way of summary,
9 that the Welsh approach has not been to establish
10 specialised Long Covid clinics but instead to deliver
11 Long Covid services through primary care?
12 **PROFESSOR BRIGHTLING:** That's correct. So in the summer of
13 2021, the plan was to fund a primary care network at the
14 cost then of -- funding of £5 million and that then
15 included therapists and primary care physicians but if
16 you needed to then refer on, you were referring on to
17 a whole variety of different organ specialties.
18 That funding was then renewed for a further year
19 and then the funding is being continued but the funding
20 is now being taken into support for long-term conditions
21 in general, so there isn't a specific pot nor the
22 service exclusively for Long Covid.
23 **Q.** In your view are there any advantages to the Welsh
24 approach?
25 **PROFESSOR BRIGHTLING:** So it's clearly correct to be able to

1 offer help and support within the community but by
2 having the support exclusively in the community and then
3 to have this very disconnected secondary care support
4 has a number of disadvantages. It has a disadvantage to
5 the patient in terms of being able to have a one-stop
6 clinic and being able to get the best services as
7 quickly as possible.
8 It then has implications for training because
9 there then isn't a group of specialists that are then
10 actually evolving the subject area and it also then
11 becomes a barrier for research and taking things forward
12 because you then don't have a base in which to then be
13 able to look for new diagnostics, new disease
14 understanding and new therapies.
15 **Q.** If we have in our minds perhaps the gold standard, do we
16 need both specialised Long Covid clinics and the
17 appropriate training within primary care to make sure
18 people are referred to them?
19 **PROFESSOR BRIGHTLING:** The simple answer is, yes, but
20 I would suggest that we can compare this with some of
21 the other disease areas. You asked us very early on to
22 think about the relative prevalence of Long Covid
23 compared to other chronic conditions and Rachael
24 referred to chronic obstructive pulmonary disease and
25 heart failure which are very common respiratory and

1 cardiac diseases, with a very similar prevalence of 1 to
2 2 million.
3 If you think of heart failure as an example, the
4 British cardiology society and the British Heart
5 Foundation did a recent survey so there's around about
6 1,700 consultant cardiologists in the country and of
7 those about 1 in 8 consider themselves primarily as
8 heart failure specialists. So that's over 200 heart
9 failure specialists.
10 If you think of full-time equivalents of doctors
11 that would then say our primary role is actually being
12 a Long Covid specialist, then that really is down to
13 single figures or even only ten or so.
14 So the contrast is if you were going to put people
15 on to a double-decker bus in central London you'd need
16 probably three double-decker buses for the heart failure
17 specialists whereas if you had a people carrier or
18 a small minibus you'd probably have room to spare if you
19 were to then fill them with people with Long Covid
20 specialism. So there's an enormous contrast between
21 the two.
22 **Q.** At your paragraph 77 you observe that services differ
23 between the seven health boards in Wales in terms of
24 staff composition, durations and types of intervention.
25 I wonder, what are your views on that level of

1 variation?
2 PROFESSOR BRIGHTLING: I think that's actually probably also
3 an understatement because, as I've said, now the care
4 has moved away from the Long Covid services into
5 long-term disease clinics. So it's likely that there's
6 probably even more variation in terms of the type of
7 care.
8 I think it's a disservice to the patients because
9 clearly you want that as you described earlier, that
10 multi-disciplinary team approach with that one-stop
11 clinic where patients are then able to get an early
12 diagnosis and then bespoke treatment for their own
13 problems.
14 Q. Scotland, please. How were Long Covid services
15 initially provided in Scotland?
16 PROFESSOR BRIGHTLING: So in Scotland again there was
17 a delay in setting up services. So this was really into
18 the last third of 2021. There was £10 million of
19 funding to set up those clinics. The clinics really
20 were quite challenging because the services simply
21 couldn't cope with the number of referrals, and the
22 clinics have then been disbanded as Long Covid clinics
23 and then the activities and the referrals have then been
24 taken up in a variety of long-term condition clinics
25 across the different parts of Scotland.

1 Q. Yes, at your paragraph 29 you explain that one of the
2 Long Covid services in Scotland was unable to meet
3 demand and closed after 18 months due to a lack of
4 funding.
5 Do you know whether any reason was given for the
6 lack of funding in circumstances when demand was clearly
7 high?
8 PROFESSOR BRIGHTLING: No, we don't.
9 Q. Northern Ireland. Is it right that until November 2021
10 there was no central funding for Long Covid services in
11 Northern Ireland?
12 PROFESSOR BRIGHTLING: So we're aware that the
13 Northern Ireland model, again similar to Scotland, came
14 later in terms of then setting up multi-disciplinary
15 teams. How that model was funded is something that --
16 is unclear to us and is not in the public domain.
17 Q. Are you able to help us with the position before the
18 funding was applied in November '21 how, if at all, were
19 Long Covid services developing in Northern Ireland
20 before then?
21 PROFESSOR BRIGHTLING: So obviously neither of us have any
22 direct workings in Northern Ireland but anecdotally from
23 colleagues it definitely appeared that the structures
24 were not well-formed and that it was not until those
25 multi-disciplinary teams were then created where there

1 was actually some form of Long Covid service. But like
2 all of the countries I've described, really the services
3 have not been exclusively for Long Covid in a long-term
4 nature with long-term funding.
5 Q. Can I take all that we have discussed about Long Covid
6 healthcare in adults together. The Long Covid core
7 participant group describes the provision of Long Covid
8 services across the UK as a postcode lottery. Do you
9 agree?
10 PROFESSOR BRIGHTLING: So I think they have a very -- a very
11 valid point, in that we recognise what is the right kind
12 of care model and how that's been delivered from the
13 get-go has been different across the four nations, and
14 with the clinical services even in England, which was
15 better funded, the types of services, as Rachael has
16 described, is different between different centres.
17 Q. And are you able to help the Inquiry understand the
18 consequences of that disparity for patients?
19 PROFESSOR BRIGHTLING: So I think what's worrying is not
20 just the consequences of the disparity now but the
21 likely consequences of that ever-increasing disparity as
22 we then go into next year.
23 So at the moment, then, there's differences in
24 terms of the training and confidence in primary care,
25 the referrals. There's then differences then in terms

1 of the level of care that's then done in secondary care,
2 who is delivering that, and differences across the four
3 nations, with funding, as you can hear, then decreasing.
4 The Long Covid clinics and the services are
5 largely driven by people who still have other specialist
6 roles, whether that be in respiratory, cardiology,
7 infectious diseases and others, and the pull has been
8 very much to pull many of those people back to their
9 original areas of specialty.
10 So there's real risk if you start to undermine the
11 clinics that then the whole discipline of being able to
12 look after people with Long Covid starts to become
13 undermined. And that then clearly has consequences in
14 terms of training and future research.
15 So the very strongly held view is -- from us is
16 that the clinics are really the foundation to which all
17 the other elements are also necessary but then can then
18 feed into those clinics and the clinics can then be the
19 axis as well for delivering research and training. So
20 providing those clinical services is absolutely
21 paramount.
22 Q. Long Covid SOS has described the benchmark that
23 Long Covid care should meet in the following way:
24 a one-stop shop with a mix of specialities,
25 professionals allied to healthcare and, importantly,

1 a point of contact for the patient.
2 Can I ask whether you agree with this as
3 a description and whether so far, in your view, this
4 benchmark has been met?
5 **PROFESSOR BRIGHTLING:** So I agree, and in some cases, yes,
6 but in many it's fallen short.
7 **LADY HALLETT:** Can I just ask -- I understand exactly what
8 you're saying, and supposing I were to accept your
9 opinion and make a finding and/or recommendation -- for
10 those who are of the mistaken view that Covid is over
11 and therefore we just need to get on and get people back
12 to their original specialisms, as you were saying,
13 Professor, could the clinics, if they were funded, these
14 one-stop shops, could they be used for other conditions?
15 In other words, could you persuade the money people to
16 spend the money because it's not just going to be
17 dedicated to Covid that they, as I say, mistakenly
18 believe is over?
19 **PROFESSOR BRIGHTLING:** The simple answer is yes. I'd love
20 to be of the view that Long Covid can end up being "been
21 and gone Covid", where it no longer is a concern in the
22 years to come. I think until we have new effective
23 therapies that will be some time yet.
24 **LADY HALLETT:** I understand that.
25 **PROFESSOR BRIGHTLING:** But I completely agree with the point

1 that you've made, is that there are other conditions,
2 other post-viral syndromes, so ME/CFS is an example,
3 where with you could then have services expanded in
4 those areas and then also to include services for
5 Long Covid and possibly other additions.
6 So overall these conditions are not going to go
7 away in their totality.
8 Rachael, I don't know if you wanted to add ...
9 **PROFESSOR EVANS:** Yes, so absolutely agree, and
10 unfortunately I think there is this belief that
11 Long Covid somewhere along the line is going to
12 disappear, and we've seen from ONS that is not the case.
13 You asked me earlier about post-viral syndromes.
14 This could be the proper legacy to get this right for
15 next time. If you've got these experts, you've these
16 expert clinics, then for the next viral pandemic you may
17 need to bring in other specialists, it may look
18 different, but at least you've not lost that core
19 knowledge from this. And that's really vital.
20 **MR MILLS:** And on that core knowledge, do we now have
21 evidence that Long Covid clinics are both clinically and
22 cost effective?
23 **PROFESSOR EVANS:** Absolutely. I want to put one further
24 caveat to the "one-stop shop", because we're -- I think
25 Long Covid SOS, and certainly my interpretation, is

1 meaning for that assessment that we're not spreading
2 specialists, but definitely there needs ongoing support
3 and ongoing care, just like for any other long-term
4 condition.
5 Those clinics, if they have complex diagnostics,
6 complex assessment, complex interventions that are
7 personalised, we've shown data that shows that they are
8 clinically effective and cost effective.
9 And as Chris has highlighted, there's a whole
10 other reason for needing those clinics for research
11 training and for future pandemics.
12 **Q.** New topic, please, access to healthcare and treatment
13 for children with Long Covid.
14 Can Long Covid present differently in children and
15 young people compared to adults?
16 **PROFESSOR BRIGHTLING:** So, first of all, neither of us
17 are paediatricians. So we've been very fortunate to be
18 able to work closely with paediatricians and some of the
19 text within our report is then from discussions with
20 paediatricians.
21 So the main symptom clusters are very similar.
22 There are some additional syndromes that occur in
23 children but many of the things that you are concerned
24 about in adults are also relevant to children and young
25 people.

1 **Q.** As far as you are aware, are there any dedicated
2 services for children and young people with Long Covid
3 in Wales, Scotland or Northern Ireland?
4 **PROFESSOR BRIGHTLING:** Not as far as we are aware.
5 **Q.** Again, as far as you are aware have attempts been made
6 in these countries to introduce such services?
7 **PROFESSOR BRIGHTLING:** They may have been but not as far as
8 we're aware.
9 **PROFESSOR EVANS:** Yeah, I think there was concern around the
10 lack of volume of patients to require dedicated clinics.
11 I'm not saying this is my belief, I'm just saying that's
12 what was postulated and therefore it was felt that the
13 people -- children and young people with Long Covid
14 could be dealt with paediatric services in specialist
15 care.
16 **Q.** If we consider the position in England then, can you
17 help us, how have Long Covid services for children and
18 young people developed?
19 **PROFESSOR EVANS:** So it was slower than for adults. So just
20 like we were hearing there were delays in understanding
21 and delivering healthcare for adults with Long Covid,
22 there was even more delay for children and young people.
23 Eventually there were 15 clinics set up, and I think
24 this was largely due to the enthusiasm for one site in
25 London that really did lead this and then NHS England

1 supported delivering 15 clinics.
2 I think that's the maximum clinics that we've ever
3 had and I think there are, again, at least some of those
4 that have since closed.
5 **Q.** You describe in your report that those clinics utilised
6 a hub-and-spoke model. Can you help us with how that
7 model operates and what the advantages are of it?
8 **PROFESSOR EVANS:** Yes, so I think, similar to the concerns
9 from the other nations about the volume and the number
10 of clinics needed, it was felt to have these specialist
11 clinics, where you can really get the specialist
12 knowledge, the specialist teams, and then they would
13 actually then be a sort of port of call for other
14 paediatric services to get advice. And certainly the
15 virtual MDTs again were open to other clinics, is my
16 understanding of how that worked.
17 **Q.** Are there any inequalities in accessing these hubs that
18 had been identified?
19 **A.** Well, as we've heard from adults that struggled to get
20 access to healthcare for Long Covid, the same if not
21 worse is mirrored in the literature for children trying
22 to -- with adults -- with their parents, trying to seek
23 healthcare, where apparently it was very difficult.
24 **Q.** Can we move now to consider research into Long Covid
25 treatments. Starting with the funding position. By way

1 of headline, at paragraph 10 you explain that at the
2 time of writing your report more than £50 million had
3 been invested in Long Covid research projects in the UK,
4 but -- and this is at your paragraph 114 -- dedicated
5 funding for Long Covid ceased after February 2021. Is
6 that a fair summary of the position?
7 **PROFESSOR BRIGHTLING:** It is.
8 The UK should be very proud of the research that
9 it's done with acute Covid, and with Long Covid research
10 the funding in the UK, and importantly the discoveries
11 that were made in the UK, have really been
12 world leading. So right at the very beginning of the
13 early period post pandemic the UK had actually performed
14 very well, and the early funding of that 50 million
15 supported 19 projects through a core as well as some
16 additional projects that were really looking across the
17 breadth of Long Covid. So we started well.
18 **Q.** We started well and then what happened?
19 **PROFESSOR BRIGHTLING:** So the challenge to me really is that
20 the problem has actually continued, such that you then
21 need to have further understanding around mechanisms,
22 around potential diagnostics, so leading you on to
23 treatments. And other countries have recognised this.
24 So in contrast to the UK, where the funding was very
25 much front-loaded and, as you said, has then largely

1 ceased, about 18 months ago, that other countries really
2 then picked up. So in Australia there was
3 AUS$50 million put into Long Covid research just over
4 a year ago. There's been now in excess of
5 100 million euros within Europe to fund a series of
6 projects. And then from the US, which has really by far
7 exceeded everyone else in terms of funding, has
8 allocated over $1 billion in research funding for
9 Long Covid.
10 So the way I view this is, really, the research
11 for Long Covid is very much a marathon and the UK has
12 won the first 400 metres but has now paused.
13 **LADY HALLETT:** Can I just check a date. I think Mr Mills
14 may have put to you funding ended February '21'. Was it
15 in fact February '23 because you just said 18 months
16 ago?
17 **PROFESSOR BRIGHTLING:** So the last funding call was
18 in '21 --
19 **LADY HALLETT:** Right.
20 **PROFESSOR BRIGHTLING:** -- but some of the funding hasn't
21 been increased but been extended. So, for example, the
22 funding for the consortium that we lead, PHOSP-COVID,
23 has been extended through to 2026 but not the -- but the
24 original funding was right back in 2020.
25 **LADY HALLETT:** What I wrote down, and it just may be

1 I misunderstood the question so I just need to -- so
2 initially -- so at the time of writing the report,
3 I wrote down, over £50 million invested in research.
4 What I then wrote down and it may be this is where I got
5 it wrong, but ended in February '21.
6 **MR MILLS:** If it helps, Professor, I'm at your
7 paragraph 114.
8 **LADY HALLETT:** Thank you, that might help me.
9 **MR MILLS:** Last sentence:
10 "Despite this, dedicated research funding for
11 Long Covid ceased after February 2021 ..."
12 **PROFESSOR BRIGHTLING:** So the last call was July 2021 which
13 was the last funding round which was then -- the funding
14 before that was February 2021, so it's July, so then
15 looking at section 9, this is where it's correct, if
16 that's a misrepresentation in that sentence. So the
17 funding that then came through from NIHR to fund 15 new
18 Long Covid projects was July 2021.
19 **MR MILLS:** I see.
20 **LADY HALLETT:** Sorry, it's me. I mean, "funding ended"
21 sounds like no more funds after February '21 but that's
22 not what you say.
23 **PROFESSOR BRIGHTLING:** No, that's the award.
24 **LADY HALLETT:** That's the award.
25 So no more awards after February '21?

1 **PROFESSOR BRIGHTLING:** Correct.
2 **LADY HALLETT:** But the awards that had been made up
3 to February '21 could then be drawn on thereafter?
4 **PROFESSOR BRIGHTLING:** Correct.
5 **LADY HALLETT:** Sorry, you wanted to add something,
6 Professor.
7 **PROFESSOR EVANS:** I was just going to add that there were
8 just very small amounts that were given to certain
9 studies for legacy funding, as Chris was staying for
10 PHOSP-COVID, but it was very small. So the two calls
11 were announced November 2021 and February 2021, they
12 were the 50 million.
13 **LADY HALLETT:** And they are then there for people to draw on
14 when they --
15 **PROFESSOR BRIGHTLING:** So typically the funding periods
16 would have been for two or three years.
17 **LADY HALLETT:** Right.
18 You're obviously used to all this funding, sorry.
19 Mr Mills, sorry to interrupt, I just wanted to
20 make sure I got my facts straight.
21 **MR MILLS:** Not at all, my Lady.
22 Can we think about pharmaceutical treatments. Are
23 you able to share today any results we have from
24 clinical trials of pharmaceutical interventions for
25 Long Covid?

1 **PROFESSOR BRIGHTLING:** So if we think about the trials that
2 have really focused on this. So in the UK it's been the
3 STIMULATE-ICP study which is not yet reported. So they
4 have focused on really three avenues. So one is trying
5 to tackle the problems with the autonomic dysfunction
6 with antihistamines with the activation of the lining of
7 blood vessels with the anti-clotting agent and then also
8 an anti-inflammatory, colchicine, but that's not yet
9 reported.
10 In the US trials there were a combination of
11 drugs/pharmacological and non-drug/non-pharmacological
12 trials and with those they've been looking at the viral
13 persistence with Paxlovid. Importantly, Paxlovid really
14 focuses on replicating virus, so if you have a reservoir
15 of virus then treating it with Paxlovid may be less
16 effective than some other antiviral approaches. And
17 I think even if that reported as negative, it still
18 wouldn't exclude that as a possibility.
19 They're also then looking at drug interventions to
20 try and then modify sleep.
21 There have been a number of small study which have
22 then been encouraging to then be able to take on larger
23 interventions but none of those have reported in
24 sufficient numbers to yet have therapies that are
25 licensed for Long Covid.

1 One of the most promising approaches is also to
2 think about what I would describe as a precision
3 medicine approach and what I mean by that is if you can
4 identify the underlying mechanism that's driving
5 Long Covid with an individual, you can then have a test
6 that can identify that individual and then a treatment
7 that then can then target that particular mechanism.
8 And one of the ways of doing that is to then think
9 about: is there viral persistence, are there particular
10 inflammatory pathways, are there then problems about
11 autonomic dysfunction, problems about the risk factors
12 and you can identify individual tests that map on to
13 each of those.
14 One such study that's taken that approach is then
15 targeting a particular inflammatory substance called
16 IL-6 which was found to be really important in acute
17 Covid and you can target that with an injection
18 treatment and that's a study called PHOSP-I that Rachael
19 is leading on and may wish to comment on as well.
20 **PROFESSOR EVANS:** Yes, the PHOSP-I study we started earlier
21 this year -- I'm trying to think of the date then, and
22 we're still in the recruitment phase at the moment, and
23 to really highlight what we've really needed is those
24 Long Covid clinics that are specialist clinics to get
25 the right patients and to be able to have those linked

1 with a research centre that is capable of delivering
2 a very difficult experimental medicine trial. So it's
3 a really good example of what we were trying to state
4 yesterday -- it feels like yesterday -- earlier this
5 morning, sorry, about the need for the Long Covid
6 clinics because it's been absolutely essential to
7 deliver the trial.
8 **Q.** Moving on to non-drug treatments then.
9 At paragraph 63 of your report you observed that
10 there are tensions around the use of physical activity
11 in Long Covid rehabilitation programmes. Could you tell
12 us about that, please?
13 **PROFESSOR EVANS:** Absolutely. And it speaks really to what
14 we have as a fairly simple definition of Long Covid
15 whereas it really is a very complex condition and it is
16 made up of lots of different types of condition with
17 different types of symptoms and just like Chris was
18 highlighting the need for a precision medicine approach
19 for medication trials, the same is very likely to be
20 needed for trials of rehabilitation.
21 So the tensions around physical activity is that
22 for any of us we need to be physically active, that's
23 good for long-term health, it prevents the development
24 of long-term conditions. So all of us need to be
25 physically active. Of course, Long Covid with the

1 fatigue and all these difficult symptoms impair physical
2 activity.
3 The rehabilitation interventions are really for
4 healthcare professionals and the people living with
5 Long Covid to work together to try to improve physical
6 activity with the aim of improving symptoms. For many
7 people that's a very successful approach. But there is
8 this subgroup of people with Long Covid with this really
9 challenging symptom of post-exertional symptom
10 exacerbation where we really have to be careful.
11 That doesn't mean that we don't deliver any
12 rehabilitation but it has to be personalised, it has to
13 be at the right time and I don't think we know that for
14 everyone at the moment. When somebody has got that
15 really fulminant fatigue they can't even really move
16 around the house, they're getting crashes, that's not
17 the right time for these interventions.
18 So, it has to be, at the moment, very individually
19 judged and we would like to get to the point where we've
20 got research trials that really highlight who and how we
21 should do this.
22 So the tensions are that we've got this very
23 careful balance between all of us wanting to improve
24 physical activity but how do you do it and it's this
25 balance between pacing, and actually then progressing

1 what someone is doing and that has to be incredibly
2 carefully done with experts.
3 **Q.** I wonder, could I ask you to just introduce us to the
4 concept of pacing for managing someone's Long Covid
5 symptoms?
6 **PROFESSOR EVANS:** Yes, and this is a technique that's been
7 used for decades in other long-term conditions and in
8 other post-viral syndromes, so it's been used in HIV in
9 particular. The aim is to understand that everyone's
10 got a certain amount of energy and this becomes very
11 clear in Long Covid and that energy is -- can be used in
12 a physical task, an emotional task or a concentration
13 task.
14 So pacing is how to use the energy for things that
15 people want to do, or have to do, but then to almost get
16 some rest back to reset and not trigger that fatigue.
17 **Q.** Can you tell us about any other rehabilitation
18 interventions that are currently being used or being
19 considered for use?
20 **PROFESSOR EVANS:** Yes, so rehabilitation is an incredibly
21 broad term and I was talking earlier really about
22 exercised-based or physical activity-based
23 interventions. So there are a number of randomised
24 trials now that have read out this year that overall
25 give very positive results of the type of programme

1 where you have this close working with the healthcare
2 professional and the person, and then progress the
3 physical activity and symptom management as you go
4 through the course in a personalised way.
5 Other interventions that are being used are pacing
6 and also with a little bit of progression those trials
7 are still ongoing. As trials of breathing techniques
8 and respiratory muscle training they've also shown
9 promise. So there's a number of trials that are ongoing
10 at the moment. Some have finished with positive results
11 and some are ongoing.
12 **Q.** Is there a trial also around sleep?
13 **PROFESSOR BRIGHTLING:** If I can comment on that.
14 So the NIH Recover, so this is in that very large
15 funding tranche in the United States, they then have
16 both pharmacological and non-pharmacological
17 interventions for sleep. So it includes drug
18 interventions such as melatonin to try and then reset
19 the body's clock and also then cognitive behavioural
20 type interventions.
21 There's also within the NHS, Sleepio, which can
22 also be accessed as a cognitive behavioural tool for
23 then trying to manage sleep.
24 **Q.** If we take everything we have discussed about this topic
25 together are there any areas of research focus you would

1 recommend today to advance the treatment of Long Covid?
2 **PROFESSOR BRIGHTLING:** So I think what we really need to
3 have is a group of platform trials. So what I mean by
4 that is the STIMULATE-ICP was focusing on repurposing
5 therapies that are already available for other
6 treatments and are largely low cost. But we recognise
7 that there may be a need to have more specific therapies
8 for certain types of changes particularly changes in the
9 immune system that we are now recognising in subgroups
10 of people with Long Covid.
11 So to do that you need a trial that's established
12 where you have common entry into the trial, common
13 outputs in terms of then the way we measure how well
14 somebody has done and then individual arms so that you
15 then identify the patient that is likely to respond to
16 an intervention and then put them into a trial where
17 it's tested against a placebo, so a randomised control
18 trial but within a platform.
19 And one of the things that we will be trying to
20 seek is support from NIHR and UKRI. We had asked for
21 support for a platform trial now a couple of years ago
22 but things have really moved on in terms of our
23 understanding in the science and what end points to
24 have, so we shall be asking again for support for such
25 a trial.

1 The arms themselves may need support from industry
2 as well, and when I've had discussions with industry
3 some of the companies are still looking to support
4 trials within Long Covid. But the story in industry is
5 very similar to the story we were telling around the
6 clinics in that during the pandemic there were Covid
7 groups that were formed in most major pharmaceutical
8 companies that were interested in both acute Covid but
9 were also thinking about therapeutics for Long Covid and
10 those groups have almost entirely now been disbanded and
11 gone back to their individual therapeutic disease areas,
12 so actually getting support from companies is also
13 challenging.
14 We have had some traction and I think we are in
15 a position soon to then be able to go back to government
16 funding through NIHR and UKRI for such a trial which
17 would complement the activity that then is being through
18 STIMULATE-ICP and complement the non-pharmacological
19 interventions that we've just been discussing.
20 **Q.** New topic, please, Long Covid treatment and health
21 inequalities. Before we consider what you are able to
22 say about inequalities in Long Covid treatment, can
23 I perhaps invite you to set out the factors that limit
24 our current understanding of this area?
25 **PROFESSOR EVANS:** Yes, I think one of the major if not the

1 limitation is data, and that data being from routine
2 clinical healthcare records. We rely on that a great
3 deal from UK to understand how healthcare is delivered,
4 but it absolutely relies on people having a correct
5 coding in their healthcare record.
6 We've already heard that there's difficulty
7 seeking healthcare, difficulties getting the diagnosis,
8 difficulties with the terminology, and we just don't
9 have enough people still, in 2024, that have Long Covid
10 actually having their Long Covid code on the database.
11 That then means that we can't -- because to really
12 understand healthcare inequalities you really need to
13 understand the prevalence to be able to do large-scale
14 comparisons around how different demographic factors are
15 actually affecting healthcare and the condition itself,
16 I'm talking about needing good quality epidemiological
17 studies, and that's what you need the data for. So that
18 has been really limited.
19 NHS England were keeping a good record of who was
20 being seen in the Long Covid clinics, so at least we had
21 some idea of the demographics of the people that were
22 actually receiving care through the clinics, but I don't
23 think we have that any longer.
24 And the whole thing after 2021 became even more
25 challenging after routine testing reduced, because at

1 least if you knew roughly the incidence of the
2 infections you could understand roughly what you would
3 expect the prevalence of Long Covid to be in certain
4 areas, but without that it's really difficult to
5 actually understand what the gap is, to understand where
6 the problems lie.
7 **Q.** Please can we go on screen to INQ000421758.
8 Professors, you will recognise this. This is
9 paragraph 88 of your report.
10 We have data collected by NHS England from
11 July 2021 to July 2022 of the demographics of adult
12 patients attending Long Covid clinics.
13 What does this list tell us about inequalities in
14 the context of Long Covid treatment?
15 **PROFESSOR EVANS:** I think there's going to be limited
16 interpretation that we can really draw on this, however
17 the gender balance or the sex at birth balance between
18 females and males is probably where you would expect it
19 to be.
20 The difficulty is that 20% of people seem to be
21 missing their ethnicity data and we just don't know for
22 a fifth of people what is their background ethnicity,
23 and therefore we really can't comment whether that data
24 is really representative of our general population. Our
25 suspicion would be that it isn't, and I think those of

1 us running Long Covid clinics think that there are
2 definite people that we're missing, and they are people
3 that we miss in all healthcare.
4 **Q.** It sounds as if this tranche of data is indicative of
5 the problematic global picture you've been describing?
6 **PROFESSOR EVANS:** Absolutely.
7 **Q.** Can we next go to INQ000319639.
8 This is an extract from the statement of
9 Caroline Abrahams, of Age UK, who the Inquiry heard from
10 yesterday. I'd just like to look at the first sentence
11 of paragraph 79:
12 "There may also be under-recognition and under or
13 delayed-diagnosis of Long-Covid in older people whose
14 symptoms including problems with balance and mobility,
15 and chronic fatigue, may be written off as
16 'age-related'."
17 Is this a concern you recognise?
18 **PROFESSOR EVANS:** Yes, absolutely. And that probably
19 happens on an individual level, where people start
20 experiencing things and they put it down to their age
21 and delay seeking healthcare. And then healthcare
22 professionals as well, if they're not clued into
23 Long Covid, could absolutely underestimate it.
24 I would also say that the flip side is very true
25 though, that in the clinic we also are concerned if

1 somebody is presenting with Long Covid and memory loss,
2 we absolutely don't want to assume that that is all
3 Long Covid if there are potentially reversible or
4 treatable conditions. And that's why you need these
5 specialist clinics with those MDTs, so this is exactly
6 the type of problem that we discuss.
7 **Q.** Thinking about a different cohort of individual. At the
8 start of your evidence we explored healthcare workers as
9 being at higher risk of developing Long Covid during the
10 pandemic. Can you help the Inquiry understand what can
11 be done to support healthcare workers with Long Covid to
12 return to work?
13 **PROFESSOR EVANS:** Absolutely. There are a number of
14 challenges for healthcare workers, not least that many
15 of them did contract the virus during their day-to-day
16 work while trying to help people.
17 The things that we need -- I mean, their general
18 care will clearly be the same as for somebody else with
19 Long Covid, but as an organisation I think the NHS needs
20 to really support people returning to work.
21 The vast majority of people I see actually try to
22 return to work too soon, that it is the thing that is
23 prioritised over everything else. So even though it
24 they can barely do something, they're telling you that
25 they're still trying to get to work.

1 One of the things we've really learnt around --
2 that we've all needed really good links with,
3 occupational health, and the occupational health teams
4 on the whole have been very proactive to understand
5 about Long Covid, to help the people that they're trying
6 to help, meaning more broadly.
7 Within the NHS we have very fixed phase returns.
8 There's a process and it's very rigid. And a common
9 theme that you're hearing today is how long Covid is not
10 fixed, it is incredibly variable, changeable and the
11 fatigue really needs a very carefully planned, flexible,
12 phased return. So the NHS can do a lot better to
13 facilitate that.
14 And the vast majority -- I can just speak from
15 personal experience -- the vast majority of healthcare
16 workers, if not all of them, want to get back to work.
17 It's their goal.
18 **Q.** At your paragraph 92 you say that proactive care could
19 improve health equity. Can I ask what you mean by
20 proactive care in the context of Long Covid.
21 **PROFESSOR EVANS:** Absolutely. It's relevant to all
22 Long Covid but it was particularly relevant for the
23 people post hospital.
24 So, many people, obviously hundreds and thousands
25 of people came into -- or hundreds of thousands now --

1 came into UK hospitals with this lung infection, very
2 typically. If we just leave follow-up care, if they're
3 discharged home and then we just leave follow-up care
4 for that individual to then initiate coming back into
5 the healthcare system, they would face exactly the same
6 issues as we've heard from those non-hospitalised.
7 With proactive care it means actually that you
8 have the cohort of people that were admitted to hospital
9 and you ask all of them whether or not they're fully
10 recovered. And we've actually managed to do this
11 locally using an automated AI system, because obviously
12 we want to target services to where -- to the people
13 that haven't recovered. Our early data from the
14 PHOSP-COVID study did show that actually 70% of people
15 are not recovered by one year, so actually you're trying
16 to -- you're delivering proactive care where the
17 majority of people are going to need care, and you're
18 trying to just ensure that everyone is not left to their
19 own devices to seek healthcare.
20 Healthcare inequalities come in when you've got
21 different healthcare-seeking behaviour.
22 It's much more difficult to implement something
23 like that at scale for the community just because 95% of
24 people will, thankfully, recover from Covid-19. But we
25 definitely need -- going forward need to think: we've

1 got very sophisticated tools and technology, there must
2 be a way of being able to proactively reach out to
3 people that have not recovered and therefore reduce the
4 burden, really, on the individual to do all the
5 healthcare seeking themselves.
6 **Q.** Both in your report and in evidence you shared earlier
7 today, you have compared the rapid development of care
8 for acute Covid-19 with the comparatively slower
9 development of Long Covid care. In your view, does this
10 reflect a common disparity between acute care and
11 chronic care?
12 **PROFESSOR EVANS:** It does, unfortunately, where healthcare
13 does seem to be highly prioritised to acute care. And
14 I'm not saying I want to take anything away from that,
15 but we need to have equal priority for people living
16 very difficult lives with long-term conditions. It's
17 not seen anywhere near as much as acute illness, both in
18 the public and the healthcare system.
19 **PROFESSOR BRIGHTLING:** I'd like to add the timing is
20 different as well. So this doesn't have to be done at
21 the same pace and scale, because we know that the main
22 problem at the height of the pandemic was the acute
23 problem. People were dying. So clearly having a very
24 well structured acute service and research that was then
25 identifying therapies in the acute setting was entirely

1 the right thing to do. Identifying a vaccine was
2 entirely the right thing to do. But the problem that
3 we've seen is that there was some initial investment
4 that was done quite slowly for Long Covid and that's
5 neither been sustained nor accelerated in spite of the
6 fact that this is still a major problem.
7 **Q.** Can we turn now to your lessons and recommendations.
8 I'd like it approach it in this way, please.
9 First, we'll look at your recommendations for how to
10 diagnose and treat the long-term consequences of
11 a future pandemic pathogen and then we'll look at
12 recommendations you have about the treatment of
13 Long Covid.
14 So, the former. As far as you are aware, does
15 the UK currently have a plan in place to address the
16 long-term consequences of a future pandemic illness?
17 **PROFESSOR BRIGHTLING:** So within the UK there is some
18 funding that was already in place ahead of Covid-19 for
19 pandemic preparedness. But the magnitude and scale of
20 this funding is really very small.
21 So what it allowed them to do was to develop a --
22 what we call a hibernating or a sleeping study for
23 looking at the observational study to try to follow the
24 pandemic in its early stages. And that was the
25 ISARIC study, which was very successful. So it was very

1 successful at them being able to start to understand
2 what does the acute pandemic look like, what are the
3 at-risk groups, and be able to give us early
4 demographics and early epidemiology. It was a big
5 success, success in the UK and UK led.
6 But we didn't have that for long-term conditions,
7 and as far as we're aware there still isn't in place
8 a plan for a similar event in the future that may then
9 lead to long-term conditions.
10 And yet, as we alluded to early on, we already
11 knew from other coronaviruses, so with SARS-CoV-1 and
12 MERS, that there were a high proportion of patients that
13 then developed long-term consequences. Unfortunately,
14 those conditions did not have anywhere near the number
15 of people that were affected.
16 So it didn't have the same global impact. But it
17 only has required this breakthrough virus, with
18 Covid-19, to then really reveal just what an enormous
19 problem the -- what is now called Long Covid has really
20 been and any other post-infection consequences in any
21 future pandemic. So there clearly does need to be some
22 preparation, which could include hibernating studies for
23 research but also thinking about the clinical models as
24 well, as we've already discussed, like -- with
25 an expansion of the existing clinical service. That

1 could itself or it could be in parallel an activity to
2 also then have preparedness for them being able to
3 accelerate at scale new clinical services at the point
4 when there's a new pandemic.
5 So I would hope that there are positive things
6 that can be a legacy from this pandemic.
7 **Q.** Anything you would add to that, Professor Evans?
8 **PROFESSOR EVANS:** No, I don't think so, thank you.
9 **Q.** Turning then to your recommendations for the treatment
10 of Long Covid. Can I start with this, please. In your
11 view, is the future planning and resourcing for
12 Long Covid care adequate?
13 **PROFESSOR EVANS:** I don't think so. Not from what I'm
14 seeing. I think I would have answered this quite
15 differently last year. I've been trying to, sort of,
16 reflect on that. And I'm really concerned that the
17 expertise, the clinical care that was set up in England,
18 that as Chris has said should have been accelerated, as
19 really reduced, and I am concerned what it's going to
20 look like a year from now when it's more business as
21 usual in the integrated care systems.
22 And we absolutely understand that the NHS is under
23 extreme strain but it is absolutely our job to highlight
24 this condition and highlight the need that these
25 specialist clinics and the Long Covid care, both primary

1 care, community care and then the specialist clinics and
2 interventions, needs to be continued. The ONS data from
3 2024 clearly shows it's not going away.
4 **PROFESSOR BRIGHTLING:** One thing that really worries me is
5 how all of the voices that we hear from the patients'
6 testimonies could end up falling silent, because if the
7 clinics slowly start to evaporate, the expertise is not
8 kept and expanded, you then have a situation where
9 patients then don't have a service to support them and
10 they're then just falling into whatever the local system
11 is that is currently there, which is very likely
12 inadequate.
13 And that in many ways means, perversely, the
14 problem seems to go away, because then you're not
15 actually seeing the condition, because it's no longer
16 visible. And to me that would be -- that would be
17 a real travesty. And I think we're -- I think we're at
18 a tipping point, really, where there's a real
19 opportunity to learn from what we have already achieved
20 and to really then build back up the services, maintain
21 them, develop expertise, identify new diagnostics, new
22 therapies and actually make really big strides. But in
23 contrast there's a risk that these things will actually
24 fall to one side.
25 **Q.** In respect of prevention, at your paragraph 125 you

1 highlight the role that vaccination can play. Is there
2 evidence that vaccination has an impact on the severity
3 and incidence of Long Covid?
4 **PROFESSOR EVANS:** Yes, absolutely, and this is now through
5 a number of different studies that show that people that
6 are fully vaccinated are at less risk of getting
7 Long Covid, and those that do overall, and again talking
8 in cohorts, overall they have less severe Long Covid.
9 Yet the at-risk groups of getting Long Covid and
10 of course someone that's already had Long Covid would
11 very much be in that group, never seem to be on the
12 at-risk group for vaccinations. They are still very
13 much geared and, again, this group should be included to
14 the older population that are more at risk of the acute
15 illness and of course mortality.
16 **Q.** You've referred both in your report and earlier today to
17 the importance of training healthcare professionals, and
18 at your paragraph 129 you note the importance of
19 providing occupational advice to patients and vocational
20 rehabilitation. I wonder whether you could explain what
21 those two concepts mean in the context of Long Covid?
22 **PROFESSOR EVANS:** Absolutely. We've had -- we've not really
23 discussed them today but they're in the report. We have
24 existing rehabilitation programmes for lots of different
25 long-term conditions but actually they tend to be on the

1 whole for older populations and the vocational aspect of
2 rehabilitation really hasn't particularly been included,
3 certainly for Long Covid this is largely a working-age
4 population that want to get back to work and vocational
5 rehabilitation is really the way to do that. That it is
6 very focused, you've got the right experts within that
7 MDT, with a very different skill set to the other
8 healthcare professionals and the whole target is about
9 how to help people to get back to work.
10 And they are also a critical link back into the
11 occupational health role to then support the
12 organisation that the person is working in to actually
13 have that real phased return that's personalised and
14 actually going to help people return to work. And
15 that's good for everybody, that's good for the
16 individual and it's certainly good for the healthcare
17 system to have our healthcare workers back into the NHS.
18 **Q.** Throughout your evidence you have made certain
19 recommendations as we have progressed. Can I finish
20 then with this. Are there any other recommendations for
21 the future of Long Covid treatment that you would like
22 to share with the Inquiry?
23 **PROFESSOR BRIGHTLING:** I think I'd simply like to say that
24 this isn't fixed, it hasn't gone away, and we really
25 have made quite phenomenal progress in a short space of

1 time such that we're ready now to move into further
2 treatment trials to then try and then underpin the
3 clinics, and it's just critical that that's supported
4 and accelerated and not undermined.
5 **MR MILLS:** Professor Brightling and Professor Evans, thank
6 you.
7 My Lady, that's all I ask.
8 **LADY HALLETT:** I was thinking of breaking now before I ask
9 Ms Hannett to ask her questions. So I'll break now,
10 at 2.45, and come back at 3 o'clock.
11 **(2.44 pm)**
12 **(A short break)**
13 **(3.00 pm)**
14 **LADY HALLETT:** Last leg, Professors.
15 Ms Hannett.
16 **Questions from MS HANNETT KC**
17 **MS HANNETT:** My Lady, thank you.
18 Professors Brightling and Evans, I ask questions
19 on behalf of the Long Covid groups. I'll direct
20 questions to both of you but as with Mr Mills, do please
21 answer as you feel appropriate.
22 And actually, we are very grateful to counsel to
23 the Inquiry who has put a number of the questions to you
24 that we intended so I shall cut my cloth accordingly.
25 Can I start, please, by asking you about

1 paragraph 3 of your report where you state that since
2 writing the Module 2 report Long Covid remains
3 a significant health priority. Please can you explain
4 in a little more detail why you consider Long Covid to
5 be a current and ongoing significant public health
6 priority?
7 **PROFESSOR EVANS:** Yes, of course. So it is a significant
8 and ongoing priority both in terms of volume of people
9 affected, as -- to repeat the ONS figure that 2 million
10 people living in the UK currently are estimated to be
11 living with Long Covid and also it's an absolute ongoing
12 priority for the people that have been severely impacted
13 for the condition and the need for both research and
14 clinical care to be continued.
15 **PROFESSOR BRIGHTLING:** If I may, I'll add a couple of extra
16 dimensions. Not only is it clearly of remaining
17 importance for the individuals who are suffering but it
18 also has an economic and societal impact as well. So
19 the estimate just on loss of income is in the order of
20 1.5 billion according to the Institute of Fiscal Studies
21 and then there's been estimates of the overall cost
22 based on the clinical healthcare costs, the carers'
23 costs and the other socioeconomic costs due to loss of
24 earnings and it's been estimated to be somewhere in the
25 region of 0.5 of the UK GDP. So I would have thought

1 the day before a budget that actually taking into
2 consideration not just the personal impact but the
3 societal impact, and economic impact is really
4 important.
5 **Q.** Thank you. I'm going to turn to ask you about access to
6 adult Long Covid services. You've given evidence
7 already about the difficulty and delay for patients in
8 accessing services in all four nations and that reflects
9 the experience of members of the Long Covid groups. In
10 relation to Long Covid services, Long Covid care
11 currently comprises both rehabilitation and clinical
12 management of Long Covid. Are rehabilitation services
13 without some form of clinical management of Long Covid
14 symptoms sufficient to care for all Long Covid
15 sufferers?
16 **PROFESSOR EVANS:** I would say no. I think there's that
17 tiered approach and stratified approach to clinical
18 care, so a light touch approach for some, definitely
19 having that multi-disciplinary team and rehabilitation
20 service but I believe you must have medical oversight of
21 these services so that you can ensure that first part of
22 the journey, getting the diagnosis right, answering
23 people's questions appropriately, they have individual
24 questions about individual symptoms, they must have time
25 with somebody that can answer those as best they can and

1 where it's unknown, have trust that the person that's
2 just saying, "Actually, at the moment, we don't know",
3 that really is the best answer.
4 But I do believe they must have medical support.
5 That multi-disciplinary team that we talk about needs to
6 have medical staff involved.
7 **Q.** And assuming that there's a medical staff present, what
8 other different professional backgrounds or different
9 types of healthcare professionals, what impact can they
10 provide on the quality of the care that can be provided?
11 **PROFESSOR EVANS:** Absolutely. I think it is so important
12 that there is one professional that really is taking
13 control of the person's care and then absolutely need
14 a range of specialists to help support that care, and
15 that doesn't mean sending somebody off to multiple
16 specialist appointments where they're going to hear
17 different views, different focus, and have to spend time
18 and money and energy doing that, it is much more
19 efficient for everybody, both the individual and the
20 healthcare system to have these clinics with relevant
21 expertise and that now we probably know more than we did
22 in 2020, 2021, certainly the MDT that I run has changed
23 quite significantly over the four years to learn which
24 specialists we really need.
25 Locally for us that's cardiology, respiratory,

1 neurology, rheumatology, liaison psychiatry, mental
2 health support and rehabilitation, a suite of
3 multi-disciplinary team you need to deliver the
4 interventions.
5 **Q.** Just by way of follow-up, in your experience in terms of
6 the Long Covid clinics that are available in England, is
7 the type of multi-disciplinary care that you've just
8 described that you deploy replicated in all of the
9 Long Covid clinics in England?
10 **PROFESSOR EVANS:** So I would say at the beginning going into
11 2021 was probably our sweet spot of getting things as
12 good as it's been. There were several clinics that
13 looked like that. I'm not sure ever there were 100
14 clinics that we had, but we were working towards that,
15 and actually there have been really good examples of
16 peer-learning within clinics where you can share good
17 practice and patients were absolutely key to that. That
18 worked very well.
19 Now, I think we're really running the risk that
20 actually those clinics are few and far between and
21 actually those clinics are then getting really
22 stretched, you're then not being able to deliver care in
23 a timely, effective way. So, as we were saying before,
24 we really need to advance this, not be in retreat mode.
25 **Q.** Thank you. Just then looking at Long Covid services for

1 children and young people. Can you expand a little more
2 on why you recommend a dedicated Long Covid
3 multi-disciplinary team to provide support for children
4 and young people?
5 **PROFESSOR EVANS:** Absolutely. In a similar vein to adults
6 and absolutely children and young people can have
7 different symptoms and manifestations of Long Covid to
8 adults but the principles of care should be the same and
9 actually, just like we were talking right at the end
10 about occupational and vocational rehabilitation,
11 actually working with schools and education is such
12 an important time in a child's life often, going to
13 school and education, to have that actually interrupted
14 for a month let alone many months and maybe a couple
15 of years we really need those clinics to have that
16 expertise to support the wider social support needed for
17 children.
18 **Q.** You perhaps may have already covered this but just for
19 clarity can you comment on whether general paediatric
20 services are sufficiently well equipped to respond to
21 the needs of children and young people with Long Covid?
22 **PROFESSOR EVANS:** So I'll answer that with a caveat that I'm
23 not a paediatrician but I can't see why it would be
24 different and in fact I would say it was probably more
25 important that you had dedicated specialists for

1 children. So just like I wouldn't advocate that -- and
2 actually, there very often isn't generalists as such,
3 but specialists tend to have their own specialty and
4 then I think you'd be at risk of the same repeating
5 multiple appointments and not actually ever getting
6 a solid answer or a solid plan.
7 **Q.** Thank you. Then just moving to healthcare and
8 treatment. You have given evidence on post-exertional
9 symptom exacerbation. Do you agree that advising
10 Long Covid sufferers to participate in graduated
11 exercise can exacerbate Long Covid symptoms?
12 **PROFESSOR EVANS:** So I agree that exercise at certain times
13 and in certain individuals can be extremely challenging.
14 Everybody needs to be assessed and then again as part of
15 that complex assessment post-exertional symptom
16 exacerbation is one of those things that need to be
17 explored.
18 The exercise rehabilitation that we're advocating
19 that is being used in clinical trials is this
20 personalised approach. So it's not a fixed regime, it's
21 personalised to the individual, with pacing and
22 progression working with the individual person. That's
23 definitely what we would advocate.
24 **Q.** And would you recommend that advice on PESE
25 (post-exertional symptom exacerbation) is included in

1 the NICE guidelines on managing long-term symptoms of
2 Covid-19 to prevent medical professionals providing
3 potentially harmful advice on exercise?
4 **PROFESSOR EVANS:** Yes, absolutely, it needs to be
5 incorporated both in terms of definitions and in
6 clinical care, and it would be one of the phenotypes
7 that future research trials should actually distinguish
8 even further.
9 **PROFESSOR BRIGHTLING:** Can I just add a further comment
10 though. So in the ME/CFS diagnosis, the -- PESE is part
11 of the definition, whereas with Long Covid it clearly is
12 recognised as being really important in some
13 individuals, as Rachael's explained, so I agree it
14 should be part of the guideline but not necessary as
15 part of the definition of the diagnosis.
16 **Q.** Understand. And just while we're talking about the NICE
17 guidelines, they haven't been updated since
18 November 2021. Apart from PESE, are you aware of any
19 other significant developments in the understanding of
20 management of Long Covid which should now be reflected
21 in those NICE guidelines?
22 **PROFESSOR EVANS:** I think there's certainly enough learning
23 and clinical trials that have been conducted that
24 another synthesis would be timely. And I think, as we
25 keep saying, that if you've got clinical care and

1 experts in the field, then you will promote needing
2 these guidelines.
3 One thing I do want to highlight, on a much more
4 positive side than perhaps we've heard a lot today, is
5 that we're really in a good position because of the
6 Long Covid advocacy groups, Long Covid Support,
7 Long Covid SOS, Long Covid Kids, and I think actually
8 we've taken a lot of learning about how to work with
9 people living with the condition, both in terms of
10 research and in clinical care. So for future guidelines
11 we're already planning how we can work together and --
12 whether that's NICE or a different organisation, to
13 actually synthesise what clinical care and current
14 research looks like.
15 **Q.** Thank you.
16 Just moving on to research and Long Covid. You've
17 obviously discussed two buckets of government funding
18 for research into Long Covid, one in autumn 2020 and
19 the second in spring 2021. Just looking backwards first
20 of all. Can you comment on how the speed of approval
21 and funding for research into Long Covid compared with
22 the speed and funding for research into treating acute
23 Covid and whether there's any justification for the
24 distinction.
25 **PROFESSOR BRIGHTLING:** So there's a number of differences

1 that I think are worth pointing out. So the speed in
2 terms of the decision-making for the funding was
3 actually faster than you would typically have within
4 normal funding rounds, but much slower than was done for
5 the acute episode.
6 What was perhaps the greatest problem was actually
7 when things were then supported but there was a major
8 problem in terms of the research governance in the UK.
9 So one example of that would be the MHRA, who would
10 clearly have to be involved when it's an investigation
11 of medicinal product, as was the case with
12 STIMULATE-ICP. So you then end up in a situation where
13 the funding is awarded but there's a very large delay
14 then from the point where funding is awarded to then
15 actually be able to start the trial.
16 The same was true for Rachael's study that she
17 described earlier, PHOSP-I, where there was almost
18 a year from the initial applications for all of the
19 approvals because at that time there was a real problem
20 with the MHRA governance processes. This is now much
21 better but it did impact particularly adversely on
22 Long Covid studies. At a time when you wanted to be
23 able to move things very quickly some of the studies
24 became very slow.
25 In contrast, PHOSP-COVID, which was the study that

1 we co-led, was actually approved and patients were then
2 recruited very quickly. So the point from approval to
3 then ethical approval was a matter of days, and then
4 first patient was a matter of weeks. So it showed that
5 at the height of the pandemic things could be done at
6 incredible pace, which was not the case with later
7 studies.
8 **Q.** You were asked all the questions we were going to put
9 you about research in adults apart from the one I have
10 just asked, but could I just ask you about research for
11 Long Covid in children. Has there been any biomedical
12 research to better understand Long Covid in children and
13 young people?
14 **PROFESSOR BRIGHTLING:** So there is work that's particularly
15 focused now, through the NIH Recover programme. In
16 the UK there's very limited research in terms of then
17 looking at the underlying biology, in terms of them
18 doing sampling, but considerable work in terms of then
19 looking at the epidemiology and the phenotypes and the
20 description of Long Covid in children and young adults.
21 **Q.** In your view, would that be a recommendation that you
22 would make, that that sort of work ought to be carried
23 out in the UK?
24 **PROFESSOR BRIGHTLING:** So I think there need to be a suite
25 of research. So we talked earlier about the types of

1 approaches we would recommend in terms of intervention
2 trials. But also the more fundamental understanding
3 should be supported through particularly through UKRI in
4 the UK, and that would allow for more discovery research
5 which would include children and young people as well as
6 adults.
7 **Q.** Penultimate topic. Data and Long Covid. You gave some
8 evidence earlier about the quality of the data in the
9 Long Covid clinics. We've also had evidence earlier in
10 this module about Long Covid coding in primary care and
11 I wonder if you're able to comment on the quality and
12 the accuracy of that coding?
13 **PROFESSOR EVANS:** Yes, I commented earlier that it's been
14 a real issue around getting data at large scale using
15 electronic healthcare records because of the poor
16 quality of coding. And when electronic studies have
17 reported on Long Covid it really does underestimate the
18 prevalence of Long Covid and the impact.
19 **Q.** And that data then, by implication I think you're
20 suggesting it should be collected, how should that
21 situation be improved in terms of collecting the data to
22 enable your research and so on?
23 **PROFESSOR EVANS:** That's a really good question and
24 certainly early in the pandemic there was a lot of work
25 done actually, led through the Royal College of General

1 Practitioners, around coding for Long Covid, but for
2 whatever reason over the last few years it's still very
3 much underused.
4 **Q.** And in terms of -- that's prevalence data. In terms of
5 impact of -- data on the impact of Long Covid, ie the
6 impact of its severity on sufferers, should that also be
7 collected? And if so, by whom?
8 **PROFESSOR EVANS:** Absolutely, and that's also really
9 missing. The ONS team did a really good job, and again
10 I know that patients living with Long Covid very much
11 were involved in that survey to make sure that the
12 impact on daily life was recorded.
13 There have been, you know, just -- they're very
14 crude but it's a good guide is the Covid functional
15 scale, and I think we should be using that in primary
16 care and secondary care. It's a 1:5 scale very similar
17 to -- we use for breathlessness for certain long-term
18 conditions, and actually they tend to be, and certainly
19 the evidence so far shows, that that scale is quite good
20 at highlighting who has got the worse impact for
21 health-related quality of life.
22 Obviously occupation can be assessed. The problem
23 with returning to work is that some people return to
24 work even though they're not able to really fully engage
25 or they've got no other life apart from doing that. So,

1 again, that's a crude way of measuring impact.
2 With the scale, that can then be used to
3 prioritise -- when I keep saying about stratifying care,
4 actually those in the sort of 0 to 1 categories then can
5 have a light-scale approach, those that are more heavily
6 impacted they would be a really good guide for GPs to
7 think: yes, that's who I need to be referring on to
8 specialist care.
9 **Q.** Thank you.
10 Last topic, public awareness on Long Covid.
11 You've given evidence on the current risk of developing
12 Long Covid from new Covid-19 infections and
13 reinfections, and, Professor Evans, you gave evidence
14 just now on the need for those with Long Covid to be
15 prioritised for vaccination. Can you just explain why
16 that is important in the context of reinfection?
17 **PROFESSOR EVANS:** So generally vaccination has a protective
18 effect to getting Long Covid. Even if we don't
19 understand all the mechanisms of why certain individuals
20 get Long Covid, there are absolutely individuals at risk
21 and we have to start thinking that -- and because
22 infections are still common, they're still out there in
23 the community, SARS-CoV-2 hasn't gone away, if you were
24 susceptible to getting Long Covid, whether that was your
25 personal demographic, something in your immunology,

1 whatever it was, surely you must be at risk of getting
2 it the next time, and therefore, if you've already to
3 got a condition, you definitely don't want to get it
4 again and get a condition worse. So that's what I was
5 basing that comment on.
6 **Q.** Does the same point apply to the eligibility for
7 children and young people for vaccination?
8 **A.** I don't think I can comment on that just because
9 I really don't have the medical knowledge.
10 **Q.** I understand.
11 I'll move on to my next question which is: can you
12 advise on whether there are sufficient public health
13 communications, if any, on the current risk of
14 Long Covid in the context of the ongoing transmission of
15 Covid-19?
16 **PROFESSOR EVANS:** Can you just repeat the first part of
17 that.
18 **Q.** Of course, I'll simplify it. Are there sufficient
19 public health communications on the risk of developing
20 Long Covid given that Covid infections are all around us
21 still?
22 **PROFESSOR EVANS:** Again, it's a really good point that
23 actually all the way through the pandemic we naturally
24 had the statistics from the hospital admissions, the
25 deaths but actually at no point did we ever really get

1 in the public eye the volume of people with Long Covid
2 nor the impact, and actually I think the public are
3 largely still unaware of the potential longer-term
4 consequences of getting the virus and reasons to
5 avoid it.
6 **MS HANNETT:** Thank you, Professor Evans and
7 Professor Brightling.
8 Thank you, my Lady, those are my questions.
9 **LADY HALLETT:** Thank you, Ms Hannett.
10 Ms Peacock -- who is behind you but if you could
11 make sure, please, that your answers go into the
12 microphone. Thank you.
13 **Questions from MS PEACOCK**
14 **MS PEACOCK:** Good afternoon, I ask questions on behalf of
15 the Trades Union Congress. My questions relate to the
16 impact of Long Covid on black, Asian and minority ethnic
17 healthcare workers.
18 You've already been taken to paragraph 88 in your
19 report which sets the percentage statistics on
20 ethnicities of patients who accessed the Long Covid
21 clinics. Professor Evans, you helpfully explained that
22 there is missing data on ethnicity within those
23 percentages and missing data in respect of those who may
24 not have access to clinics.
25 Do you consider that Long Covid disproportionately

1 impacted, both in terms of prevalence and severity, upon
2 black, Asian and minority ethnic healthcare workers? Or
3 perhaps my question is, do the data exist for you to
4 answer that question?
5 **PROFESSOR EVANS:** Yes, I was -- before you put the caveat
6 in, I was about to answer that I think unfortunately we
7 just don't have good enough data and we urgently need
8 that to understand, even in the clinics we've got, who
9 are we actually missing. And there are -- because
10 Long Covid is a symptom-based condition, it absolutely
11 depends on language and understanding both for the
12 person themselves if they've got the condition to know
13 to access healthcare, and then for healthcare
14 professionals to be able to interpret that.
15 And even with the research and this has been
16 written about, even the way that we -- the outcomes that
17 we use they all need to be culturally sensitive. So
18 there's a whole host of research work that needs to be
19 done there and what we need to do in clinical care to
20 really be able to understand how Long Covid is affecting
21 different populations.
22 **Q.** And just focusing on what we do know, the data which are
23 available, I'd like to briefly identify two passages in
24 your report which you've already touched upon in
25 evidence.

1 First, at paragraph 87 you note that:
2 "... Long Covid is more common in females, middle
3 age, pre-existing health conditions including obesity
4 and social deprivation. It is also known that female
5 sex, obesity, and pre-existing health conditions make
6 someone more likely to develop severe Long Covid rather
7 than milder disease."
8 And then secondly you explain at paragraph 94:
9 "Healthcare workers were at higher risk of
10 exposure to SARS-CoV-2 infection throughout the Covid-19
11 pandemic and early studies highlighted the risk of
12 severe disease associated with certain ethnic
13 backgrounds."
14 In absence of clear data and just taking what we
15 do know given the higher incidence of Covid-19 infection
16 in healthcare workers, the higher prevalence of
17 pre-existing health conditions in black, Asian and
18 minority ethnic groups, the higher prevalence of severe
19 disease in black, Asian and minority ethnic groups, the
20 higher level of vaccine hesitancy and refusal in those
21 groups, in particular black, Pakistani and Bangladeshi
22 groups, and the higher levels of social deprivation
23 associated with structural racism, is it fair to say the
24 data we do have give rise to a real concern that
25 Long Covid may disproportionately impact black, Asian

1 and minority ethnic workers?
2 **PROFESSOR EVANS:** Absolutely, and I think it's that impact
3 not only -- well, in all ways in how people then access
4 the healthcare. There's been some very specific
5 qualitative work which is actually a very difficult read
6 which is highlighting the challenges that people from
7 different backgrounds have both with experiencing
8 Long Covid and then seeking healthcare support and their
9 voice would definitely say that there are issues there
10 that we urgently need to address.
11 **Q.** Studies are ongoing to understand the potential
12 disproportionate impact in the way that we've been
13 discussing and in particular the NHS Race and Health
14 Observatory reach-out study, which is in its third and
15 final year, as I understand it, and so far has published
16 two interim reports. If Long Covid is found to have
17 disproportionately impacted upon black, Asian and
18 minority ethnic healthcare workers, what do you consider
19 could and should be done in a future pandemic to avoid
20 any such disproportionate impacts being repeated?
21 **PROFESSOR BRIGHTLING:** One of the things that we don't fully
22 understand until it happens is what the risk factors are
23 going to be for a future pandemic. So I think what we
24 need is we actually need those hibernating studies that
25 we've described, the clinics that are ready to be

1 increased at scale, but also a recognition that there
2 are groups that so far we've not, I think, served as
3 well as we could for the reasons that you've described.
4 That doesn't mean that we can assume that the next
5 pandemic will disproportionately affect one pre-defined
6 group versus another but it's likely to be affecting
7 certain groups, certain risk groups, and as long as we
8 recognise that and as long as we set things up in order
9 to make sure that we are identifying that and acting
10 accordingly that to me is the real key.
11 **Q.** So building on that lack of certainty that you've
12 identified in respect of a future pandemic, the Chief
13 Medical Officer who we've heard from,
14 Professor Sir Chris Whitty, he gave evidence that in his
15 view the key to improving the safety of higher-risk
16 individuals was principally to optimise the safety for
17 all in the workplace, so rather than sectioning out
18 groups. Does that logic apply here in terms of
19 disproportionate impact of Covid-19 on healthcare
20 workers that perhaps prevention is the best cure and
21 avoiding occupationally-acquired Covid-19 infection for
22 all workers would be the best way to approach the issue?
23 **PROFESSOR BRIGHTLING:** So on one level I agree that
24 obviously if you can have optimal management for all
25 then that would be ideal but we recognise that there

1 will be disproportionate risks and for that reason
2 I would disagree with Sir Chris Whitty in that I would
3 suggest that we need to not assume what those
4 disproportionate risks are but at least be cognisant of
5 them, prepare for them, and then adjust and direct
6 resources in order to try and mitigate those risks.
7 **Q.** So identifying those risks early and assessing based on
8 them?
9 **PROFESSOR BRIGHTLING:** Correct.
10 **MS PEACOCK:** I'm grateful. Those are my questions.
11 **LADY HALLETT:** Thank you, Ms Peacock.
12 Mr Stanton, who is also behind you so I'm afraid
13 you are going to have to test your neck muscles.
14 **Questions from MR STANTON**
15 **MR STANTON:** Good afternoon, Professors. I ask questions on
16 behalf of the British Medical Association.
17 I'd like to ask some questions about the topic of
18 managed returns to work which is an issue you've already
19 touched upon with Mr Mills. And the circumstances
20 I have in mind are as described by Nicola Ritchie
21 earlier in her evidence, particularly thinking about her
22 fears for her ability to continue with her career.
23 At paragraph 129 of your report you note that
24 flexible, individualised long-phased returns appear to
25 be better managed in the private sector than in the NHS.

1 Are you able to provide any examples from both the
2 private sector and the NHS to illustrate this difference
3 in approach and what do you think are the reasons for
4 flexible phased returns being better managed in the
5 private sector?
6 **PROFESSOR EVANS:** So those comments I do need to caveat that
7 they are my anecdotal clinical experience from having
8 now delivered a Long Covid clinic most weeks for
9 four years, and in -- I'm certainly not saying that
10 everything in the private sector was better but
11 anecdotally, certainly in smaller companies, there just
12 seemed to be better care, better links to occupational
13 health, and a bit more listening and guidance and
14 probably just a bit more flexibility.
15 It has felt that the NHS has this very fixed
16 process which we all understand, a very large employer
17 has to have some guidance, but -- and there are pockets,
18 definitely of occupational health physicians that are
19 desperately trying to learn about Long Covid and work
20 with the individual, but from my side as a clinician
21 I've just heard that feedback too often that "I wasn't
22 ready to do the" whatever hours it was, this many weeks,
23 the next weeks, the next -- you know, the very fixed
24 targets and then people are, yeah, stopping working when
25 they don't want to and that, again, my opinion is that

1 doesn't seem helpful for anyone. It's not helpful for
2 the NHS and it's not helpful for the individual.
3 And actually, as I've said before, I can't think
4 of anyone actually that I've worked with over the last
5 four years that hasn't wanted to return to work. So
6 it's everyone's got the same goal and actually with some
7 people we've had really good experience of really
8 careful phased returns, different types of work for
9 a period of time. Some adjustment on the healthcare
10 professional's, particularly, front that they might not
11 be able to go and deliver exactly what they were doing
12 before. And we have had some real success stories.
13 **Q.** Thank you.
14 In addition to the individual impacts of
15 poorly-managed returns, can you give some idea of the
16 types of adverse impacts on the wider NHS and also on
17 the quality of patient care?
18 **PROFESSOR EVANS:** Absolutely. It becomes a terrible storm
19 where the figures from after the pandemic in the NHS of
20 the sickness rates were extremely high due to, and we've
21 heard in this Inquiry from ICU, from other departments,
22 you know, just the trauma that people working in the NHS
23 went through, through the pandemic. So there are higher
24 sickness rates anyway. Some of that I expect is
25 Long Covid. So the organisation needs to support their

1 healthcare workers to get back to work to help the
2 organisation as well as the individual.
3 And sickness absences in the NHS, the workload is
4 already probably 110% of what you feel it should be. As
5 soon as there's people missing, I mean it just gets
6 desperate and unfortunately the main people that are
7 impacted by that are the patient.
8 **Q.** Is there also a loss of specialism as well or a risk of
9 a loss of specialism by not facilitating proper returns
10 to work?
11 **PROFESSOR EVANS:** Absolutely. Certainly for healthcare
12 professionals there's been a huge amount of investment
13 in training. Nicola, a very skilled physiotherapist,
14 you don't want to lose that expertise. And I think
15 perhaps as well we need to think about other -- when
16 I was saying the flexibility of returning to work,
17 proactively thinking, well, what other jobs could people
18 do if they can't do exactly what they were doing before,
19 much more flexibility, and I think that's where I just
20 felt it was very much a personal anecdote having been in
21 the clinic, I just felt that sometimes the private
22 sector seemed to get that a bit better and I suppose
23 that was a bit shocking especially as for healthcare
24 workers, they, certainly in 2020, had actually
25 contracted the virus at work.

1 **Q.** Thank you. Moving on to a slightly different but
2 connected topic of early intervention. Can I ask, how
3 can the NHS improve its early intervention and diagnosis
4 of Long Covid so as to minimise, where possible, the
5 severity of the impacts that we've discussed? And also
6 the wider societal impacts such as the economic cost of
7 Long Covid which you refer to at paragraph 38 of your
8 report?
9 **PROFESSOR EVANS:** That's a huge question. So to start with,
10 as we've said, actually having a healthcare service and
11 system that is Long Covid-ready. Having the research to
12 understand much more about this condition. Having the
13 treatment so that we can get the treatments in early.
14 And that still needs a huge piece of work between
15 clinicians, researchers, government, patients.
16 **Q.** Thank you. And finally a question about health
17 inequalities, please. Having regard to your reference
18 at paragraph 79 of the report that social deprivation is
19 known to be a key driver of health inequalities, and has
20 been associated with a risk of Long Covid, can I ask
21 whether in your view the state is ensuring that
22 resources for managing Long Covid, such as specialised
23 clinics and support programmes, are equitably
24 distributed between poorer and wealthier areas?
25 **PROFESSOR EVANS:** So I don't know the facts for that but

1 I expect we're absolutely at the mercy of the inverse
2 care law for Long Covid that, as I was saying before,
3 the patient groups have had a huge role in advocacy, and
4 I expect a lot of the clinics are in secondary care next
5 to academic centres, and absolutely we need to really
6 relook at where clinics are and to ensure that it's the
7 right support into different communities.
8 **Q.** And connected to that and finally, at paragraph 85 of
9 your report you indicate that Long Covid care is
10 disproportionally accessed by people from higher
11 socioeconomic groups. Can you give any indication as to
12 why that should be?
13 **PROFESSOR EVANS:** So that comment was from the NHS England
14 post-Covid hubs for children and young people. I think
15 they were mainly just trying to highlight that even all
16 the barriers that we've heard of, again how to actually
17 access healthcare, how to actually then persevere to get
18 through the healthcare system has been incredibly
19 difficult, and it's likely to be those with more
20 knowledge, more ability, that are able to do that, and
21 therefore it is even worse for people that have got more
22 difficult lives, different priorities, and we just need
23 to make access easier for everybody but ensure that
24 we're not missing very important groups.
25 **MR STANTON:** Thank you very much. Those are all my

1 questions.
2 Thank you, my Lady.
3 **LADY HALLETT:** Thank you, Mr Stanton.
4 Mr Simblet is again behind you but a bit closer.
5 **Questions from MR SIMBLET KC**
6 **MR SIMBLET:** Good afternoon. I'm asking questions on behalf
7 of the Covid Airborne Transmission Alliance (CATA), and
8 it's in relation to what's in your report and your oral
9 evidence in relation to dedicated Long Covid clinics and
10 rehabilitation services promoting a unified approach to
11 Long Covid care. And as you said earlier, clinics are
12 a foundation for Long Covid care, clinically effective,
13 cost effective.
14 So, in that context, given as you also said
15 earlier that there are worrying consequences for the
16 ever-increasing disparity in Long Covid care, would you
17 go as far as to say that there should be statutory
18 minimum criteria in relation to NHS Long Covid services
19 and would they promote consistency in the service
20 patients receive across the UK?
21 **PROFESSOR EVANS:** So the short answer is yes, and the
22 NHS England service specification really did set out to
23 highlight what good care would look like. I don't think
24 I've got anything else to add to how you actually make
25 that happen but absolutely there should be a -- for

1 a given population, having that tiered approach so that
2 you stratify care according to the need, so it's not
3 that I'm saying that everyone with Long Covid needs that
4 top end service, that's not correct, but everyone with
5 complex needs should be able to access complex care.
6 **Q.** Thank you.
7 I see Professor Brightling nodding. Is there
8 anything you needed to add?
9 **PROFESSOR BRIGHTLING:** I think it's also important that the
10 same equity of access is across all four nations.
11 **Q.** Thank you. Those were my questions, thank you very
12 much.
13 **LADY HALLETT:** Thank you, Mr Simblet.
14 Lastly, Mr Thomas, who is going to come around to
15 where Mr Simblet was.
16 **Questions from PROFESSOR THOMAS KC**
17 **PROFESSOR THOMAS:** Good afternoon, Professors. I'm
18 representing FEMHO, the Federation of Ethnic Minority
19 Healthcare Organisations.
20 Can I first start with discussing the data and the
21 limitations on the data. In your report you noted the
22 ongoing challenges in understanding the full scope of
23 Long Covid, particularly due to the limitations in the
24 data related to ethnicity. Can you share any progress
25 made in understanding how ethnicity may influence the

1 risk of developing Long Covid.
2 **PROFESSOR BRIGHTLING:** So the -- so you're absolutely
3 correct this is an area that needs more work. So what
4 we do know is when we originally recorded the ethnicity
5 in the early studies that there were certain risk
6 factors that were coming through very consistently, so
7 age and sex and comorbidities in particular, whereas
8 with ethnicity I think the picture was much more
9 complex, in contrast to, really, the acute Covid, where
10 clearly there was an increased risk, whereas in
11 Long Covid it seems that that increased risk is less
12 clear. And I think that's because of this poor data
13 recording, exactly as Rachael has described, and I think
14 that's what we really need to strive for.
15 But your question was: are we aware of that
16 actually happening? And I think we can say that that,
17 amongst other things that we've listed, really is on the
18 list of things that still need to really be done.
19 **Q.** Okay.
20 Professor Evans, I think you agree that the
21 current data limitations continue to hinder
22 a comprehensive understanding of disparities faced by
23 ethnic minorities; is that correct?
24 **PROFESSOR EVANS:** Can you just repeat the last bit, sorry?
25 **Q.** In response to questions from Ms Peacock just a moment

1 ago, I think I understood your evidence to be that
2 current data limitations continue to hinder
3 a comprehensive understanding of disparities faced by
4 ethnic minorities; is that correct?
5 **PROFESSOR EVANS:** Absolutely. We just -- both
6 epidemiologically and in clinical care we just don't
7 have good enough data to really understand what the gaps
8 are to then be able to think through the other questions
9 of what we then do about them.
10 **Q.** Which leads me on to my last question on this topic,
11 which is this: what measures would you recommend to
12 enhance a collection and analysis of data regarding
13 Long Covid in ethnic minority communities? And I take
14 that feeds into what's just been said but if there's
15 anything else?
16 **PROFESSOR EVANS:** Well, I think it just needs to be really
17 thought about carefully. That's the first thing.
18 I think most of the Long Covid studies that were
19 set up did have that in mind. Certainly we can speak to
20 the study that we run. We were very aware that we
21 wanted to make sure it was inclusive, that we got the
22 right participants, and we did quite a bit of work to
23 how to engage certain communities in research. And
24 certainly in our institution we have the centre for
25 ethnic health that does this not for just Long Covid but

actually trying to make communities almost research-ready, so that we make sure that we've got the research designed in a way to be inclusive and actually communities ready to trust and be participants in that research. That's one thing.

We've not talked much about outcome measures today but, again, a lot of our outcome measures for Long Covid, around symptoms, around how people feel, we need to make sure they are both language and culturally appropriate. And that is absolutely something that we can be working on in between pandemics. You don't need a pandemic to suddenly start being able to have appropriate outcome measures. So that's certainly not the whole package of answers to your question, but that's at least a couple of things that we should be doing.

Q. That leads me very nicely on to the second area, which is addressing health inequities and cultural barriers in Long Covid diagnosis.

At paragraph 92 of your report you mention that health inequities can arise from varying health-seeking behaviours. Question: to what extent might racism, stigma, discrimination and cultural differences contribute to these difficulties in recognising Long Covid symptoms among the ethnic minority

communities?

A. So, again, very important question, I think the question around stigma and scepticism we've heard from all populations with Long Covid.

I mentioned the study that was very uncomfortable reading which was a qualitative piece of work where they went out and interviewed people with Long Covid from different backgrounds, and absolutely the patient testaments there is they do feel all the things that you've listed there have been, for a greater or lesser extent, experienced by some patients.

Q. What improvements could healthcare systems make to ensure timely and supportive diagnoses for Long Covid within these communities? So I'm trying to look forward and in a positive way. What could be done?

PROFESSOR EVANS: Absolutely. And I'm trying not to steer into the whole population but there is so much work that we need to do that really accounts for everybody. I've already just mentioned for -- about the work that the centre of ethnic health are doing. I can't think of anything else.

PROFESSOR BRIGHTLING: I think one of the things Rachael alluded to earlier, which I think is where we perhaps need to go, is also that early case identification.

So at the moment we're very much relying on

a reactive process with what we've already described really as an inadequate national service for Long Covid. Whereas what we actually need to do is recognise what are the key presenting symptoms, what is the language used around those symptoms in different ethnic groups, and then actually be going out and seeking where those people actually are in the community and how they're being received at the moment in primary care.

And as Rachael's alluded to, this is something that -- there's leaders within Leicester, where we are, with Kamlesh Khunti and others, who are really trying to develop exactly these kind of approaches. But they're in very early stages and I think it's something that's going to be really important, because Long Covid may not present in terms of -- the words that people may use to describe it may be culturally different between different ethnic groups.

Q. I have two more topics. The next one is examining ethnic variability in Long Covid symptoms and the effect on healthcare workers.

So, at paragraph 94 of your report you highlight that healthcare workers, particularly those from certain ethnic backgrounds, face a higher risk of severe Covid-19 outcomes.

Question: is there any evidence suggesting that

Long Covid symptoms manifest differently across ethnic groups?

PROFESSOR EVANS: I think there's evidence that symptoms are interpreted and described differently amongst other -- amongst different ethnic backgrounds and different cultures, I expect. So we know that's so for the breathlessness where I -- my research is mainly based, that actually sometimes people will use pain to describe the distress of breathlessness, and actually a healthcare professional, if they hear "pain", they'll interpret that completely differently.

I expect that the -- I think everybody, if they -- especially before we knew what Long Covid was, really struggled to articulate what they were feeling because there is just this, you know, blast of symptoms, you know, not just -- again, not trivialising chest pain if someone has chest pain, but that can be one symptom for a cardiac condition. Long Covid, many people have 20-plus symptoms. So I think everyone finds that very difficult to describe. And then if you put cultural differences, differences around health seeking, when it is felt to be appropriate to go and seek health, are you worth going to seek healthcare, there's a lot of stigma particularly from certain populations, not just ethnicity but more in areas of social deprivation.

1 Sometimes people feel that they've, you know, deserved
2 to be ill and therefore that stops them seeking
3 healthcare.
4 If they've heard that actually there's not that
5 much trust in the healthcare system and if already they
6 don't have much trust in a healthcare system that will
7 all negatively impact our ability to actually support
8 that population.
9 **Q.** My last question on this topic is this. Has there been
10 any targeted research conducted to understand how
11 Long Covid affects ethnic minority healthcare workers
12 compared to their counterparts?
13 **PROFESSOR EVANS:** So there's the UK-REACH original study.
14 They have definitely done further work looking at how
15 Long Covid has affected healthcare workers of different
16 ethnic backgrounds. I'm not aware of all the results
17 yet but they've definitely got a series of ongoing
18 research at the moment, so that is active.
19 **Q.** Final topic. Again at paragraph 79 of your report you
20 discuss the role of social deprivation in driving health
21 inequalities related to Covid-19 and Long Covid.
22 Question: could socioeconomic factors such as
23 limited healthcare access or lower awareness of
24 Long Covid symptoms contribute to under-reporting within
25 deprived communities?

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1 **PROFESSOR EVANS:** Absolutely, and then I think we've also
2 heard how much effort, time, energy, it's taken to
3 navigate the healthcare system even by people that have
4 a skill set to be able to do it albeit completely
5 challenged while being ill. So yes, I think -- yeah
6 definitely.
7 **Q.** And what public health measures could be implemented to
8 raise awareness and improve access to care for
9 Long Covid in socioeconomically deprived populations
10 and, again, trying to help the Inquiry here in terms of
11 trying to look for positive things that could be done,
12 recommendations?
13 **PROFESSOR BRIGHTLING:** Again, I think it would be good to
14 consider case finding because, as we've just heard from
15 Rachael, not only do you have problems with people that
16 are actually seeking healthcare, it's whether they've
17 actually got healthcare available they can even seek in
18 some of these areas because we all recognise that it's
19 still often quite difficult to access primary care for
20 some individuals.
21 So if you actually have better ways of then
22 actually going out into the community and trying to
23 identify where there are challenges in terms of ongoing
24 symptoms, so actually trying to then identify cases, and
25 then being proactive, so, again, trying to then think

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1 about how you can then proactively try to help to manage
2 those symptoms in people in those areas.
3 **Q.** And finally, and I'm just piggybacking on something you
4 just said earlier to Ms Peacock, from what you said
5 earlier about better support from NHS for workers with
6 Long Covid and occupational health, it being very rigid
7 and inflexible, are you aware of reports of disparities
8 in employer support for ethnic minority healthcare
9 workers? Are you aware of any reports of disparities?
10 **PROFESSOR BRIGHTLING:** So I'm not aware personally of that
11 but absolutely there are disparities that have been in
12 the public domain around the way different ethnic groups
13 have then been treated in terms of their exposures at
14 work, and then therefore their risk of then long-term
15 consequences. So that I appreciate is in the public
16 domain but not something that I've personally
17 confronted.
18 **PROFESSOR THOMAS:** My Lady, those are my questions.
19 **LADY HALLETT:** Thank you, Mr Thomas.
20 **PROFESSOR THOMAS:** Thank you.
21 **LADY HALLETT:** Thank you very much, Professors. You'll know
22 far better than I but one of the most distressing things
23 about Long Covid, I understand from sufferers, is not
24 being believed and I'm sure on behalf of all the
25 sufferers they want me to thank you and your colleagues

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1 for all the work that you do, not only getting
2 recognition for the condition but trying to treat and
3 support people who have it.
4 So thank you for all your clinical work and your
5 research work, but thank you also for the work you've
6 done for the Inquiry. This may be your last appearance,
7 I don't know, but if it is, thank you for all the help
8 that you've given.
9 Right, 10 o'clock tomorrow. Thank you.
10 **(Witnesses withdrew)**
11 **(3.55 pm)**
12 **(The hearing adjourned until 10.00 am**
13 **on Wednesday, 30 October 2024)**
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