

OPUS2

Scottish Covid-19 Inquiry

Day 24

March 14, 2024

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1 Thursday, 14 March 2024
2 (9.45 am)
3 (Proceedings delayed)
4 (10.08 am)
5 THE CHAIR: Right. Good morning, Ms Bahrami, and good
6 morning, Mr McConnell, and those in the room. I'm very
7 sorry for the delay, which was to do with a computer
8 malfunction, but I hope it's all now sorted.
9 MS BAHRAMI: Good morning, Lord Brailsford.
10 THE CHAIR: Can you hear me?
11 MS BAHRAMI: Yes.
12 THE CHAIR: Good. You heard what I said then, did you?
13 MS BAHRAMI: Yes, we did. Thank you, my Lord.
14 THE CHAIR: Right. Over to you.
15 MR EDWARD MCCONNELL (called)
16 Questions by MS BAHRAMI
17 MS BAHRAMI: Thank you. Good morning, Mr McConnell. Your
18 full name is Eddie McConnell; is that correct?
19 A. That's correct.
20 Q. And you're the chief executive of Down's Syndrome
21 Scotland?
22 A. That's correct.
23 Q. Could you tell us a bit about the work that
24 Down's Syndrome Scotland does, please?
25 A. Yes, I'm happy to do that. So Down's Syndrome Scotland

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1 is the only charity in Scotland that supports people
2 with Down syndrome and their families from birth right
3 through to their older age, at every stage. It was
4 established as a charity 40 years ago, just over
5 40 years ago, and we have 1,400 members across Scotland.
6 800 of them are what we call family members, parent
7 carers, and 600 of them are adults with Down's syndrome.
8 We are supported by ten local branches of Down Syndrome
9 Scotland, based in local communities, and they're
10 organised by our parent volunteers.
11 We have — our work is very focused on supporting
12 families and people with Down syndrome. We believe that
13 every individual with Down syndrome has immense
14 potential and we also believe we have much to learn from
15 them. So our job, our privilege, is to get right
16 alongside families and right alongside people with
17 Down syndrome to bring out that potential as best we
18 can.
19 Q. Thank you. I want to jump forward a bit in your
20 statement before going back again, but at paragraph 27
21 you say that, although you used the word "resilient" to
22 describe the families you work with, they were only just
23 about coping before the pandemic. To help us
24 understand, please would you tell us a bit more about
25 the general difficulties, pressures and responsibilities

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1 on those families who have a family member with
2 Down syndrome?
3 A. Well, thank you. So what — I can speak from personal
4 experience as well as a father of a son with
5 Down syndrome and therefore I can really relate to what
6 our families tell us. So many of our families face, on
7 a daily basis, quite a lot of discrimination and
8 barriers, and what they would say to us is that it's not
9 because they have a child with Down syndrome, it's
10 because of the attitude of others, which at one level
11 might just simply be ignorance about the condition of
12 Down syndrome, but at an extreme level is also about —
13 and we have evidence of this — some discrimination and
14 prejudice that takes place in terms of attitudes towards
15 people with Down syndrome.
16 So for families who have a young person with
17 Down syndrome in the family, their daily experience is
18 they often have to fight to secure the rights of their
19 loved ones and it's a fairly exhausting daily
20 experience. They have the same rights — our citizens
21 with Down syndrome have the same rights as every other
22 member of society, but on a daily and weekly basis those
23 rights are often not upheld and sometimes quite
24 blatantly violated.
25 So for families it becomes a real fight to secure

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1 provision and support, whether that's in the early days
2 in terms of medical support or interventions or support
3 to access education in the place of their choice,
4 whether that's mainstream education or whether that's
5 special need provision. All families tell us that is
6 always a fight, and that continues throughout their
7 life, whether it's then leaving school and accessing
8 social care support for families.
9 They would wish that society understood the
10 potential of their loved ones and it wasn't so much of
11 a fight to secure those rights, and the consequence of
12 that is it becomes really exhausting for our families
13 because it is a daily struggle to secure those rights
14 and those provisions that of course people with
15 Down syndrome are entitled to.
16 Q. Thank you. Moving back a bit — this section starts at
17 paragraph 18 onwards — at the outset of the pandemic
18 you say that social care provision was withdrawn. Was
19 this state-provided social care or social care that
20 parents paid for or both?
21 A. So it would be a combination of both, but in the main
22 what we're reporting here is social care that was
23 provided by social care providers that were often
24 commissioned by local authorities to provide that care
25 and support. So in a number of instances they are

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1 themselves charities but they are also social care
 2 providers and are often --- in most cases actually ---
 3 commissioned by the local authority or the Health and
 4 Social Care Partnership to provide support to people,
 5 disabled people, locally .
 6 Q. And what was the impact on individuals with
 7 Down's syndrome and on their families and unpaid carers
 8 of this support being withdrawn?
 9 A. So the families told us that the impact was huge because
 10 it was immediately withdrawn. There was no transition;
 11 there was no discussion about how we might move to a new
 12 set of arrangements. So they received phone calls from
 13 their social care provider simply advising them that
 14 social care could not --- could no longer be provided.
 15 So initially it was a real shock for families . They
 16 were themselves, like many of us, trying to get their
 17 head round what was happening and of course their main
 18 concern was about protecting their loved ones in that,
 19 and the provision of social care support is part of
 20 protecting and supporting them. So to have that
 21 withdrawn was for many of the families a lifeline that
 22 was actually withdrawn from them. It meant they became
 23 carers 24/7. It meant that they became carers
 24 overnight, in many cases, 24/7. And although
 25 I described them previously as a resilient population,

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1 many of them were exhausted and very quickly were on
 2 their knees in terms of trying to navigate their way
 3 through the pandemic on their own because that social
 4 care support was removed.
 5 The impact on people with Down syndrome was really
 6 profound. It's really important for our community to
 7 have structure and to have support and to be part of
 8 wider society, and that's what social care facilitates .
 9 So to remove that so quickly means that people with
 10 Down syndrome lost their connections, they became very
 11 isolated , loneliness was identified very quickly and we
 12 know that their mental health deteriorated very quickly.
 13 And for some in our community that manifested itself as
 14 behaviours that were different . Some people describe it
 15 as "challenging". We would describe it as an expression
 16 of frustration . But that change in behaviour had then
 17 to be managed and supported by unpaid carers, families,
 18 family members on their own, without that social care
 19 support.
 20 So it was really profound, the impact of withdrawing
 21 social care support and the uncertainty that went
 22 alongside that in terms of not knowing if this was
 23 a matter of weeks or a matter of months and when
 24 would it come back. Indeed would it come back was also
 25 quite a significant factor that many families talked to

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1 us about.
 2 Q. Thank you. You actually mentioned being aware of
 3 a family that was asked to continue paying for the
 4 service despite not knowing when or if it would come
 5 back so that they could keep their place. Do you know
 6 whether that family did in fact pay?
 7 A. So it was a really difficult moment for everybody and
 8 I assume therefore it was a really difficult moment for
 9 social care providers, who were trying to understand
 10 what the future might look like, and we know that, we
 11 understand that. But it seemed really perverse to us
 12 that that social care provider would say to a family
 13 member, "We're withdrawing your support. However, we
 14 think it's best that you keep paying for that so that
 15 your space is there when things return to normal or
 16 return back". I'm pretty sure the --- I'm pretty
 17 confident that the family member challenged that view
 18 and I'm pretty confident the social care provider
 19 revisited their idea that the payment should continue.
 20 Q. Thank you. Now, you go on to say that support to
 21 families with caring responsibilities came a lot later
 22 on during the pandemic, after much petitioning from
 23 organisations such as yours. Could you tell us about
 24 that petitioning activity? What forms did it take?
 25 Which people or entities did you have to petition and

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1 what resources were required for that?
 2 A. So throughout the pandemic and in those early months of
 3 the pandemic throughout 2020, we were in constant
 4 contact with the Scottish Government's learning
 5 disability policy team. They were, before the pandemic,
 6 our go-to civil servants in terms of feedback about what
 7 was happening to our community, so they were the natural
 8 place to engage with as we started to spot concerns
 9 happening.
 10 I think the challenge was that --- they were really
 11 receptive to our views and very supportive of our
 12 concerns, but their challenge was then to take that to
 13 the civil servants who were dealing with those concerns.
 14 So an example of that is that we were concerned that our
 15 family carers weren't getting the kind of level of
 16 support that we felt they needed. We were trying to
 17 provide that as a charity as best we can --- many
 18 charities stepped in to do that --- and we really felt
 19 that, as unpaid carers, we really needed some additional
 20 support, including financial support. And it became
 21 a very long journey through Government, I presume
 22 through different departments, probably up inside
 23 Government and down, to eventually deliver some carer
 24 support through the network of carers --- carers'
 25 charities that are based locally . But it came much

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1 later in the pandemic.
 2 We would also say — and I think I've mentioned this
 3 in my statement — that for a number of charities who
 4 have conditions, specific charities or charities that
 5 support people with Down syndrome, we would have liked
 6 that support directly coming to us because we have that
 7 established knowledge and relationship with that
 8 particular group, and it seemed a very long way round to
 9 try and get support that was very generic and not
 10 specific enough for our community, so ...
 11 Q. Do you think a better approach might have been for those
 12 organisations that address a specific diagnosed
 13 condition, that they were to receive payments, and for
 14 those conditions where there is no specific diagnosis or
 15 there is no dedicated organisation, that for them it
 16 would go through a carer centre, so perhaps a dual
 17 approach would have been better and more efficient?
 18 A. So I think one of the issues that we would reflect is
 19 that, when we raised a concern with Government through
 20 our established channels, we were not engaged in the
 21 conversations that took place to decide how to respond
 22 to that concern, and I think that's a pity. I think the
 23 consequence of that is that we could have influenced
 24 a different outcome or, as you have put it, different
 25 options rather than just one option coming forward. So

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1 it was a frustration for us that we often lost the
 2 conversation once it entered Government because
 3 Government had to speak with other departments and then
 4 the solution that popped out was often not perfect and
 5 then we had to work round and come up with additional
 6 solutions to make that more perfect. And I think there
 7 should have been greater flexibility — there should
 8 have been greater involvement of us in those
 9 conversations about those solutions and there should
 10 have been greater choice about how that support was
 11 provided.
 12 I do want to acknowledge that we did receive
 13 additional emergency funding from the
 14 Scottish Government, but this is — this point that
 15 we're focused on here is particularly about support for
 16 carers, which was primarily driven through the carers'
 17 centres' network.
 18 Q. What did the carers' centres do with the money being
 19 given to them by the Government?
 20 A. So I think they attempted to reach most carers in their
 21 locality. I can certainly reflect that in my own
 22 experience as an unpaid carer. I was contacted by email
 23 and I was sent some online resources and I was invited
 24 to participate in some online sessions around
 25 well-being.

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1 Q. Okay.
 2 A. But that support was very generic and, to be balanced
 3 about this, it was helpful for those who might have
 4 a broader disability, but in the context of our
 5 community and people with Down syndrome, who have a very
 6 specific set of conditions, particularly health
 7 conditions, associated with that, it was too blunt an
 8 approach and needed to be more precise. And we felt
 9 that there should have been choice and there should have
 10 been a direction of some of those resources directly
 11 into the relationship that we had with families and
 12 people with Down syndrome directly.
 13 Q. Thank you. Could you tell us, do individuals with
 14 Down's syndrome have a named disability social worker
 15 that could help in identifying people and people that do
 16 have a need for funding and additional resources?
 17 A. So many families who have a young person with
 18 Down syndrome, as they approach the end of school will
 19 start that transition process, and often with the help
 20 of Social Work, and that will sometimes lead to the
 21 identification of a specific social worker who might
 22 support the development of a transition plan and
 23 ultimately a budget to support that person in adulthood.
 24 The experience of that across Scotland is really
 25 extremely inconsistent —

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1 Q. Right.
 2 A. — so some people may have a named social worker, some
 3 people may be in a basket — it's often referred to as
 4 "a basket" — and placed in a basket to see who's
 5 available in terms of social worker to pick that case
 6 up.
 7 We know that many of our families are still not
 8 accessing the level of support that they're entitled to,
 9 in terms of self-directed support and a budget, and, as
 10 I said earlier, for many of our families, accessing that
 11 support is often a fight and a struggle. It's often
 12 predetermined by the available resources rather than the
 13 needs and the support needs of the individual, which is
 14 what is actually set out in legislation in terms of
 15 Self-directed Support Act. It's meant to be driven by
 16 the needs — the identified and agreed needs — support
 17 needs of the individual, and often families report to us
 18 their feelings that it's driven by the available
 19 resources rather than the explicit needs, support needs,
 20 of the individuals concerned.
 21 Q. And that was prior to the pandemic, so, presumably, the
 22 pandemic exacerbated that and made things much more
 23 difficult?
 24 A. Yes. So I would say that one of the experiences our
 25 families have reported to us was many of the

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1 professionals who were involved in providing a range of
 2 different support, whether they were health
 3 professionals, like allied health professionals or
 4 social workers, even in education — many of those
 5 professionals stepped right back during the — in the
 6 early days of the pandemic. So not only did social care
 7 get withdrawn almost overnight, but for many of our
 8 families that access to professional support stepped
 9 right back as well. So they felt enormously alone and
 10 enormously vulnerable, more vulnerable, acutely
 11 vulnerable, and that's where organisations like
 12 ourselves and other organisations needed to step in and
 13 provide, as best we could, some of that support.
 14 Q. Thank you. And you've told us about the importance of
 15 socialising for those with Down's syndrome and you go on
 16 to say that, whereas the general population were able to
 17 interact with peers and family online, that members of
 18 the Down's syndrome community weren't accessible online.
 19 Why was that?
 20 A. So our community is an enormously diverse community. So
 21 quite often, if you don't know our world, you'll — if
 22 somebody mentions people with Down syndrome, you'll
 23 think of some of the celebrity people with
 24 Down syndrome, Tommy Jessop, for example, who is
 25 a public figure, as we know, in the world of TV and

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1 media. Those well-known figures are really important in
 2 our community because they're really positive role
 3 models, but they probably only represent the top 5% to
 4 10% of our community.
 5 So our community is a really diverse community and,
 6 as you move across that community, the communication
 7 support needs of that community become more profound,
 8 significantly profound. So it's really important that
 9 people understand that the diversity of the community in
 10 Scotland is quite extensive and therefore the support
 11 needs of that community are really quite extensive. We
 12 always help people to understand that every person with
 13 Down syndrome is a unique individual and they therefore
 14 have a unique set of support needs, and it's important
 15 for people to really understand that quite clearly.
 16 Q. Yes. Thank you. And you say in your statement that the
 17 consequence of not being able to interact, at least
 18 online, has had an effect on confidence levels and that
 19 the confidence levels aren't even back to pre-pandemic
 20 levels yet. Is your organisation's view that perhaps
 21 exceptions should be made in the case of people with
 22 Down's syndrome and certain other conditions to allow
 23 physical interaction to continue in some way and, if so,
 24 do you have any views on how that could be achieved,
 25 outdoor interactions or any other way to ensure that

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1 this gap doesn't arise again?
 2 A. So if you give me permission, I'd like to go back to the
 3 previous question because I think I probably can provide
 4 a fuller response to the previous question but still
 5 help answer this next question, if that's okay.
 6 So it's really important for people with
 7 Down syndrome to have structure in their lives and to
 8 have those connections and to feel part of not just
 9 their community — to feel part of a wider community.
 10 We believe that society benefits from having them
 11 closely involved. So the removal of that structure has
 12 a really profound impact on them and, as I said earlier,
 13 it does result in changing behaviours. It definitely
 14 resulted in examples of mental health and well-being
 15 deteriorating, depression occurring and loneliness and
 16 isolation becoming very significant with that community.
 17 It's an interesting question about whether creating
 18 face-to-face opportunities or physical spaces for people
 19 to continue to meet may have helped. I think what was
 20 uppermost in all our minds at that time was keeping our
 21 community safe, so the notion of moving to create any
 22 face-to-face meetings was not considered something that
 23 we should be doing at that stage because little was
 24 known about this virus at that point in time.
 25 Q. Yes.

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1 A. We knew that people with Down syndrome, long before the
 2 pandemic came along, had significant health issues, had
 3 significant health inequalities. What the pandemic did
 4 was amplify them. So any idea of safely bringing people
 5 together was not in our consideration in the early — in
 6 the first year of the pandemic, so we relied very
 7 significantly on connecting our community through online
 8 platforms. We brought forward our digital plans and
 9 within six weeks we rolled out a very significant online
 10 secure platform to allow our families to connect. Our
 11 motivations in those early days were about keeping our
 12 families and people with Down syndrome safe, but we also
 13 needed to keep them connected. That was really
 14 important because that sense of connection is really
 15 vital in their lives and we knew it had been withdrawn.
 16 So we introduced — for young teenagers with
 17 Down syndrome, we introduced our online teen-space
 18 programme, which was regarded by many families as an
 19 absolute lifeline, the option for teenagers to come
 20 online and connect with other teenagers. We did
 21 similarly for adults with Down syndrome. We created a
 22 friends-space programme online.
 23 That felt the right thing to do, even though we were
 24 very conscious that for many in our community they
 25 simply didn't have access to digital technology to take

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1 part, and the reason they don't have access is to do
 2 with that diversity of their — of our community. So
 3 while some are very technically literate, others need
 4 considerable support, and others, who might be, for
 5 example, in supported accommodation, often don't have
 6 the right to have access to their own technology and
 7 communication and — so while relying on that online
 8 world was the right thing to do to try as best we could
 9 to keep people connected, we were very mindful that for
 10 significant parts of our community that wasn't an option
 11 for them. So we placed, for that community, significant
 12 what we call "kindness calls". We got in touch with
 13 families to understand how they were doing, just to have
 14 a conversation with them online.
 15 I think the whole access to technology is — has
 16 been, on one level, really helpful because we were able
 17 to connect people who were not connected before, so we
 18 were able to connect a family in Orkney with a family in
 19 Dumfries, when previously, without that online
 20 provision, they were unlikely to meet because of the
 21 distance, but they connected because we had an online
 22 provision. So that's positive and we continue a lot of
 23 that today.
 24 The negative is that for quite a large significant
 25 element of our community, they simply don't have access

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1 to digital technology in the way that you and I take for
 2 granted each and every day and they need considerable
 3 support with that, which might be as simple as the
 4 provision of a device, but it will almost certainly be
 5 support to access and use that device in a safe and
 6 responsible way.
 7 Q. Thank you. You mentioned there that essentially other
 8 health conditions, comorbidities, with Down's syndrome
 9 are well known and there are some that could exacerbate
 10 COVID infections, but that those — but you mention in
 11 your statement that those with Down's syndrome weren't
 12 initially on the shielding list. Presumably, that would
 13 have caused some anxiety and uncertainty for those with
 14 Down's syndrome and their families, and your
 15 organisation was involved in highlighting this issue.
 16 You then tell us, once that was accepted, I think
 17 following an Oxford study that showed those with
 18 Down's syndrome to be at higher risk, that there was
 19 a gap between national Government making that decision,
 20 that people with Down's syndrome should be on that list,
 21 and then the local health boards implementing that
 22 decision. Could you expand on the evident shortcomings
 23 in support and care following that decision?
 24 A. This is a really important element of our submission and
 25 it's really important that I emphasise that the health

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1 conditions of people with Down syndrome were well
 2 documented and well known about before the pandemic came
 3 along. We know that people with Down's syndrome are
 4 prone to respiratory difficulties, we know that one in
 5 five children born with Down syndrome have a cardiac
 6 difficulty, cardiac challenges, and we know that their
 7 immune systems are compromised. So these are
 8 well-documented, well-known, for want of a better
 9 expression, risk factors associated with people with
 10 Down syndrome. So I guess we were really frustrated at
 11 the start of the pandemic that that wasn't acknowledged
 12 and understood, and I think there's still a question to
 13 be asked why that — there's still an answer to be given
 14 why people with Down syndrome were not properly
 15 recognised as a high-risk group.
 16 I've said in my statement that it might be therefore
 17 inferred that people with Down syndrome were clearly
 18 left behind at the start of the pandemic and it might be
 19 that some people with Down syndrome died as
 20 a consequence of not having been on, for example, the
 21 shielding list. So we petitioned quite strongly and
 22 continuously throughout that period.
 23 So the shielding list, if I recollect correctly,
 24 came into place in March 2020. People with
 25 Down syndrome were added to the shielding list

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1 eight months later, in November 2020, and it came as
 2 a consequence of research that we supported
 3 internationally with what's called the "T21 Research
 4 Society", which is a society that focuses particularly
 5 on research around people with Down syndrome and, as you
 6 rightly mentioned, the study conducted by
 7 Oxford University, which identified and confirmed that
 8 people with Down syndrome were in fact ten times more
 9 likely to be hospitalised and possibly die if they
 10 caught coronavirus.
 11 The chief medical officers across the UK, on the
 12 back of that evidence, moved very quickly to issue
 13 a letter, a consistent letter, across all of the four
 14 home countries to say that people with Down syndrome
 15 would now be added to the shielding list. That started,
 16 I think — if I recollect correctly, that started
 17 probably in September and started to gain some momentum
 18 in October and a letter was eventually issued at the
 19 start of November. The issuing of the letter was then
 20 the start of another period of implementation.
 21 So our experience from families who spoke to us, who
 22 were really anxious of why their loved ones were not on
 23 the shielding list — because they understood that being
 24 on the shielding list would provide additional support,
 25 would recognise that they had underlying health

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1 conditions and complex issues that needed to be
 2 acknowledged and supported, and they also believed,
 3 rightly or wrongly, that they might have prioritised
 4 access to a vaccine when it came along and any
 5 additional health support that might be provided.
 6 It was a common experience of our organisation that,
 7 once national guidance was issued, the filtering of that
 8 guidance to delivery and implementation at a local level
 9 took some time and also was implemented not
 10 consistently; not consistently sometimes within local
 11 health boards and certainly not consistently across
 12 health boards in Scotland. We often found ourselves —
 13 and this is set out within the submission — we often
 14 found ourselves having to phone GP practices and telling
 15 them that people with Down syndrome were on the
 16 shielding list, and that came as a consequence of
 17 families contacting us and saying, "I've been in touch
 18 with my GP. He's adamant people with Down syndrome
 19 aren't on the shielding list". We would contact and
 20 provide a copy of the Chief Medical Officer's letter.
 21 So there was a significant gap between national
 22 guidance and local implementation, and we stepped in to
 23 try and close that gap as best we could, but it was
 24 enormously frustrating for families. It created another
 25 level of stress and it was quite clear that the

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1 communication channels were not well developed, and we
 2 found ourselves often being the one to tell health
 3 professionals of the changes that were happening
 4 nationally. So certainly in terms of lessons learnt,
 5 I think there's a significant gap between national
 6 direction and guidance and local implementation that has
 7 to be examined more closely in any future pandemic
 8 planning.
 9 Q. Thank you. And your view, then, is that that gap is
 10 largely down to inadequate communication at the local
 11 government level — is that right? — or local health
 12 board level? Sorry.
 13 A. Yeah. So I'm not sure we know why that gap happens.
 14 I think you'd probably have to ask others why that gap
 15 happens. All we know is that we found ourselves in the
 16 position, six weeks after an announcement had been made,
 17 still telling people locally what the current position
 18 was and having to, as I've referenced earlier — in the
 19 experience of families, having to fight for their
 20 rights, fight for their support. We found ourselves
 21 often sometimes in quite combative conversations with
 22 general health practitioners, with health board
 23 officials, to make them realise that in fact people with
 24 Down syndrome were now on this shielding list and you
 25 needed to acknowledge that and now provide the

22

1 additional support that came with that.
 2 Q. Thank you. Clearly, during the pandemic, the work that
 3 your organisation had to do increased dramatically and
 4 you've explained the reasons for that. You do say that,
 5 in time, you received emergency COVID funding but before
 6 that you had to dip into the organisation's reserves.
 7 The organisation had already been struggling to keep up
 8 with demand so that placed quite a bit of pressure on
 9 you.
 10 While you were dealing with this, you then of course
 11 had to apply for the funding and wait for that to be
 12 granted. Could you tell us, amidst dealing with the day
 13 job essentially of the organisation, how did you find
 14 the application process and the steps required to be
 15 taken until funding was granted?
 16 A. So maybe just a wee bit of context about how we as an
 17 organisation arrived into the pandemic, and you've
 18 referred to some of that there. So, as an organisation,
 19 we were financially very challenged before the pandemic
 20 came along. I joined in August 2019, knowing that we
 21 had to look at restructuring the organisation to live
 22 within its means. We had a significant — it's a matter
 23 of public record — we had a significant legacy debt.
 24 So ironically we had our own recovery plan in place
 25 before the pandemic arrived. When the pandemic arrived,

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1 we had to reduce the size of the organisation very
 2 quickly. Half of the staff immediately went onto
 3 furlough and subsequently we had to make redundancies —
 4 a significant number of redundancies of staff. About
 5 half of the staff group had to leave us at that point.
 6 So we were dealing with quite challenging issues
 7 ourselves as a charity and, as a consequence of that,
 8 that manifested itself as quite a challenging cash flow
 9 position. We know we weren't alone as a charity, we
 10 know many charities faced that problem. I would say
 11 that, initially, the emergency funds that became
 12 available flowed to us quite quickly. I would say that
 13 some funders really understood the importance of getting
 14 finance to us quickly so that we could continue the work
 15 we were doing and I would say those processes were
 16 accelerated in a helpful way.
 17 It's really interesting that funders, including
 18 Government, can really amplify their confidence in the
 19 organisation to do the work we're doing and how
 20 important that is. They can do that in the time of
 21 a pandemic, but when we recover from the pandemic, we
 22 find ourselves returning to a much more significant set
 23 of criteria and hoops that we need to jump through. So
 24 in some ways we wonder why they had that confidence in
 25 us in that crisis, but now that the acute state of that

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1 crisis has gone, we wonder why it is so difficult now to
 2 achieve the same level of funding and support.
 3 So I would want to commend some of the funders for
 4 the flexibility they had and the speed at which they
 5 moved to release funds to us, but today that's a very
 6 different — we seem to have gone back to how things
 7 were before the pandemic, and yet it's really
 8 interesting that there was such a level of confidence in
 9 us as vital players to provide support to a vulnerable
 10 and marginalised community in the pandemic. They're
 11 still a vulnerable and marginalised community. That
 12 hasn't changed.
 13 So we — enquiries to our helpline peaked during the
 14 pandemic, they haven't come down, so they're still up at
 15 that level. We had a 20% increase in what we call
 16 "complex support enquiries". One in four of our
 17 enquiries to our helpline are what we designate as
 18 complex, enquiries needing a minimum in that initial
 19 contact of two to three hours of support, but a lot of
 20 ongoing support. It's now one in three of our enquiries
 21 are complex enquiries, so the need is still going up.
 22 So — and yet the access to the resources that were
 23 available in that very flexible way is no longer
 24 available in that flexible speedy way.
 25 We believe, like many charities, we stepped in and

25

1 responded to the national emergency. We truly believe
 2 we saved lives, we genuinely believe we did that, but we
 3 don't believe that we are valued sufficiently now as
 4 part of the national response and part of the recovery
 5 going forward, and we're really disappointed that the
 6 contribution we made then has not been supported to
 7 continue as the country tries to move forward and
 8 recover and we still believe that we're in that recovery
 9 stage.
 10 THE CHAIR: You of course raise an interesting point,
 11 Mr McConnell. I don't doubt anything you tell me. It
 12 makes common sense to me, to be perfectly frank. The
 13 problem or the issue I have is that the situation you
 14 are in now is outwith my terms of remit or the terms of
 15 this Inquiry's remit. We have, as you know, I think,
 16 specific dates which terminate in the end of 2022.
 17 I understand that I would probably be entitled to make
 18 comments about recognition that you deserve for the work
 19 that you did, your organisation did, but it's difficult
 20 for me to say anything about the position you find
 21 yourself in at the moment, I'm afraid.
 22 A. Thank you for that, Lord Brailsford. I understand that
 23 completely. Perhaps the point I was probably making was
 24 that, in the pandemic, people really valued and
 25 understood the contribution we could make and it's

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1 disappointing that that is not — you know, lots of
 2 innovation, different ways of working prevailed. People
 3 came together in a different way of working. Perhaps
 4 the most obvious example from our own community was
 5 actually the speed at which people who were homeless
 6 were moved off the street within a matter of weeks, and
 7 who would have thought that was possible before
 8 a pandemic came along?
 9 So some of the innovation that came as a result and
 10 some of the developments that came as a result of
 11 responding to the crisis of — by putting people
 12 together and working closely together and being in
 13 a sense less concerned about whether you're third
 14 sector, public sector, health sector, but that you're
 15 focused on people who needed support, I think as
 16 a lesson learned from the Inquiry, we would hope that
 17 that lesson would be amplified, that — you know, as
 18 something very good that came out. People worked
 19 differently together. And I understand, going forward,
 20 it's beyond the remit of the Inquiry to necessarily say
 21 what's happening today, my Lord.
 22 THE CHAIR: Certainly the general point you make is
 23 something that can be considered and made if need be.
 24 A. Thank you.
 25 MS BAHRAMI: Thank you.

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1 Now, you mentioned your staff taking calls from the
 2 public and the number of complex calls, which you class
 3 as calls requiring more than two hours, increased.
 4 You've also said in your statement that the nature of
 5 those calls changed. Before the pandemic, the calls
 6 were really mainly focused on Down syndrome itself, but
 7 during the pandemic people called you in relation to
 8 their mental health, their concerns, lack of benefits or
 9 benefits I suppose not covering all of their needs. And
 10 then you go on to talk about a parent who became so
 11 desperate for help for her daughter that she actually
 12 harmed her daughter as she thought that was the only way
 13 to obtain help. Could you expand on that, in particular
 14 why did she think that was the only way to achieve that
 15 aim and was she then in fact able to achieve that help
 16 or to get that help?
 17 A. So I think it's important to recognise that, for many of
 18 our families, they became very desperate, they became —
 19 because the support they had experienced had been
 20 withdrawn. They were really, really anxious and really
 21 worried. The nature of the calls, which quite quickly
 22 pre-pandemic were about Down syndrome and adjusting to
 23 having somebody with Down syndrome and what that means
 24 in your life, were replaced by conversations about
 25 stress, about worry, anxiety, mental health concerns,

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1 about impacts with benefits, about not having sufficient
 2 funds, and all of that happening when they were
 3 24/7 carers.
 4 Q. Yes.
 5 A. So looking — understandably wanting to really look
 6 after their loved ones to the best of their ability but
 7 doing so 24/7 — so they were exhausted and many of them
 8 continue to be exhausted today.
 9 I don't — and we would never — pass judgment on
 10 somebody who was so desperate that she was getting no
 11 support from — in that person's case, from Social Work
 12 and felt that the only way to get that support was to do
 13 something quite disastrous, to in a sense invoke
 14 statutory involvement in her family because her view was
 15 nobody was responding to her pleas for help — so she
 16 took that really desperate measure, really desperate,
 17 and we absolutely do not have any judgment on that in
 18 terms of it was clear she herself had very significant
 19 mental health needs that were not being supported or
 20 recognised. It's uncertain — and I should say for the
 21 record, you know, because there was statutory
 22 involvement in terms of the police — it's uncertain
 23 whether she did actually did harm her daughter, so it's
 24 important for us to just acknowledge that. She alleged
 25 that she was going to harm her daughter and she saw that

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1 as the only way to get support because nobody was
 2 listening. She was absolutely at the end of her tether.
 3 Q. Do you have any thoughts on how that could be avoided in
 4 future? Is it simply an issue of resource or are there
 5 other steps that could be considered?
 6 A. So I'm reluctant to always come back to resource. I'm
 7 sure that's a tired argument that lots of people hear.
 8 I think one of the more significant issues — and again
 9 I mentioned this within the submission — it's the gaps
 10 in data that exist for our community. So many people
 11 with Down syndrome are not known to local authorities.
 12 They're not identified locally. They're not on any
 13 register. That became abundantly clear to us in the
 14 pandemic, when we found ourselves having to pass on
 15 information to GP practices, to local health boards, of
 16 people we knew about who had Down syndrome that were not
 17 appearing on their lists and were therefore not
 18 receiving a shielding letter or were not receiving an
 19 invitation to vaccine.
 20 So there is this notion that's often referred to
 21 across our community and other charities of the
 22 invisibility of people with Down syndrome. So I think
 23 one of the issues is that data collection needs to be
 24 significantly improved. There are significant gaps in
 25 knowing where people with Down's syndrome, who are

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1 a vulnerable community, who are significantly
 2 marginalised — knowing where they are, and that has
 3 to — we would argue that has to be prioritised going
 4 forward and, certainly as part of any new planning for
 5 any new emergency, that has to become a priority. So we
 6 were very much doing that retrospectively in the
 7 pandemic because we knew from families contacting us
 8 that they hadn't received a shielding letter or they
 9 hadn't been in any contact with the vaccination as it
 10 started to roll out. So I think this issue of gaps in
 11 data is very significant for people with Down's syndrome
 12 and more broadly for people with learning disabilities
 13 in Scotland.
 14 We often say that we know there are 4,500 to 5,000
 15 people with Down syndrome in Scotland, but we quickly
 16 support that with a qualification that that is almost
 17 certainly a very significant underestimate because of
 18 the gaps in data. So while resources are really
 19 important and directing those resources, I think of
 20 equal importance is addressing the invisibility of many
 21 people with Down's syndrome by improving data collection
 22 and ensuring those gaps are closed.
 23 Q. Thank you. Now, I'd like to move on to the impact of
 24 school and day service closures, and I think it relates
 25 back to this issue as well of parents having to take

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1 everything on themselves. A lot of parents were having
 2 to home-school their children who didn't have health or
 3 genetic conditions. Where parents were trying to
 4 home-school their children who have Down's syndrome,
 5 particularly if they also had other children, presumably
 6 that would be more demanding, and you mention there was
 7 an abundance of general materials for home-schooling
 8 children but that those children with Down syndrome
 9 found those materials overwhelming. Am I correct in
 10 understanding that those materials were of limited
 11 benefit to those children with Down's syndrome and, if
 12 that's correct, is it your view that education
 13 authorities should have developed more specific
 14 materials?
 15 A. We're definitely of a view — and families have told us
 16 this — that the home-schooling support was not at all
 17 adequate, and there will be exceptions to that. We
 18 should acknowledge that. But across the board what we
 19 were hearing was that the needs — the specific needs of
 20 our community and the wider learning disability
 21 community weren't really properly recognised in terms of
 22 resources that were being made available.
 23 So there seemed to be this rush to just get as much
 24 resources to families as possible without at the same
 25 time thinking, "How do we need to adapt this resource

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1 for people who have additional support needs?”. So in
 2 many instances parents found themselves having to invent
 3 that themselves. It was a consistent feature at that
 4 time when young people were being home—schooled. It was
 5 a consistent feature that families were reporting just
 6 feeling completely overwhelmed. They had the 24/7
 7 responsibility as an unpaid carer and now they were
 8 being asked to take on responsibility to home—school
 9 with resources that didn’t really facilitate that in any
 10 effective way. So many of our families simply pushed
 11 that information to one side because it overwhelmed
 12 them.

13 That’s a common feature of some public institutions,
 14 who I think are motivated to say, “We must get as much
 15 information as possible to all of our families and to
 16 all of our communities”, but we would encourage them to
 17 step back and understand how that information is
 18 delivered, how it is made inclusive and how it is made
 19 relevant to the particular communities. And there was
 20 no nationally consistent effort around all of that. So
 21 we have been clear in the submission that we think,
 22 going forward, there needs to be some sort of national
 23 standards agreed about what that looks like. Our view
 24 is that people with additional support needs were not
 25 heavily considered in a prioritised way within the

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1 efforts made by education authorities, and certainly
 2 that’s what families told us and they felt very — with
 3 exceptions, there are exceptions to that. We know
 4 that — but they felt very abandoned, is the word they
 5 often used when talking to us.

6 Q. Thank you. For the parents themselves, you say that
 7 employment gives them a moment where — and you’re
 8 hesitant to use the word — but you say where they can
 9 be normal, and that was lost, so they were, as you’ve
 10 said, 24/7 carers, but you also say that some of them
 11 found themselves out of a job as a result of their
 12 caring responsibilities. Did those parents decide to
 13 leave their jobs or were they terminated by their
 14 employers because of their other responsibilities?

15 A. I think probably in most instances parents were trying
 16 to juggle too much and in the instances where some found
 17 themselves out of work, they probably took that decision
 18 because they weren’t experiencing a flexible employer
 19 who was going to support their situation and they
 20 realised that they could not continue to work full—time
 21 while also being a 24/7 carer.

22 So I think it would be fair to say that those
 23 families who did that, who found themselves out of work,
 24 probably initiated that as a survival mechanism. You
 25 know, that’s how they thought they were going to be able

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1 to survive. And while there will have been some
 2 employers that were really supportive, it was certainly
 3 the experience that a number of families found
 4 themselves having to give up work or certainly reduce
 5 significantly their hours of work in order to deal with
 6 the pressures they were under.

7 Q. Thank you. Now, there came a point, of course, where
 8 the restrictions started to ease and when children
 9 started to return to school and/or day services. You
 10 describe that return as being “horrific”. Could you
 11 please tell us why you describe it in that way? In what
 12 way was it horrific for the children and for their
 13 families?

14 A. Many of the families advised us that they were really,
 15 really worried about the return to school because there
 16 wasn’t clarity about how infection control would occur
 17 in school and they were really worried. So many of the
 18 families simply didn’t let their children return to
 19 school, so they were then even more on their own, trying
 20 to do their best. But by this point, of course, they
 21 had realised that their young people were ten times more
 22 likely to die if they caught the virus, so their anxiety
 23 level was significantly heightened. So understanding
 24 that alongside a call to just get back to school when
 25 there was no clarity about how infection control would

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1 be managed and there was common — I think it was quite
 2 common for people to hear that there was break—outs of
 3 COVID happening in the schools, either in the teaching
 4 staff or indeed with pupils — so the consequence of
 5 that is that many of our families simply didn’t return
 6 their children to school because they were just so
 7 terribly worried that, in the absence of clarity about
 8 how infection control would be managed, they would
 9 find — they would expose their child or young person to
 10 even greater risk. So the consequence, the unfortunate
 11 consequence, is that they became even more isolated,
 12 they became even more worried and anxious and even more
 13 stressed, and that combination of things was described
 14 by a number of families as “quite horrific”.

15 Q. Thank you.

16 THE CHAIR: Can I ask a question at this stage, please,
 17 which really harks back to something you said a little
 18 while ago, Mr McConnell? It’s simply a point of
 19 clarification. I fully understand what you’ve just
 20 been saying about the concern that parents of
 21 a Down’s syndrome child had because of the vulnerability
 22 of their offspring when they were going back to school,
 23 but a little while ago you said that Down’s syndrome
 24 sufferers were — or those that had Down’s syndrome were
 25 ten times more likely to contract COVID and the

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1 consequences therefrom. Did you mean, when you said
 2 that, the entirety of those that have Down's syndrome or
 3 were you specifically referring to ten times more likely
 4 for children? The reason I ask is because I think we
 5 know as a matter of generality that children were much
 6 less likely than adults to contract COVID in the first
 7 place.
 8 A. Thank you, my Lord. I think that's an important point
 9 of clarification. So the Oxford study that identified
 10 that people with Down's syndrome were ten times more
 11 likely to be hospitalised or indeed die should they
 12 contract COVID was focused on adults.
 13 THE CHAIR: Focused on adults.
 14 A. Yes. So that's the factual situation.
 15 THE CHAIR: That's the factual —
 16 A. Yes. But, nonetheless, in the absence of any similar
 17 study for children or young people, you can imagine the
 18 parents, as a consequence, knew that —
 19 THE CHAIR: Oh, yes, absolutely.
 20 A. — and were extremely, extremely anxious.
 21 THE CHAIR: And indeed, to be fair, whilst it may be the
 22 case that — I think the medical evidence is the case
 23 that children were less vulnerable, I think, in the
 24 absence of specific evidence to the contrary, one would
 25 be entitled to assume that, even if children were less

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1 likely to contract COVID, a child with Down syndrome was
 2 ten times more likely, even from a lower base, as other
 3 children, but — as a working hypothesis in the absence
 4 of information.
 5 A. Yes, and I think that's reasonable for families to adopt
 6 that as their approach —
 7 THE CHAIR: Absolutely.
 8 A. — in the absence of that clear information being
 9 available to them.
 10 THE CHAIR: I don't disagree with that at all.
 11 A. Thank you.
 12 MS BAHRAMI: Thank you.
 13 I'm just keeping an eye on time as well.
 14 THE CHAIR: I'm going to obviously allow you a little
 15 longer — well, I'm going to allow you a full quota of
 16 time. We started late so you can finish late.
 17 MS BAHRAMI: Thank you, my Lord.
 18 THE CHAIR: But you are actually running towards the end on
 19 that basis.
 20 MS BAHRAMI: Yes, thank you, my Lord.
 21 Mr McConnell, can you tell us about the impact of
 22 the pandemic on pre- and post-natal care of those who
 23 were told while pregnant that their baby had
 24 Down's syndrome? Was that at around the same level or
 25 was the support through the NHS reduced?

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1 A. So when a family or a mother receives a diagnosis
 2 ante-natally or post-natally that their child may have
 3 Down syndrome or a confirmed diagnosis that their
 4 newborn child has Down's syndrome, a number of things
 5 swing into place quite quickly. So our charity will
 6 quite quickly be involved with that family and we quite
 7 often have referrals. So the physical connection with
 8 that family wasn't able to happen because of the
 9 restrictions for a number of those families where a baby
 10 was born with Down syndrome in that period. Like many
 11 families themselves, they were also very isolated
 12 themselves in that health setting, so it was
 13 particularly difficult for them at a time when support
 14 is really, really needed to help them make the
 15 adjustment and understand their maybe unexpected news
 16 for some of them — because for some of them it is
 17 unexpected news. So I think it was particularly
 18 difficult for those newborns in the pandemic.
 19 We certainly made sure that resources were reaching
 20 them, but one of the things that's really powerful for
 21 new families is putting parents in contact with other
 22 parents, and while we were able to do that online, it's
 23 really powerful for a parent to meet another parent who
 24 has been through the experience and we were unable to do
 25 that. So that's a significant element that was missing

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1 from their reasonable care at that point in their lives.
 2 Q. Thank you. I want to move on to speak about the
 3 clinical frailty scale. Now, my understanding is that
 4 that scale is designed to apply to people who are
 5 perhaps elderly or who have a condition that is terminal
 6 and they are close to the end of their life, but during
 7 the pandemic you found that it was being applied to
 8 those with Down syndrome and your organisation took
 9 action for that. When you contacted the Government, how
 10 did you find the response and how quickly did they
 11 react?
 12 A. So I would have to say that they responded in shock
 13 initially, when we contacted them to make them aware
 14 that a number of families had reported to us that their
 15 loved one was possibly not going to be prioritised for
 16 treatment. They were in hospital but they were not
 17 going to be prioritised because somebody had
 18 inappropriately, completely inappropriately, used the
 19 clinical frailty scale just because the person had Down
 20 syndrome, and that's a wholly inappropriate use. And
 21 indeed I have to say they moved very quickly and
 22 guidance came out to say that the clinical frailty scale
 23 should not be used in determining support and treatment
 24 for people with learning disabilities and in particular
 25 people with Down syndrome.

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1 So I have to say that happened very quickly, that
 2 that guidance came out. Of course it was just guidance
 3 and we're always aware that, when it's guidance, it
 4 doesn't carry a statutory — it wasn't a statutory
 5 instrument, and the consequence of that is we then
 6 redouble our efforts to make sure people know locally
 7 that this guidance has come out. But, similar to my
 8 earlier comments, the gap between that national guidance
 9 coming out and local implementation was very varied and
 10 of course there's that substantive point that it remains
 11 guidance as opposed to an instruction or a statutory
 12 instrument, if you like.

13 Q. You make the point in your statement that generally
 14 across primary care — and I think implied in that also
 15 is in hospital care — that some seem to view the lives
 16 of those with Down's syndrome as less worthy than
 17 others. And you give an example of a man in his 20s who
 18 attended the cardiologist with his mother, and the
 19 cardiologist, during the pandemic, said, "I do not know
 20 whether it's worth operating on someone like him". It's
 21 quite a profound statement, even if they're not
 22 mistakenly using the clinical frailty scale. What
 23 happened in that case? Did the young man get the
 24 treatment that he required?

25 A. So my understanding is he did get the treatment he

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1 required but it required an intervention from us as
 2 a charity to explain why that was a wholly inappropriate
 3 response. This is an issue that our community sadly
 4 live with day in, day out. There are many great health
 5 practitioners, many great medical professionals, who
 6 understand the value of people with Down's syndrome and
 7 who understand that Down's syndrome is a genetic
 8 condition — it is not a disease, it is not an illness,
 9 it is a genetic condition — and that what you need to
 10 focus on is the health conditions that might be
 11 associated with that, but never ever use Down syndrome
 12 as a reason not to treat people or not to prioritise
 13 them for treatment.

14 We know that, despite the efforts of the last
 15 40 years, where we have extended life expectancy of
 16 people with Down syndrome — when the charity started,
 17 life expectancy was just 20 years. Today life
 18 expectancy is 60-plus/70-plus — but it remains the case
 19 that, for people with Down's syndrome, they continue to
 20 die on average 28 years younger than the general
 21 population and, in the majority of those cases, those
 22 deaths are preventable and certainly premature. And we
 23 know from research conducted by the University of
 24 Glasgow that there is often ignorance and prejudice
 25 about the condition that results in people having wholly

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1 inappropriate views about the individual who just
 2 happens to have Down syndrome. So the person was
 3 supported but it required a very heavy intervention by
 4 our charity to bring about a different change in
 5 circumstances.

6 Q. And so these views exist generally but, during times of
 7 stress on the NHS or during pandemics, it just becomes
 8 much more prevalent. And presumably if somebody isn't
 9 used to working with your organisation, then they have
 10 to either deal with this themselves or just accept the
 11 view of the clinician that their child isn't someone
 12 worth carrying out this treatment on?

13 A. So we're very clear that at best it's ignorance that
 14 creates that view of a clinician but actually, in some
 15 cases, it's definitely prejudice and discrimination. So
 16 we work very hard as a charity to tackle that through
 17 training. This is an issue that has existed for our
 18 community long before the pandemic came along, but it
 19 amplified — it was amplified. We were shocked to
 20 discover how quickly it came to the surface and how
 21 prevalent it was in the pandemic. So we've always known
 22 it's there, but we were quite shocked, and the most
 23 obvious example of that was in the conversations around
 24 do not resuscitate orders.

25 Q. Yes, and I actually wanted to come on to that now.

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1 THE CHAIR: You have about ten minutes.

2 MS BAHRAMI: Thank you, my Lord.

3 The do not attempt cardio-pulmonary resuscitation or
 4 DNACPR, you mention in your statement that a seriously
 5 ill woman in her 80s received a call from the GP in
 6 respect of her fit and healthy son who was in his 40s,
 7 with the GP stating that she wanted to place a DNACPR
 8 decision on the woman's son's file, and the woman, you
 9 say, was quite surprised by that. She perhaps — you
 10 imply that she perhaps expected a call in respect of
 11 herself, not her son. Do you think that that was an
 12 isolated incident or do you think that these
 13 conversations in respect of people with Down's syndrome
 14 were taking place very frequently?

15 A. So we definitely know it wasn't an isolated incident.
 16 We know that a number of families had unsolicited calls
 17 from — in this instance, that particular example, from
 18 the GP's practice. The mum in that instance was
 19 actually very confused as to why the conversation was
 20 happening because her own health was extremely
 21 compromised. Sadly she's no longer with us. She has
 22 passed away. So she was confused why the call was about
 23 her son, who is in his 40s and a very fit, very active,
 24 healthy man, who in fact had very — had no significant
 25 health conditions. So she moved from that position of

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1 confusion, reached out to us, to a position of real
 2 anger because she could only — her only rationale for
 3 that conversation taking place is because the GP that
 4 made contact had decided that, because her son had Down
 5 syndrome, that, "Maybe we should just put" — if you
 6 forgive me for using the short term, "do not
 7 resuscitate" — "a do not resuscitate order in place
 8 just in case", and it's completely wrong. It is
 9 completely unacceptable and it reveals terrible bias —
 10 terrible bias — and frankly we would say prejudice
 11 against somebody who has Down syndrome.
 12 We moved very quickly to escalate that within
 13 Scottish Government and within Public Health Scotland.
 14 I have to be honest and say that the response we had to
 15 the clinical frailty scale issue was quite rapid. I'm
 16 probably less clear what the response was on the do not
 17 resuscitate orders, but I know that guidance was
 18 eventually issued after a number of months to be clear
 19 that, while people with Down syndrome are part of
 20 society in general and we know that in society in
 21 general there will be times for conversations about the
 22 appropriateness or not of a do not resuscitate order, it
 23 can never be justified to have that conversation just
 24 because the person has Down syndrome. Down syndrome is
 25 not an illness, it's not a disease. It's a genetic

1 condition.
 2 Q. To your knowledge, did the GPs listen when people said
 3 they didn't want this? Because we know that clinicians
 4 are able to place such notices on people's files
 5 regardless of agreement. Best practice is that they
 6 discuss it. But, in these cases, did GPs proceed to
 7 just place these notices on people's files or following
 8 a conversation with the families did they agree that it
 9 wasn't appropriate?
 10 A. I think our recollection is that, following another
 11 heavy intervention, most stepped back. We couldn't be
 12 certain, though, that these orders weren't — and we
 13 certainly know of one family where an order was put in
 14 place, wholly inappropriately, without the knowledge of
 15 the family, so that was completely unacceptable.
 16 Q. Yes. And you say that eventually perhaps some
 17 communications were put out that this was inappropriate.
 18 Where a notice was placed on a file, do you know whether
 19 that led to GPs revisiting previous decisions that were
 20 based solely on an individual having Down's syndrome or
 21 do those individuals still have DNACPR decisions on
 22 their file?
 23 A. We don't know for certain, and one of our challenges is
 24 that we — the families who reach us, we often believe
 25 there are other families who don't reach out to us, who

1 may be, because of other pressures they have in their
 2 lives, be very deferential to that clinician's
 3 viewpoint. So we do know that, even if there's one
 4 family that reaches us, we have to respond because we
 5 suspect there are many families who haven't reached out
 6 to us and find themselves in a similar position. So
 7 I can't say with certainty whether those orders still
 8 sit on their files or not. I think it's probably for
 9 others to answer that question.
 10 Q. Thank you. Thank you very much for your time. We have
 11 in your statement as well lessons that you believe
 12 should be learned and we've covered some of those in the
 13 course of your evidence and we will take all of that, of
 14 course, into account, even the points that we haven't
 15 covered. Is there anything in particular that you're
 16 keen to emphasise that we haven't discussed already?
 17 A. Well, thank you for that and thank you for the
 18 opportunity today. I do want to go on record and say
 19 that this has been a really supportive experience,
 20 meeting with all the staff at every stage.
 21 Lord Brailsford, in this process, and the staff in the
 22 Inquiry have been enormously supportive and helpful in
 23 allowing us to bring these issues out and give voice to
 24 people who very rarely are heard from in terms of people
 25 with Down's syndrome.

1 I think the most important thing that we must learn
 2 and recognise is that there remains a view — and while
 3 we've made progress, there remains a view that people
 4 with Down syndrome are not as equal as other members of
 5 society, and we really need to be vigilant in the
 6 planning — in the new planning for any future pandemic
 7 or any future national emergency. I think our sector
 8 should be much more closely involved in the planning,
 9 much more respected as an equal partner in that planning
 10 process. For many of us, it felt things were being done
 11 to us and we were reacting all the time. So I think,
 12 going forward, a really important lesson is to recognise
 13 and value the role of charities like ours in planning
 14 for a future emergency and to really value and
 15 appreciate us in every stage of coping with a future
 16 emergency going forward.
 17 Fundamentally we believe people with Down syndrome
 18 are people of immense potential. We believe they have
 19 an awful lot to teach us and we have a lot still to
 20 learn from them, so we must do everything in our power
 21 to protect and safeguard them in any future national
 22 emergency.
 23 MS BAHRAMI: Thank you very much for taking the time to join
 24 us today.
 25 A. Thank you.

1 THE CHAIR: Yes, indeed. Thank you, Mr McConnell, for your
 2 time. I'm sorry you were delayed this morning at the
 3 start.
 4 A. Thank you.
 5 THE CHAIR: Very good. Right, we'll have about 15 minutes
 6 which means probably just before quarter to 12. Thank
 7 you very much indeed.
 8 (11.22 am)
 9 (A short break)
 10 (11.42 am)
 11 THE CHAIR: Good morning, Mr Stephen. Can you hear me all
 12 right?
 13 MR STEPHEN: Good morning, my Lord. Yes, I can.
 14 BARONESS FRASER OF CRAIGMADIE (called)
 15 THE CHAIR: Good morning, Ms Fraser. I'm very sorry for the
 16 delay in hearing your evidence this morning. We
 17 experienced — I don't know if it was computer or
 18 internet difficulties but one or t'other. We've held
 19 you back and I'm sorry for that.
 20 A. No problems.
 21 THE CHAIR: Thank you. Mr Stephen, when you're ready.
 22 MR STEPHEN: Thank you. I'm obliged, my Lord.
 23 Questions by MR STEPHEN
 24 MR STEPHEN: Good morning. Can I ask you to confirm your
 25 full name, please?

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1 A. Yes, my name is Stephanie Mary Fraser.
 2 Q. And your full title is "Baroness Fraser of Craigmadie",
 3 but I think your content to be called "Stephanie" for
 4 the purposes of today.
 5 A. I'm completely happy with that, thank you.
 6 Q. I'm obliged. Thank you.
 7 THE CHAIR: My apologies, Lady Fraser. I wasn't aware.
 8 A. That's all right, my Lord.
 9 MR STEPHEN: Your age and contact details are known to the
 10 Inquiry so I won't ask you about those, and you've
 11 already helpfully provided a written statement. For the
 12 record, the Inquiry reference number for that statement
 13 is SCI-WT0461-000001. Are you content for that written
 14 statement and the oral evidence you're going to give
 15 today to constitute your evidence to the Inquiry?
 16 A. I am.
 17 Q. Are you happy for that evidence to be recorded and
 18 published?
 19 A. I am.
 20 Q. Thank you. And everything you said in that statement
 21 and indeed today will be taken into account by the
 22 Inquiry, even if there's something that we don't touch
 23 on.
 24 Final reminder, just on housekeeping, I suppose, is
 25 there is a restriction order in place so please don't

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1 mention any individual names when I'm asking you
 2 questions. If it's a staff member, please refer to them
 3 as such, rather than their name.
 4 Now, the organisation you're representing today is
 5 Cerebral Palsy Scotland; is that correct?
 6 A. That's correct, yes.
 7 Q. Formerly that organisation was known as
 8 "Bobath Scotland" —
 9 A. Yes.
 10 Q. — which leads me to ask you two questions: what is
 11 Bobath and why the change of name?
 12 A. Bobath is a therapy concept that is internationally
 13 recognised as a management for cerebral palsy. It was
 14 the first therapy concept that — I mean, cerebral palsy
 15 is caused by damage to the infant brain. The damage to
 16 the brain doesn't change throughout life but how
 17 cerebral palsy affects you and how that damage affects
 18 you can become progressively worse as you age. The
 19 Bobath concept was the first to look at actually
 20 functionally and clinically functionally how someone
 21 with cerebral palsy was able to function, that actually
 22 by combining multi-disciplinary physiotherapy,
 23 occupational therapy and speech and language therapy,
 24 you could improve the function of what somebody with
 25 cerebral palsy could do, whereas previously people had

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1 just sort of thought, "You can't do anything about the
 2 brain injury so there's nothing to be done".
 3 So Bobath Scotland was established in 1995 by
 4 a group of parents, in conjunction actually with
 5 NHS partners, to bring the therapy concept to Scotland
 6 so that parents could access it. We operate from
 7 a centre in Glasgow but we cover the whole of Scotland.
 8 What we've realised is that services for people with
 9 cerebral palsy are concentrated in paediatric services,
 10 they're concentrated around child development and the
 11 development of the body, and once you reach sort of the
 12 age of 16, but, you know, adulthood, there's a feeling
 13 that there's nothing more to be done, and so there was
 14 nothing for adults. So, from 2012, our organisation has
 15 been concentrating on how do we support adults and how
 16 do we develop a specialist service for adults.
 17 As the organisation grew, it became apparent that we
 18 needed to better represent all the activities we do
 19 because we do not just provide therapy. We provide
 20 information, we provide support, we bring the community
 21 together, we run an annual Cerebral Palsy Scotland
 22 conference, we raise awareness of cerebral palsy, we
 23 lobby for better policy and services to improve the
 24 lives of people with cerebral palsy, and so we had
 25 a long-term strategic plan to change the name to

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1 "Cerebral Palsy Scotland" so that people could find us
 2 and better understand what we do. Unfortunately for us,
 3 I suppose, we had fixed to change our name and to
 4 rebrand at the beginning of the financial year in 2020,
 5 which was in the middle of the pandemic.
 6 Q. Yes, which we'll come on to. Indeed. Thank you.
 7 Your current position is chief executive officer of
 8 Cerebral Palsy Scotland?
 9 A. That is correct.
 10 Q. How long have you held that position for?
 11 A. I joined in January 2012.
 12 Q. What does that role involve?
 13 A. So I am responsible for — you know, I am responsible
 14 for the organisation. I am responsible to a board of
 15 trustees, but I am responsible for the staff, for our
 16 beneficiaries, for the services that we provide, for the
 17 strategic direction, and basically the buck stops with
 18 me.
 19 Q. I think you say in your statement, in addition to your
 20 role as CEO, you also chair the Scottish Government's
 21 National Advisory Committee for Neurological
 22 Connections.
 23 A. I do. When that committee was formed, which I think was
 24 in 2016, I was appointed deputy chair and I became the
 25 chair in November 2019.

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1 Q. And you're also a former trustee for the
 2 Neurological Alliance Scotland as well?
 3 A. Yes, and Cerebral Palsy Scotland is a member of the
 4 Neurological Alliance.
 5 Q. I think you say in your statement that those connections
 6 stood you in rather good stead when we of course come to
 7 the pandemic.
 8 A. Yes, they did.
 9 Q. You've touched there already on what cerebral palsy is,
 10 so thank you for doing that. I was going to ask you
 11 that question. How many people in Scotland are living
 12 with cerebral palsy, just for background?
 13 A. The short answer is we have no idea. The longer answer
 14 is that cerebral palsy is the most common cause of
 15 physical disability in children. Around 1 in 500 births
 16 every year in Scotland will result in a diagnosis of
 17 cerebral palsy. But cerebral palsy is an umbrella
 18 condition and because, as I said, it's caused by damage
 19 to the infant brain, there tends to be a wait and see
 20 procedure before a diagnosis may or may not be given.
 21 I mean, we sometimes see adults in their 30s, 40s,
 22 50s, who have never had a formal diagnosis, so, you
 23 know, something may or may not happen that is detectable
 24 and, on average, it's picked up because the development
 25 of the child is not progressing as we would expect and,

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1 therefore, a diagnosis tends to be given most commonly
 2 around the age of two. But, as I said, there is this
 3 wait and see, you know, because maybe — the infant
 4 brain is an amazing thing and it may just rewire in some
 5 different way. You know, there are people who are born
 6 who have huge issues at birth who don't develop
 7 cerebral palsy and others where, you know, we don't
 8 actually know when the damage happened.
 9 So that's one of the issues that — you know,
 10 diagnosis isn't uniform. There isn't a consistent way
 11 of achieving that, and, you know, because how people are
 12 affected varies so widely, their access and need for
 13 services vary so widely. So we do not know where people
 14 live, how many people there are in Scotland and how they
 15 are consuming services. Some lead very fulfilled lives.
 16 Cerebral palsy doesn't kill you. You know, your life
 17 expectancy is as normal. But the other things that it
 18 might cause and the issues that it might cause you to
 19 develop as you age can be extremely significant. You
 20 know, this point about — some people need services
 21 every day, very — you know, a huge amount of services
 22 for the rest of their lives.
 23 Q. And I think you make that point, don't you, that
 24 everyone is different?
 25 A. Yes.

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1 Q. Just because you've met one person with cerebral palsy
 2 doesn't mean you've met everybody?
 3 A. Yes.
 4 Q. And I think you also mention that there's no drug or
 5 procedure that makes that disappear —
 6 A. No. I mean, the thing about cerebral palsy, it's
 7 nobody's fault or tends to be nobody's fault. It's bad
 8 luck. It can happen to anybody. It doesn't matter how
 9 much money you've got, whether you took folic acid when
 10 you were pregnant or not. None of that matters. It is
 11 what it is. There's no fancy drug or something — you
 12 know, anything to suddenly be developed and it's not
 13 going to go away.
 14 Q. Thank you. Can I ask you what services your
 15 organisation provides to those with cerebral palsy?
 16 I think you've touched on a bit of this already, so
 17 I don't necessarily want you to repeat yourself, but is
 18 there anything you'd like to emphasise that — you know,
 19 how you assist those that do have cerebral palsy?
 20 A. We provide one-to-one therapy services for families, and
 21 that involves their carers and anybody, you know,
 22 involved in their life, so it could be siblings, it
 23 could be teaching assistants, it could be local
 24 community therapists. So that is multi-disciplinary
 25 therapy depending on what their goals or needs are, that

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1 includes physiotherapists, occupational therapists or
 2 speech and language therapists and actually we now work
 3 with a psychologist as well.
 4 We also work and train with professionals who
 5 support people with CP, so, you know, we train them to
 6 become qualified in the Bobath concept, for example, but
 7 we also bring in trainers from around the world for
 8 specific issues. We support -- you know, whether --
 9 again we run information days for anybody, whether it's
 10 families or whether it's professionals or students.
 11 We've worked with, for example, Glasgow Caledonian
 12 University, with their physio students. We run our
 13 annual conference, which brings organisations around
 14 Scotland and around the UK, actually, that provide
 15 helpful or services relevant for people with
 16 cerebral palsy.
 17 We also run groups, when we have funding for them,
 18 for specific groups of people, so, for example, every
 19 fortnight we have a babies group, where families and
 20 children who may not have a diagnosis of cerebral palsy
 21 but are concerned about motor development -- we run
 22 a very informal group for families and babies. But
 23 we've run groups for teenagers, we've run groups for
 24 adults to teach them how to cook or live independently
 25 more and, as I say, that's funding--dependent, and --

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1 yes, and we campaign for better services for people with
 2 cerebral palsy.
 3 Q. Thank you. Your organisation's 25th anniversary was in
 4 2019. You touched on this at the outset. You had an
 5 anniversary ball, I think, just under the wire, as it
 6 were, in February or March 2020.
 7 A. In February -- in February we managed to do our last
 8 fundraising event pre-COVID, yes.
 9 Q. And you talk in your statement, at paragraph 33, about
 10 the optimism that you had about the future. The
 11 pandemic then, of course, immediately strikes. How
 12 did you personally feel at that point and what were the
 13 immediate actions as an organisation you took in light
 14 of the pandemic?
 15 A. Well, I remember that fundraising ball and we were all
 16 slightly nervous about whether we could shake hands or
 17 how did we greet people, so we sort of could see that
 18 something was coming our way, and one of the things that
 19 sort of concerned us was that cerebral palsy was being
 20 mentioned as a condition very early on by both UK and
 21 Scottish governments. So in the media there was a --
 22 you know, it was given as an example of, "You might be
 23 more vulnerable to this virus if you have a condition
 24 like cerebral palsy". So what we saw was a huge spike
 25 in enquiries to us as to what we could do. We also saw

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1 a huge raising of the level of anxiety of the people
 2 that were coming to see us and were engaging with our
 3 services.
 4 So, you know, we'd already started thinking about --
 5 you know, there was things like the hand--washing advice.
 6 Well, if you can't use your hands -- and many people
 7 with cerebral palsy find it very difficult to use their
 8 hands -- you know, how do you help someone wash their
 9 hands? There was discussion -- so we were publishing on
 10 our website sort of blogs on how to support people to
 11 follow that. And, similarly, you know, there were
 12 discussions about should we or should we not be wearing
 13 masks, and that has an implication for people with CP,
 14 not only because they often have communication
 15 difficulties, and some have cognitive and difficulty in
 16 understanding people, so, you know, what was the right
 17 thing to do on that?
 18 So we'd had a little, you know, feeling that
 19 actually we needed to think about these things. We were
 20 fortunate that it was the end of our financial year.
 21 We'd just finished some work in Dumfries and Galloway,
 22 so, you know, the next -- if we locked down -- so the
 23 centre was locked down and formally closed from
 24 23 March, but, in the week before that, people had
 25 started to cancel appointments and be working -- wanting

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1 to work from home and things like that, and actually,
 2 because of the timing, you know, we had an awful lot of
 3 report writing and administration to catch up. We
 4 didn't have huge amounts of in--person appointments.
 5 Staff had annual leave to take before the end of the
 6 financial year. So there was a bit of managing that
 7 but, when the restrictions hit, the first thing we had
 8 to do was -- you know, I had to think about the safety
 9 of our beneficiaries and the safety and well--being of
 10 our staff.
 11 We weren't set up to suddenly go to remote working.
 12 We had some laptops, but not enough, obviously, like
 13 everybody -- I think like everybody else. The
 14 therapists all had their own iPads but then there were
 15 issues around, you know, how did they access the server,
 16 how did they access secure clinical data and how is it
 17 safe to allow people to work that. And communicate --
 18 you know, we were report--writing and communicating back
 19 to the families what we'd done, so what was the safe way
 20 to do that without the IT gatekeeping of our -- so we
 21 had to manage our way around that.
 22 Very quickly I was thinking, right -- we didn't
 23 think -- I remember talking to some of the trustees --
 24 we didn't think this was going to be a few weeks and
 25 then we'd be back. We did understand pretty early on

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1 that this was going to be a bit of a long-term haul, and
 2 so my ambition was to get through whatever it was with
 3 my staff in tact and the organisation still in
 4 existence. So, you know, I remember my chairman saying
 5 to me "Cash is king", so we did things like cancel all
 6 the organisation's direct debits. We thought, if
 7 somebody wanted our money, they could come and ask for
 8 it. You know, we needed to be in control of what we
 9 needed to do.
 10 The early weeks were very much in respond mode. We
 11 had to — you know, I was thinking about the well-being
 12 of the organisation and the staff. The therapists and
 13 the admin staff were bringing to me these increased
 14 enquiries, these issues that were bubbling up, you know,
 15 so we were thinking, "Right, how do we best help our
 16 beneficiaries? How do we stay in touch with this
 17 population that are clearly worrying about what the
 18 effects of the virus are on them?". So again we
 19 published through our website, which, remember, was
 20 going through a rehaul anyway — we put up — I think we
 21 were one of the very first people to put up advice on
 22 COVID and cerebral palsy, and we were able to say, you
 23 know, "The most important thing is to stay fit and well
 24 and actually your best defence against COVID ..." —
 25 which we didn't have any clinical knowledge of what

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1 COVID was, but we wanted to reassure and encourage our
 2 beneficiaries to stay as healthy and as well as
 3 possible.
 4 We had to quickly, obviously, take the decision
 5 about whether we were going to go ahead with the rebrand
 6 or not. We decided that we should because we'd done all
 7 the work. It was in place to, you know, go live. The
 8 rebranding of the website was different because we
 9 needed to keep advice front and centre of any website
 10 and we needed to keep refreshing it all the time, you
 11 know, because what we did was we focused on what we were
 12 hearing from the people that were contacting us and
 13 trying to respond to that and publish it as widely as we
 14 could.
 15 So by about early April we'd sort of identified key
 16 tasks that we need to do and communications was high up
 17 there. Funding and how we kept financially solvent and
 18 providing a core administration so that we could — you
 19 know, we had a system from our remote working as to how
 20 did we deal with enquiries and who was the right person
 21 to respond and all that kind of stuff and how did we
 22 continue some sort of clinical input to people that
 23 needed that. So, you know, that was the initial,
 24 "Right, how do we do that?", while we were all at home.
 25 Q. Right. Thank you. You mentioned staff in your answer

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1 and funding. I'd like to ask you about both. Did you
 2 rely upon the furlough scheme, for example? Did you
 3 maintain your staffing levels —
 4 A. Oh, completely. I could never imagine something like
 5 the furlough scheme and I can only describe it as
 6 a godsend. It enabled us to — for example, some
 7 members of staff had their own caring responsibilities
 8 and just wouldn't have been able to be at home and work
 9 at the same time, so we were able to give some staff
 10 levels of comfort that their job would still be in place
 11 but they didn't need to worry about us. It enabled us
 12 to look forward and budget without just seeing
 13 everything fall off a cliff, and we used the furlough
 14 scheme for as long as we possibly could and, you know,
 15 brought — we were able to identify, "Okay, what's the
 16 skeleton staff we need? What are the tasks we need to
 17 do?", and we were able to fund it.
 18 So, you know, who was and wasn't furloughed was
 19 based on need and it gave us the most immense comfort to
 20 know that actually, you know, our biggest cost is our
 21 staff salaries and it was wonderful to know that that
 22 was sort of taken care of, thank you very much.
 23 Q. At paragraph 45 of your statement, you talk about the
 24 stark contrast of pre-pandemic, where you were welcoming
 25 people into your centre — I think you said you were

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1 based in Glasgow every day and saw people every day —
 2 to suddenly not seeing anybody. Can I ask you how you
 3 attempted — you touched a little bit on that with the
 4 website, but how you attempted to replicate, to the
 5 extent that you could, the services that you'd provided
 6 previously to the sort of online space that you were now
 7 facing?
 8 A. Well, we had — during 2019 we had managed, as a third
 9 sector organisation, to sign up and use the NHS —
 10 I think it was called "Attend Anywhere" in those days
 11 It's now called "NHS Near Me". And we had been able to
 12 sign up to that platform, which was — I mean, thank
 13 goodness we had because that was a safe and secure
 14 clinical consulting online platform. I know other
 15 organisations were trying to do, you know, sessions via
 16 Zoom or whatever it was, but the Near Me platform gave
 17 us that ability to run virtual sessions. So that meant
 18 that from the beginning of lockdown we were able to
 19 offer virtual clinical sessions.
 20 We did — what we found was that — what we were
 21 used to is being in a room, whether it was in our centre
 22 or whether it was in Dumfries and Galloway or anywhere
 23 else or in somebody's home — what we were used to is
 24 working hands-on and with the team around, whether it's
 25 the child or the adult with carers or family or

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1 whatever, but, suddenly, no, it was virtual only. But
 2 it allowed us to deal with specific issues that came up.
 3 So, you know, for example I always think of a family in
 4 the Western Isles who had a child through lockdown who
 5 was diagnosed with CP and we were really their only
 6 contact with, "How do I..." — this wasn't — you know,
 7 it wouldn't have been the child that they expected to
 8 have, so what did they need to know as they were looking
 9 after their child.

10 We had — very often, again, we were the only people
 11 who, you know, people could bring their issues with. So
 12 as time went on, sometimes it was — you know, at the
 13 beginning it tended to be very physical issues that
 14 people were concerned about, so, "I'm getting stiffer",
 15 "I'm in more pain", "I think I'm growing out of my
 16 equipment" or whatever it might be, but as time went on,
 17 other issues became apparent, particularly, "I don't
 18 feel confident about going outside", "I don't want to
 19 let people into my house because I'm nervous of
 20 infection". So, you know, being able to offer virtual
 21 consultations for our beneficiaries I think was hugely
 22 appreciated and thank goodness we could do it.

23 For our therapists it was very hard because they are
 24 all trained to, as I said, be hands-on, to work
 25 collaboratively and to — you know, we had to go from

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1 having, if you like, the satisfaction of being able to
 2 have time and a number of appointments with people to
 3 unpick a number of different things and explore goals or
 4 whatever it might be and try things out and all the rest
 5 of it, which was how we'd worked before, to suddenly
 6 having to identify, "Well, what's the biggest problem
 7 that this person is facing and what can we do clinically
 8 to assist them to help it?". So it was going from
 9 unpicking lots of clinical issues to saying, "No, no, we
 10 need to identify one and concentrate on how do we help
 11 that for now". So it was a very difficult way of
 12 working and I have to pay tribute to my clinical staff,
 13 that they, you know, stepped up to the plate and were
 14 absolutely wonderful.

15 Q. Thank you. You talked earlier about the anxiety that
 16 people were facing, I think partly you'd said due to the
 17 messages that was coming out I think from both the UK
 18 and Scottish Government, I think you say at paragraph 48
 19 of your statement. At that time what was your reaction
 20 to that label, that risk assessment that was given by
 21 Government to your own clinicians? Was that an
 22 assessment that you agreed with, that those with CP
 23 would be more vulnerable to COVID?

24 A. I don't think any of us knew. I don't think Government
 25 knew and I don't think we knew. I did — this is where

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1 sort of, you know, my predecessor as chair of the
 2 National Advisory Committee is — went on to chair or
 3 whatever he is of the Association of British
 4 Neurologists, and so I was able to speak to people like
 5 that and to people in Government.

6 I mean, Scottish Government had in post an
 7 absolutely wonderful person who was the head of
 8 neurological services in the clinical priorities team
 9 and — you know, so people like that, we were able to
 10 have a discussion and everybody was feeling their way.
 11 I think what we all instinctively understood was that,
 12 the healthier you could remain and the better you could
 13 be, then, you know, the more likely you were to have
 14 a better defence against the virus.

15 I think the other thing that was understood,
 16 particularly by us, was that, because cerebral palsy is
 17 such an umbrella, that some people were clearly going to
 18 be far more vulnerable than others, but just by
 19 labelling everybody with CP, that wasn't terribly
 20 helpful.

21 The other thing that we've mentioned is, because
 22 there is no register, there is no marker on your GP
 23 record that you have a diagnosis of CP, adult social
 24 care services don't have a clue who, under their great
 25 banner of people that are consuming adult disability

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1 services, actually have CP versus any other condition,
 2 so therefore, you know, just highlighting a condition
 3 wasn't helpful either to them, it wasn't really helpful
 4 to us and nobody was really thinking about, "Well, is
 5 this right?".

6 As time went on, the Scottish Government produced
 7 specific guidance for people with neurological
 8 conditions and we were able to work with them on the
 9 cerebral palsy part of that, and a lot of that was
 10 written by, for example, the Association of British
 11 Neurologists, so we were able to sort of pull together
 12 the sort of clinical thinking as it was being developed.

13 Q. You touched on the blanket approach which you didn't
 14 necessarily think was entirely helpful. Is that perhaps
 15 a lesson learned, would you say, that a more tailored or
 16 nuanced approach would have been appropriate as opposed
 17 to perhaps putting everybody with CP into one bracket?

18 A. I think the problem is, if you don't know where anybody
 19 is and you don't know what condition they have, even
 20 a tailored approach isn't going to work because — you
 21 know, my real issue was that there was no thought given
 22 to people with long-term conditions, so therefore there
 23 was no consultation about, "Well, what would keep you
 24 well?". Now, I'm not sure how any of that would change
 25 if you don't know where the people with long-term

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1 conditions are and you don't know what those long-term
 2 conditions are, and there is very limited specialist
 3 knowledge in Scotland of aging with cerebral palsy apart
 4 from actually in our organisation. So until that
 5 changes, you know, it just won't be possible to tailor
 6 anything.

7 Q. You say "until that changes" and in your statement in
 8 a couple of places you mention about the lack of
 9 a register, if you like. Is that something — again,
 10 we're looking at lessons learned as an Inquiry. Is that
 11 something you — an omission, a gap, you think needs to
 12 be addressed?

13 A. Yes, and what I find really frustrating is that it is
 14 actually better for children. So Scotland have
 15 something called the "CPIPS", which is children with
 16 cerebral palsy — it's actually a hip surveillance
 17 survey. So it's not a register, it's not everything,
 18 but almost every child with a diagnosis of
 19 cerebral palsy is on the CPIPS register in paediatric
 20 NHS services, and all NHS areas across Scotland use the
 21 CPIPS survey. What I find really frustrating is, the
 22 moment these children get referred into adult services,
 23 that's just forgotten about. The data just goes
 24 nowhere. So my question is always: why not? It's not
 25 the total answer, but it's a building block that

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1 I believe would be a wonderful thing to keep going.

2 THE CHAIR: Can I interject at this moment? You're the
 3 second witness this morning, Lady Fraser, who has
 4 mentioned the possibility, the desirability, of
 5 a register, in your case cerebral palsy, the gentleman
 6 that gave evidence earlier on, Down's syndrome —

7 A. Yes.

8 THE CHAIR: — where likewise there is no register kept.
 9 I quite understand the persuasive arguments you've just
 10 been advancing, it would be certainly advantageous.
 11 But, obviously, that is something which might fall
 12 within the remit of this Inquiry in relation to
 13 recommendations, but registers of persons in a category
 14 have, as I'm sure you'll appreciate, potential pitfalls,
 15 both legalistic and practical and in relation to persons
 16 as well. Do you have views? I mean, you obviously have
 17 a view that it would be a good idea, but have you
 18 considered the potential pitfalls in instituting such
 19 a policy?

20 A. Yes, and I'm not sure a register as such is necessarily
 21 the right answer, but what I would say is that there is
 22 nowhere — not even on somebody's clinical record that
 23 they have cerebral palsy. Now, the reason for that is
 24 because clinical records are all based on ICD coding and
 25 the coding records what causes — you know, the cause of

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1 something. So in the case of cerebral palsy, it might
 2 be that, you know, somebody has had an infant stroke,
 3 for example, in which case the stroke will be recorded,
 4 or a brain haemorrhage at birth, in which case that will
 5 be recorded. What isn't recorded is the consequences of
 6 that, and that's where the CPIPS survey that I was
 7 mentioning actually does a better job because it records
 8 the sort of functioning abilities of the child. And
 9 I suppose my frustration is — you know, I agree with
 10 you, I'm not necessarily sure that registers are the
 11 answer, but I cannot understand why, in today's age of
 12 digital records and the data and information that we
 13 gather, that we can't do a better job.

14 And there's some interesting work actually that the
 15 Neurological Advisory Committee is currently doing on an
 16 epilepsy register, which is looking at — it's
 17 cross-referencing pharmacy data with people that turn up
 18 to consultant appointments with primary care data and
 19 others. And I think that's the kind of thing I would
 20 like to see advanced for a condition like
 21 cerebral palsy. The problem is that we don't have
 22 specialist consultants that people go to once a year, as
 23 people with epilepsy or MS or Parkinson's or other
 24 neurological conditions do. But what we do have is this
 25 CPIPS register, which is an asset that the

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1 Scottish Government have invested in and we seem to be
 2 doing nothing with it in the adult space.

3 So I think there's huge potential for improvement of
 4 identification, and to come back to your point about,
 5 you know, that can sometimes be problematic,
 6 I completely agree, but people with cerebral palsy feel
 7 that they are not counted at the moment; they are
 8 invisible. They feel at the bottom of the pile for sort
 9 of — you know, we don't have specialist consultants, we
 10 don't have clinical nurse specialists, they don't get
 11 called for annual reviews. There is this feeling that,
 12 you know, "Well, it's a physical developmental thing,
 13 the brain damage isn't going to change, so tough, you're
 14 just going to have to deal with it". And that is not
 15 right and that's not correct. And that's why these
 16 people, you know — it was so frustrating during this
 17 time that cerebral palsy was being mentioned as
 18 a condition — which I'm always thrilled it's mentioned
 19 as a condition — because it's so common, I'm always
 20 delighted when people realise that — but the knowledge
 21 of what the impact of cerebral palsy is for people is
 22 not well enough understood and that's the thing that
 23 I think we could change.

24 THE CHAIR: Thank you. That's very helpful.
 25 You mentioned in the course of that answer some work

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1 you'd done --- reported upon in relation to epilepsy. Is
 2 that work published as yet?
 3 A. Yes. I mean, it's published --- bits --- there are
 4 different stages of it, and, you know, if you look at
 5 the Scottish Government's --- I mean, all the work of the
 6 National Advisory Committee is published on the
 7 Scottish Government's website.
 8 THE CHAIR: If you had an easy access to that information ---
 9 A. I think there's a link. There is a link ---
 10 THE CHAIR: If you could pass that on to my team, I would be
 11 very grateful and we can follow it up.
 12 A. Yes.
 13 THE CHAIR: Thank you. I appreciate that.
 14 MR STEPHEN: I'm obliged, my Lord.
 15 Just to finish the thought before I move on to ask
 16 about something else, is it your view, then, that
 17 perhaps making the tweaks or changes that you've
 18 suggested where there is a gap at the moment would have
 19 made a tangible difference or perhaps made those with CP
 20 more visible ---
 21 A. Yes.
 22 Q. --- when the response to the pandemic was made?
 23 A. Yes.
 24 Q. Thank you. I want to ask you next about schools.
 25 I don't think you pull any punches on this, so that's

1 why I want to ask you about it. You certainly express
 2 the view that you hope that we never again close
 3 schools. This is at paragraph 60 of your statement. At
 4 paragraph 127 I think you go on to say that it was
 5 a disaster for the CP community. So I think the obvious
 6 question for me to ask you is why you hold that view.
 7 A. I think --- the point is that schools for this population
 8 are more than about just education. So many therapy
 9 appointments happen within schools. So, you know,
 10 community physios, OTs, SLTs, work with children within
 11 a school setting. It means that things like equipment
 12 is seen and adjusted and all of that. Schools provide
 13 often, you know, the main social interaction for these
 14 children, that is where --- that's their only opportunity
 15 to be out and meet peers and interact with peers, let
 16 alone the fact that school provides quite significant
 17 respite for parents.
 18 So I found it quite extraordinary that all these
 19 things stopped, that parents were left at home to --- you
 20 know, some of them might be trying to work from home,
 21 some of them might be trying to help siblings as well.
 22 At school some children with CP have one-to-one support
 23 to engage in learning throughout the day and all that
 24 stopped. It was just left to parents. For all those
 25 reasons, it left families unbelievably isolated, dealing

1 with problems that, you know, were just ignored, things
 2 like growing out of equipment, or it disengaged these
 3 children from the curriculum, you know, because, if you
 4 have a support worker to help you engage in learning and
 5 suddenly you're at home with your parents and your
 6 siblings and all the rest of it, that's pretty tough,
 7 putting it mildly and it exacerbated the isolation that
 8 these families felt.
 9 Q. What would you suggest, then, might have been
 10 a different course to take, a middle ground or
 11 alternative to what was actually done then in relation
 12 to schools?
 13 A. Well, I mean, I'm sad that home visits --- in-person
 14 visits didn't happen. I think people that required
 15 one-to-one support at school, it was extraordinary that
 16 they didn't have home visits at home. Families reported
 17 to us about --- you know, people would phone them up,
 18 "Are you all right?", you know, and in our very British
 19 way we'd say, "Yes, we're fine", kind of thing, but
 20 actually there was no real interaction there that we
 21 could see.
 22 I think the other thing layering on top of that is
 23 always the anxiety. You know, families were already
 24 unbelievably anxious about their vulnerable child and so
 25 therefore there was an anxiety about, well, "Even if

1 there was a ..." --- because I think technically these
 2 children could have attended schools, but, you know, put
 3 on top of that that your child is more liable to be
 4 vulnerable because of their cerebral palsy --- so
 5 families, you know, were absolutely --- so many I can
 6 think of that just stayed at home and stayed at home
 7 far, far longer than any of the rest of us, even after
 8 schools opened and restrictions lifted. You know, there
 9 was a real nervousness about going back into that
 10 environment, and I think that was caused partly because,
 11 as I say, cerebral palsy was being pointed to, but also
 12 there was no dialogue really with families about how ---
 13 what would have made it better for them, what would
 14 have --- what could have kept them engaged or, you know,
 15 what did they need. It's back to the nobody asked these
 16 families what did they need to continue, you know,
 17 educating their children, in terms of development and
 18 all of that. There was just no thought given. So
 19 that's why I feel quite strongly about it.
 20 Q. I'm glad I asked. Yes, you said no one asked. You
 21 yourself as an organisation carried out a number of
 22 surveys, as I understand, and we see that referenced at
 23 paragraph 65 of your statement. What did the results of
 24 those surveys reveal to you in general terms and also
 25 I think about mental health --- because we've talked

1 a little bit about physical health. You've talked about
 2 things like physiotherapy, speech and language perhaps
 3 not being offered when schools were closed. What were
 4 you seeing in terms of the results of those surveys on
 5 the mental health side?
 6 A. We did three surveys during this period, so May
 7 and September 2020 and then again in February 2021.
 8 What we found in the May survey was that the biggest
 9 issues tended to be physical, so they were stiffness,
 10 they were pain, they were, you know, things like growing
 11 out of equipment or splints or whatever. What we found
 12 as time went on, that the reported issues of decline in
 13 mental health sort of — you know, rose significantly.
 14 And what was important was that this decline in
 15 well-being wasn't restricted to the person with CP. It
 16 was felt — I mean, I think I've got a figure here of
 17 44% felt it had also impacted on other people in their
 18 family. You know, people reported that, if they had
 19 someone with CP, a child or adult, at home, then the
 20 whole family stayed at home and were restricted in what
 21 they did.
 22 We looked at care arrangements. You know, care
 23 arrangements obviously were totally scaled back at the
 24 beginning, but, by February 2021, 63% were reporting
 25 that the care arrangements they'd had pre-COVID still

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1 had not been reinstated. Very common was this feeling
 2 of isolation. Whether it was a choice or whether it was
 3 that's how they felt, I don't know. But the feelings of
 4 being isolated because of their condition increased and
 5 what also concerned us was access to healthcare. So,
 6 you know, 17% reported they hadn't even been able to
 7 speak to their GP or other healthcare professional.
 8 Appointments were cancelled and not rearranged,
 9 sometimes at very short notice. So this lack of access
 10 to what I would consider essential health services
 11 wasn't there and that was very concerning to us.
 12 Q. And so therefore would you — is your evidence, then,
 13 would you suggest that a reconsideration or a different
 14 approach should have been taken to what was deemed
 15 essential?
 16 A. Completely. I think — you know, it astounds me that we
 17 all decided that it was clearly essential that we all
 18 had access to a supermarket and could go and buy our
 19 food and milk and toilet paper and all the rest of it,
 20 but, for our population, access to physiotherapy,
 21 occupational therapy, and actually, you know, being able
 22 to access that through venues like schools rather than
 23 just in healthcare settings, that is essential.
 24 Q. Thank you. To complete that, were you ever asked for
 25 input into what should be deemed essential? Did you

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1 organisation ever provide an input to the
 2 Scottish Government about what that should be or not?
 3 A. You know, when asked, we provided an opinion whenever we
 4 could, but the feeling we got is that the different
 5 teams we were talking to at Scottish Government — so my
 6 main is interaction was through the clinical priorities
 7 team, who were as helpful as they possibly could be,
 8 but, you know, we also had interaction with, for
 9 example, the shielding team, who seemed to have been,
 10 I suppose unsurprisingly, but assembled at the very last
 11 minute to look at this, had no prior knowledge of this
 12 area and, you know, it was — any input we had, it
 13 seemed to be well received but it didn't necessarily go
 14 anywhere. So this lack of co-ordination about who did
 15 what and who was listening to whom was — it was
 16 difficult to understand whether anything we said was
 17 landing with any impact.
 18 Q. So your thoughts were given but not necessarily
 19 actioned, I think is what you're saying; yes?
 20 A. Yes.
 21 Q. All right. You've mentioned that word "shielding".
 22 I was going to come on to that anyway so let's do that.
 23 When shielding was first announced, was it clear, in
 24 your view at least, how that applied to those with CP?
 25 A. No. I think the thing with shielding is that there was

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1 perhaps a lack of understanding both for the people who
 2 were being asked to shield and from the people who were
 3 asking them to shield what it actually entailed. As
 4 I say, we did have meetings with the Scottish Government
 5 shielding team and we did raise the issues around
 6 cerebral palsy being an umbrella condition, that some
 7 people would be very badly affected and therefore
 8 possibly need to shield and others wouldn't. But the
 9 lack of being able to identify who any of these people
 10 were and where they were was going to be an issue.
 11 What we found when shielding was announced was that,
 12 again, people who felt they were vulnerable — because,
 13 remember, we'd been telling them since March that this
 14 population was vulnerable — again, the anxiety rose.
 15 So the enquiries we got were from people who — I think
 16 the other thing, if I remember correctly, the letters
 17 went out to ask people to shield not all at the same
 18 time, so, therefore, some people got letters and some
 19 people didn't. But for people with CP, they were being
 20 asked by very different professionals to shield or not,
 21 as the case may be. So the enquiries we got were,
 22 "Should I be shielding?" or "Who should I talk to about
 23 shielding?".
 24 Now, we, as an organisation, were absolutely not in
 25 a place, nor did we want to be, to make that decision,

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1 so we would refer people to their healthcare
 2 professionals . But then there was an issue about
 3 getting hold of their healthcare professionals . So not
 4 everybody with CP has a consultant neurologist, not
 5 everybody with CP has a community AHP that they can talk
 6 to. Many spoke to their GPs, but GPs do not have
 7 a specialist knowledge of CP. I mean, I don't want to
 8 denigrate any GP in this.
 9 So what we found was many professionals, if they
 10 were contacted by someone, would err on the side of
 11 caution and therefore people were being advised to
 12 shield . I just want to read something from one of our
 13 surveys that somebody --- a parent --- wrote in, you know:
 14 "We were fortunate that my child's consultant still
 15 scheduled my child's routine appointment, which allowed
 16 us a very sensible and pragmatic discussion on
 17 practically interpreting shielding policy. I feel that
 18 all parents would have benefitted from such a discussion
 19 [as read]."
 20 I think, now, that was a child who was clearly
 21 talking to a consultant paediatrician and children do
 22 have access to paediatricians . Adults do not. There
 23 isn't an equivalent, so --- you know, so therefore, who
 24 they should be talking to, it tended to be really
 25 ad hoc, really ad hoc. So we had people that were sent

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1 letters that were asked to shield, people that contacted
 2 us and/or their healthcare professionals to ask if they
 3 should be and, if they did that, our experience is that
 4 people tended to err on the side of caution, and then
 5 there was another group of people who felt so anxious
 6 about the whole thing they chose to shield themselves.
 7 Yes, whether that was right or wrong, I think there were
 8 lots of unintended consequences of shielding.
 9 Q. Thank you. I used those words "ad hoc". Do you think
 10 therefore --- perhaps is there room for improvement ---
 11 would there have been room for improvement there?
 12 A. Well, I come back to my data. My point on data is that,
 13 if we understood where these people were, where they
 14 lived and what their level of function was, then we
 15 could have had a far more systemic approach to, you
 16 know, what could have been done and how they were
 17 communicated with because, if they were very mildly
 18 affected by CP, we could have communicated --- you know,
 19 healthcare professionals, local councils, could have
 20 communicated with them to reassure them. So on both
 21 ends of the spectrum, data would have been brilliant.
 22 Q. Are those with CP who were asked to shield or, as you
 23 say, some people who perhaps chose to do so because they
 24 felt they needed to for anxiety reasons --- was there any
 25 particular consequences of having to do that that you

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1 would highlight, adverse or not?
 2 A. Well, mental health issues were significant . You know,
 3 feelings of isolation, feelings of anxiety. Access to
 4 any support and help and interaction about their
 5 condition was sort of non-existent. I mean, again, if
 6 I go back to our surveys, people were saying, "If
 7 I hadn't been able to talk to Cerebral Palsy Scotland,
 8 I don't know who else I could have spoken to about my
 9 condition". And so I think the mental health impact of
 10 shielding was enormous and, again, I come back to the
 11 fact that, if one person in the household had
 12 cerebral palsy and was either shielding or chose to
 13 shield, then we know of many instances where the whole
 14 family felt like that.
 15 We know of families who then --- you know, shielding
 16 was over the summer, schools opened in August to an
 17 extent, but those that were shielding were not about to
 18 send their children back into the school environment nor
 19 were they advised to, and, you know, as a result of that
 20 we know of families who took a very long time to even
 21 leave their houses. I mean, we had one particular
 22 family we worked with, a good --- you know, I'm talking
 23 summer 2021, not 2020, and it was about, "Let's leave
 24 the house and go for a walk in the local park". You
 25 know, that was the level of anxiety that we were dealing

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1 with.
 2 So I think the other thing is that in the adult
 3 population we saw adults who had chosen to move back in
 4 with elderly parents and so there was that combined
 5 effect of, you know, the older you were, the more
 6 susceptible you were being told you were. Ditto with
 7 cerebral palsy. So the isolation of those families and
 8 the stress that elderly parents felt caring for their
 9 adult child with CP, it just compounded because it went
 10 on and on and on and on.
 11 Q. You mentioned the mental health impact or consequences
 12 there. On the physical side, is there any consequences
 13 you noticed also, people having to shield?
 14 A. I think it's back to this access to what I've already
 15 said we would consider essential services . So, you
 16 know, the physical side, it's things like increased
 17 pain, increased stiffness, decline in function. The
 18 great thing with muscles and your body, if you don't use
 19 it, you lose it, and that is the same for people
 20 with CP. So if they're not able to, you know, be out
 21 and about, have access to physio or whatever it is that
 22 keeps them well --- I mean, some people, you know,
 23 accessed hydrotherapy, local swimming pools, whatever it
 24 is, and all those were shut too. So not being able to
 25 keep active had a physical issue, that once lost it's

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1 very, very difficult to bring back that kind of
 2 function. And it is not surprising to me that, if you
 3 are seeing yourself being able to do less and you are in
 4 greater pain and you are stiffer and you're not seeing
 5 people and not socially interacting, no wonder your
 6 mental health is going to decline.
 7 Q. Yes. Were you able to help families, individuals,
 8 with CP that were suffering these things at that time?
 9 A. Yes.
 10 Q. Is that something you could assist with?
 11 A. So we work with clinical psychologists and we were able
 12 to offer virtual — and we still do — we offer — then
 13 it was all through Near Me, and we were able to offer
 14 appointments. Regarding the CP, I mean, where we're
 15 clear is that we are not a general mental health
 16 service. We are about, if your mental health is in
 17 decline because of something to do with your cerebral
 18 palsy, then we can assist and help with that, and we
 19 have a clinical psychologist who was able to do that.
 20 Q. Let me ask you this final question then on shielding: in
 21 your view, was the balance struck correctly then on the
 22 shielding guidance that was given — given the
 23 consequences that you've outlined, mental health,
 24 physical, was the approach taken to shielding, in your
 25 view, the correct one?

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1 A. Well, if I speak completely personally, I am not
 2 convinced that we ever needed to shield so I'm not
 3 convinced the shielding policy was the right one. But
 4 that is a personal view and I think we are still dealing
 5 with the tail end of the issues that have arisen from
 6 that.
 7 Q. Right, thank you.
 8 THE CHAIR: You've got about 15 or so minutes left.
 9 MR STEPHEN: My Lord, a very timely intervention because
 10 I don't have any further questions for the witness.
 11 THE CHAIR: You must be a mind reader.
 12 MR STEPHEN: So I'm very grateful for your evidence today,
 13 both in writing and orally. This is your opportunity,
 14 I suppose, if there's anything you would like to add
 15 that we haven't covered or you would just like to
 16 emphasise before we conclude.
 17 A. Well, first of all, I'm always grateful for the
 18 opportunity to speak about people with cerebral palsy
 19 because it is such a significant population and it is —
 20 you know, I call it the "Cinderella condition" because
 21 it is just forgotten about. My reflection on all of
 22 this is that it seemed that people — throughout
 23 anything to do with COVID at all, people with long-term
 24 pre-existing health conditions were very, very low down
 25 the priority list for healthcare services and others,

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1 and for many, with even these basic support services not
 2 continuing, that was what caused the biggest issues, not
 3 the COVID. And what depresses me is that they are still
 4 down — low down on the priority today, so nothing has
 5 changed. So my hope is that it just might.
 6 MR STEPHEN: Thank you very much.
 7 A. Thank you.
 8 THE CHAIR: I'm very grateful, Lady Fraser, for your most
 9 helpful contribution. Thank you.
 10 A. My pleasure.
 11 THE CHAIR: Right. We shall come back — I think we're
 12 scheduled to come back at 1.30 and I think that's
 13 probably possible. Do you know that, Mr Stephen?
 14 MR STEPHEN: I believe so, my Lord, yes.
 15 THE CHAIR: Jolly good. Excellent. Thank you. 1.30 then.
 16 (12.42 pm)
 17 (The short adjournment)
 18 (1.30 pm)
 19 THE CHAIR: Thank you very much indeed. Good afternoon,
 20 Mr Dunlop.
 21 MR DUNLOP: I'm just checking this mike is on. Yes, it is.
 22 THE CHAIR: Can you hear me, Mr Dunlop?
 23 MR DUNLOP: Yes, I can, thank you.
 24 THE CHAIR: Good afternoon.
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1 DR CAREY LUNAN and DR CHRISTOPHER WILLIAMS (called)
 2 MR DUNLOP: Good afternoon. This afternoon, we have two
 3 witnesses speaking to one statement. We have
 4 a Dr Williams and a Dr Lunan. Dr Lunan is joining us
 5 remotely. My Lord, if it helps, the reference for the
 6 statement is SCI-WT0428-000001. Thank you.
 7 THE CHAIR: Now, good afternoon, Dr Lunan and Dr Williams.
 8 DR LUNAN: Good afternoon.
 9 THE CHAIR: Excellent. I can see you both. If you're
 10 ready, Mr Dunlop, you can start, please.
 11 MR DUNLOP: Thank you.
 12 Questions by MR DUNLOP
 13 MR DUNLOP: I wonder if you can provide the Inquiry with
 14 both your full names, please.
 15 DR LUNAN: My name is Dr Carey Lunan.
 16 DR WILLIAMS: And I'm Dr Christopher Morgan Williams.
 17 MR DUNLOP: It might be helpful to explain for the benefit
 18 of the Inquiry that you both held the same position but
 19 during the pandemic. I understand we see in the
 20 statement in the table that's in paragraph 3 that,
 21 Dr Lunan, you held the post of chair during the period
 22 from — well, the whole of 2020 and thereafter it was
 23 taken over by Dr Williams for the remainder of the
 24 period which we're interested in, which is 2021 and
 25 2022; is that correct?

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1 DR LUNAN: That's correct.
 2 MR DUNLOP: To avoid — I think we've spoken — to avoid
 3 people speaking over each other, what I'll do is a sort
 4 of default, if you like. Given that you were involved
 5 in the earlier period, Dr Lunan, I'll maybe ask you to
 6 answer the questions and if Dr Williams has anything
 7 which he thinks he can usefully add, I'll turn to
 8 Dr Williams. Obviously if the question is particularly
 9 geared towards 2021 or 2022, then I'll direct it in the
 10 first instance to Dr Williams.
 11 Now, in the statement, it's explained that the
 12 Royal College represents 5,000 general practitioners in
 13 Scotland. Are all the general practitioners in Scotland
 14 a member of the Royal College?
 15 DR LUNAN: No, they are not. It's a reasonable majority in
 16 Scotland but it's not all GPs in Scotland that are
 17 members of the college.
 18 MR DUNLOP: Can you give us an approximate number of GPs
 19 that practise in Scotland?
 20 DR LUNAN: There are just over 900 practices in Scotland.
 21 I think the percentage, certainly when I was chair, was
 22 between 60% and 70% of GPs were members, but I'm not
 23 sure what the current percentage is. It changes a bit
 24 from year to year.
 25 MR DUNLOP: I maybe misheard you there. Did you say 9,000?

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1 DR LUNAN: No, 900 practices.
 2 MR DUNLOP: 900 practices, sorry. And do you know how many
 3 GPs there are — full-time equivalent GP posts?
 4 DR LUNAN: I don't know that, no. I'm sorry.
 5 MR DUNLOP: I'll direct this to you, Dr Lunan. At
 6 paragraphs 5 to 6 of the statement, you tell us that GP
 7 practices remained open throughout the pandemic and that
 8 face-to-face appointments were available where it was
 9 both "safe and appropriate". Could you tell us what,
 10 firstly, is meant by "safe" and what's meant, secondly,
 11 by "appropriate"?
 12 DR LUNAN: So this was a very key part of the way that we
 13 had to change the way that we worked during the
 14 pandemic, subject to the advice we were getting from
 15 Health Protection Scotland around maintaining safe
 16 clinical conditions to see patients and safe working
 17 conditions for staff.
 18 So at the start of the pandemic, the advice was that
 19 we spoke to everybody first on the telephone to try and
 20 assess what their needs were. If it was straightforward
 21 and safe to assess it purely over the telephone and deal
 22 with the medical needs without having to bring somebody
 23 into the practice or visit them at home, then we would
 24 do that to minimise footfall into the practice. And
 25 that was just to reduce the risk of transmission of

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1 COVID-19. Particularly in the early stages when the
 2 virus was more virulent, it was stronger, there wasn't
 3 vaccination, we were trying to do what we could to
 4 minimise risk across the whole system.
 5 But when we did speak to people on the phone and we
 6 realised that we needed extra information that
 7 a face-to-face appointment would bring, like, for
 8 example, examining somebody or if they were very worried
 9 about something and needed to see us face to face, then
 10 we would accommodate that and either see someone in the
 11 practice or see them at home, in their own homes.
 12 It wasn't straightforward to do that. If we
 13 suspected that — if somebody had symptoms of COVID, for
 14 example, in the very early stages, we developed places
 15 in the practice that we could see them, often separated
 16 out from other patients in the waiting room, in
 17 different areas of the practice. So people might be
 18 asked to wait at a different point and come into
 19 something called a "red room" or a "hot room", where
 20 they could be seen separately and the room could be
 21 cleaned more thoroughly in between patients. And those
 22 patients would generally be seen by a doctor who
 23 themselves had a lower risk of COVID if they were to
 24 contract it. But, in general, what we did was we always
 25 offered face-to-face appointments, although the

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1 proportion of face-to-face appointments as a whole was
 2 lower than it would have been pre-pandemic, and that was
 3 purely for safety reasons.
 4 The appropriateness part of it, again, was related
 5 to whether or not bringing somebody into the practice or
 6 seeing them at home would add useful additional
 7 information that we couldn't reasonably collect by
 8 speaking to someone on the telephone. So, for example,
 9 if somebody was phoning up with significant abdominal
 10 pain, which is quite difficult to assess without
 11 examining somebody, then we would be more likely to
 12 bring them into the practice to see them and examine
 13 them or visit them at home, if they weren't able to come
 14 in, than, say, if someone phoned requesting a sick line
 15 for work, which is something that is more
 16 straightforward and could be managed over the phone. So
 17 it varied from consultation to consultation and we had
 18 to use our judgment and knowledge of what the infection
 19 control guidelines were at the time to make a decision
 20 about whether we could reasonably deal with it over the
 21 phone or bring somebody in.
 22 MR DUNLOP: Thank you. You mentioned Public Health Scotland
 23 there. In terms of "safe and appropriate", were they
 24 definitions contained within any guidance that was
 25 issued to medical staff that you're aware of?

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1 DR LUNAN: I think so, but I'd have to go back and read the
 2 original guidance. That feels like very familiar
 3 wording from the start, that that was how clinicians and
 4 practices were being asked to consider how they make
 5 that difficult risk/benefit decision about bringing
 6 somebody in or seeing them at home or being able to
 7 manage someone over the telephone.
 8 I think we all realised as clinicians that doing
 9 things over the telephone is far from ideal. It's not
 10 the way in many circumstances that we would prefer to be
 11 doing things. It can work really well for
 12 straightforward, more transactional healthcare issues,
 13 but it is a way of consulting that is more complex
 14 because you have to be very careful about making sure
 15 that you've fully understood what someone is telling
 16 you, that they've fully understood what you're advising
 17 on, that you've got a plan in place if someone is to
 18 become more sick so that they know when to contact you
 19 back and that you were confident that, without seeing
 20 them, you're able to reasonably manage the risk
 21 associated with that. So it's not a faster or easier
 22 way to consult. It was purely being done on the basis
 23 of what we needed to do at the time to try and minimise
 24 infection risk.
 25 MR DUNLOP: Just one last question on this point. But if it

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1 was -- it's a two-stage test, the safe and appropriate,
 2 or appears to be a two-stage test -- if one of those
 3 tests wasn't satisfied or both weren't satisfied and it
 4 wasn't going to be possible to go, what would you do in
 5 circumstances where that individual wasn't able to have
 6 an appointment remotely? So take, for example, an
 7 individual who doesn't have access to IT or maybe has
 8 learning difficulties or something but it can't be done
 9 remotely, yet the test can't be satisfied, what would
 10 have been done in those circumstances in your
 11 experience?
 12 DR LUNAN: So in those circumstances we would want to see
 13 someone. So if we were not convinced that either the
 14 safety or the appropriateness argument could be met,
 15 then we would have a much lower threshold of either, if
 16 someone was able to come into the surgery, inviting them
 17 to come into the surgery and obviously asking them to
 18 wear a mask and to follow the social distancing
 19 guidelines in the waiting room and that we would see
 20 them wearing PPE -- so we would explain all that to them
 21 on the phone. And if they weren't able to come into the
 22 practice because they were too unwell or for any other
 23 reason, then we could arrange to see them in their own
 24 home, which wasn't without risk as well.
 25 So we were very aware of the fact that remote

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1 consulting was more problematic for a number of
 2 different groups of patients, such as the ones that you
 3 have mentioned, maybe people with learning disability,
 4 cognitive impairment, lack of access to equipment, lack
 5 of access to a private space to have a conversation, and
 6 that was very much in the forefront of our minds and fed
 7 into the decision about whether or not someone could be
 8 safely and appropriately managed over the telephone.
 9 MR DUNLOP: Thank you.
 10 Dr Williams, as you identify within the statement,
 11 there was this public perception that the GP surgeries
 12 weren't open for business or not certainly to the same
 13 extent as they were following the pandemic. As we move
 14 into 2021 and 2022 -- we've heard from Dr Lunan -- is
 15 there anything -- I mean, did things get better in terms
 16 of face-to-face consultations? Can you speak to 2021
 17 and 2022?
 18 DR WILLIAMS: So the changes -- the organisational changes
 19 that we went through in terms of how each practice was
 20 operating were seismic. We had a large number of
 21 systems in the background pre-COVID that staff were
 22 familiar with, comfortable with, that helped support
 23 patient safety, that worked together, and we needed
 24 to -- these systems were disrupted by needing to bring
 25 in remote consulting, and remote consulting for a large

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1 number of things, things that we historically would have
 2 taken in our stride in a face-to-face manner.
 3 So I suppose, as we reached the period that you're
 4 talking about, we had had a lot more time to test the
 5 video consulting, for example. We were able to
 6 sense-check whether the purported benefits were there,
 7 whether these were technologies that were embraced by
 8 our patients or which parts of our patient population,
 9 you know, liked or were comfortable with some of these
 10 different technologies. And I suppose ultimately we
 11 found that using the phone was in many ways, you know,
 12 something that we could flex, that we could get the most
 13 out of, in terms of rapid transferring of information or
 14 trying to understand what somebody needs at any one
 15 point in time.
 16 I suppose to say general practice, doing things face
 17 to face, trying to understand what our patients' needs
 18 and wants are, trying to get a sense of which tests are
 19 appropriate or which -- you know, which -- from a number
 20 of different routes might be best for someone or helping
 21 them understand different options open to people, so it
 22 was a difficult time to leave behind so many of our
 23 comfortable working practices to try and -- to
 24 sense-check which changes were working, which were not,
 25 and again which practices we could go back to. In some

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1 ways, some of the things we did pre-pandemic we found we
2 wouldn't go back to. Times had moved on. How people
3 were using the Health Service has changed.

4 MR DUNLOP: I'll come on to matters about people coming in
5 during COVID, but one of the things that I know — and
6 it's at the early stage — in paragraphs 5 and 6 of your
7 statement you identify that a number of GP practices
8 weren't suitable essentially for the pandemic.

9 My interpretation of what the statement says is that
10 seems to be largely to do with an issue of space, and
11 I'm just wondering, with the benefit of hindsight,
12 do you think there's other things that could have been
13 done to deliver services face to face where — obviously
14 the GPs are capable of doing it, but when the
15 buildings — if it's the infrastructure, do you think,
16 with the benefit of hindsight, in the lessons to be
17 learned, which the Inquiry will be looking at, there's
18 something that could be done differently?

19 DR WILLIAMS: I might highlight, in terms of vaccination,
20 when vaccination was carried out by general practice
21 staff, there was a flexing, the use of church halls, of
22 school buildings. Now, in some respects, some of that
23 was very problematic about who was carrying out risk
24 assessments or whether permission was given, whether it
25 coincided with term time or whether there were other

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1 events booked. As I say, there's a surprising amount of
2 barriers for some of these, you know, buildings that
3 were owned by local authorities and should have been
4 converted for different purposes.

5 One limitation we have in general practice is we do
6 a lot that relies on electronic communication between
7 a variety of systems, so there is an infrastructure in
8 terms of the SWAN network across health and social care
9 and other, you know, local authority premises. So it's
10 conceivable that there were other buildings that could
11 have been brought into use, but, as I say, if there had
12 been that foresight or, you know, if there was an
13 emergency plan switch that could have been flicked —
14 but what we in practice encountered was that there's
15 lots of different ways of working between local
16 authority and NHS, for example, in terms of how, you
17 know, a building might be deployed or used.

18 MR DUNLOP: Okay. You mentioned obviously the planning of
19 it. In terms of — and we'll hear perhaps this year,
20 perhaps next year — we'll hear about various
21 pre-pandemic exercises that were carried out, such as
22 Silver Swan. Is that something that's familiar to you?
23 Do you know that —

24 DR WILLIAMS: So I'm familiar with Exercise Silver Swan, but
25 I suppose only because midway through 2020 there was

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1 a publication of this — of papers from 2015 and 2016.
2 I have done work, but with BASICS Scotland in terms of
3 being an emergency responder. There are many GPs in
4 rural areas that are — that try and make themselves
5 available to be part of an emergency response. I think
6 even amongst this community you would find a limited
7 number that are — you know, that were aware of planning
8 round about pandemics.

9 MR DUNLOP: My question is in relatively sharp focus and
10 I'll ask Dr Lunan the same question, but I wonder
11 whether you have a view on whether pre-pandemic planning
12 in respect of the delivery of GP services was adequate
13 and, if it wasn't adequate, is there anything that could
14 have been done differently.

15 DR WILLIAMS: So I can recall going to major incident
16 planning meetings in Highland in 2015 and a lot of the
17 sort of incidents that they were planning round weren't
18 pandemic, weren't infectious-disease-related. They were
19 related to power disruption, to vehicle crashes, to
20 incidents that might appear across the patch. So, yeah,
21 I do wonder — Exercise Silver Swan should have sent
22 a message that should have been more widely received.

23 MR DUNLOP: Dr Lunan, I hope you heard the question that
24 I put to your colleague, Dr Williams. If I was to ask
25 you the same question, whether the pre-pandemic planning

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1 was adequate in terms of the delivery of GP services
2 during the pandemic, I don't know whether you have
3 a view.

4 DR LUNAN: So I guess my reflection would be that the vast
5 majority of GPs working on the front line would not have
6 any awareness of Silver Swan. I didn't, as a GP working
7 on the frontline. I think that there were GPs who had
8 specific roles, such as Dr Williams mentioned, being
9 involved in pre-hospital care because there was a GP
10 working in a remote or rural setting or other GPs with
11 specific roles within local board areas, but the vast
12 majority of front-line GPs would not be aware, I think,
13 of strategies like Silver Swan. So I think there
14 probably is a case for a more general awareness
15 certainly of maybe a key member within teams or practice
16 managers, but also I think there are some other things
17 that would be useful to learn about.

18 So you mentioned space. Thinking about, you know,
19 looking to the future, if we needed to have social
20 distancing again and that was the main rate-limiting
21 factor to being able to see people, then I think we
22 would want to see faster mobilisation of use of other
23 spaces. We probably didn't have the IT infrastructure
24 that we ideally could have had as a modern NHS
25 pre-pandemic, but that was rapidly accelerated in the

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1 first few months at enormous speed and I think something
 2 that we should be really proud of. So, you know, within
 3 a few months we all had cameras, microphones. We were
 4 able to use the Near Me consulting platform and
 5 Microsoft Teams and that was unheard of before the
 6 pandemic. So, you know, there were some silver linings,
 7 in a way, if there can be any, during something that was
 8 so difficult for so many people.
 9 And PPE I guess is the other thing, in terms of
 10 ensuring do we know how we order it, do we know what we
 11 need, have we got adequate supplies to keep us going
 12 for, you know, the initial period. I think all of these
 13 things would be very forefront in our minds if there
 14 were thoughts of planning for a future pandemic.
 15 If you don't mind, just going back to your previous
 16 question, just really briefly, around space, I think
 17 that space is important to consider, as Dr Williams has
 18 said, as is having the adequate IT, but there are other
 19 issues as well that make it less straightforward than
 20 that, such as the ability to clean spaces, such as the
 21 ability to have air circulating. But the main limiting
 22 factor to being able to see lots of people face to face
 23 and longer appointments with the need to clean in
 24 between and change PPE is workforce, so that would be
 25 a rate-limiting factor no matter where the premises was.

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1 We could open up bigger buildings and have more space
 2 and bring more people in, but we'd still need to have
 3 the staff there to see them. So we may come on to
 4 workforce later. Thanks.
 5 MR DUNLOP: Can I ask, just dealing with that, if I can call
 6 that, "infection control", in terms of — this might be
 7 a better question to put to you, Dr Lunan, given you
 8 were dealing with — or you were more involved at the
 9 earlier stages of the pandemic. What impact did
 10 infection control have on the number of patients that
 11 GPs could see? Maybe you can tell us relatively briefly
 12 in the time that we have. Was there a cleaning regime
 13 between every patient, every second patient and what was
 14 the impact on the number of patient appointments in the
 15 day?
 16 A. So in the briefest terms there was a cleaning regime
 17 that had to happen between every patient because we
 18 didn't know who was asymptomatic and had COVID, so we
 19 had to clean down all services between each patient
 20 coming into our consulting rooms and we had to change
 21 PPE between patients as well. We also had to — many
 22 practices, if they had space to, would run this second
 23 room that I mentioned earlier on, a hot room or a red
 24 room, to see people who had symptoms of what we assumed
 25 might be COVID, so continuous cough or fever or loss of

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1 smell, and those rooms would be cleaned even more
 2 thoroughly and staffed by someone who was assessed to
 3 have lower risk and was more able to see those patients
 4 with less risk to themselves.
 5 So the impact was big because normally we would
 6 say — a face-to-face appointment is still sadly
 7 ten minutes. We would love it to be longer than that,
 8 moving forward, but ten minutes is the average length of
 9 time for a face-to-face appointment. But when you then
 10 factor in changing PPE, cleaning down the surfaces and
 11 all the work that is going on before someone comes into
 12 a consultation with social distancing in the waiting
 13 room, standing 2 metres apart in a queue to log in at
 14 the front desk, handing out masks to people who don't
 15 have masks, everything was slower. Obviously people
 16 were also anxious and frightened and had lots of issues
 17 that they wanted to discuss when they did come in, so
 18 the appointments tended to be longer. So it did
 19 significantly impact on the amount of people that we
 20 were able to physically see during a normal working day.
 21 MR DUNLOP: And you may not be able to put a number on it,
 22 but if I asked you to put a number on it, did half the
 23 number of appointments? Did it reduce them by a third?
 24 Are you able to ...?
 25 DR LUNAN: I would say it would at least half them.

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1 MR DUNLOP: At least half. You mentioned PPE there and
 2 I wonder if I can maybe ask a couple of questions about
 3 PPE. Immediately before the pandemic, what were the
 4 procurement arrangements for GP practices obtaining PPE?
 5 By "PPE", I have in mind masks, gloves, aprons, the kind
 6 of — what I might call the conventional PPE that
 7 medical staff might wear. How would GP practices obtain
 8 that?
 9 DR LUNAN: So they would normally be ordered through the
 10 board, the health board, and there's a national
 11 distribution centre. So it would be usually the
 12 practice manager of a practice that would be involved in
 13 ordering in stocks, and that's how it began or that's
 14 how it was done at the beginning of the pandemic.
 15 MR DUNLOP: Thank you. I think I'll maybe put that question
 16 to Dr Williams as well. I wonder if he's got an insight
 17 into —
 18 DR WILLIAMS: So there's a system called PECOS that can be
 19 used for ordering items of equipment, but although it
 20 brings some computerisation to the process, it
 21 doesn't — it's not then linked into any stock control
 22 or inventory systems within the practice, so there very
 23 much is a process, I suppose, of manual counting or
 24 trying to know when a practice — by practice, but each
 25 practice would have its own system of what it's keeping

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1 track of or how much it thinks it's got of one item.
 2 So pre-pandemic you're not using very much PPE
 3 unless somebody is coming in, you know, sort of coughing
 4 and sneezing and you want to avoid droplets or you're
 5 doing some minor surgery, you want to avoid body fluids,
 6 and suddenly, when you go into the pandemic, you've got
 7 dynamic risk assessments around everything that you're
 8 doing. I suppose, in telephone terms, you didn't need
 9 PPE to use the telephone so you could keep up a pace,
 10 but there was different PPE that would appear in our
 11 surgery and at different points and some of it was
 12 manufactured to different standards.
 13 I'm not clear how that related to the ordering. In
 14 most practices, you would find that the ordering is then
 15 given to someone who can do it consistently and who can
 16 go round and check what items are in the stock cupboard
 17 and within the rooms and would top up. So often that
 18 might be a healthcare assistant, for example, or, you
 19 know, somebody whose governance is either through the
 20 practice manager or the nursing team.
 21 MR DUNLOP: Was there any guidance in relation to -- I don't
 22 mean stockpiling as such, but having a minimum quantity
 23 of PPE? Was there any guidance either issued nationally
 24 or by the Royal College or any other body?
 25 A. There was a checking process that occurred, I think, on

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1 a weekly basis, I think, to occur -- for boards to be
 2 reassured that practices had adequate PPE, and I think
 3 they then reached a "Yes"/"No" -- you know, on
 4 a practice-by-practice basis. But I don't know what --
 5 you know, whether that was a value judgment rather than
 6 numbers because there were times when we were going
 7 through large amounts of PPE, especially when we got --
 8 when we were able to open things back up and go back to
 9 a bit more of a familiar turnover of people in the
 10 surgery for face-to-face -- you know, for a sequence of
 11 face-to-face appointments.
 12 MR DUNLOP: I mean, I should have asked that at the outset.
 13 During the pandemic -- Dr Williams, were you
 14 a practising GP during the pandemic period?
 15 DR WILLIAMS: Throughout the pandemic.
 16 MR DUNLOP: And, Dr Lunan, the same?
 17 DR LUNAN: Yes.
 18 MR DUNLOP: You've told us about the systems. The pandemic
 19 occurred at the end of March. There's not much in the
 20 PPE shelves in the GP practices. What were GPs doing
 21 then to obtain PPE? How would you go about obtaining
 22 it?
 23 DR WILLIAMS: So GP practices have always been able to
 24 source bits of equipment, either healthcare equipment or
 25 computer equipment or things that they thought were

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1 necessary that went above minimum standard, so even
 2 where a health board is responsible for providing items,
 3 and I suppose PPE was no exception. We would have
 4 patients come and drop off scrubs that they had made --
 5 you know, that they had fashioned from curtains or
 6 bedspreads or all sorts of things. People were trying
 7 to do their bit to help. We had protective bodysuits,
 8 you know, that painters and decorators might use, that
 9 people had dropped in.
 10 It was, I suppose, less easy in terms of the
 11 face mask side of things, that we were given guidance
 12 and, as I say, I think across general practice there
 13 were people that were wondering about whether, if FFP3
 14 masks were available -- you know, whether there was
 15 a higher -- a step-up level of protection, especially
 16 for people that might be involved, as I say, as
 17 emergency responders or who have more of an extended
 18 role than what you might view as, you know, some of
 19 the -- yeah, the more general practice.
 20 MR DUNLOP: Can I ask, did either of you or any of your
 21 members that you're aware of run out of PPE -- that
 22 you're aware of?
 23 DR WILLIAMS: We heard lots of expressions of anxiety and
 24 nervousness about PPE, and I think that stretched across
 25 people thinking that either they -- I mean, I had

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1 experience of aprons that weren't -- that were
 2 repurposed bin bags, you know, that weren't easy to put
 3 on and take off without -- you know, without them having
 4 then shed any droplets or particles that might have got
 5 on them. Some of these things -- some of these items
 6 were not the level we had hoped for. There were masks
 7 that had new expiry dates that went on them. I remember
 8 that particularly vividly. It wasn't in my practice.
 9 But, again, these were masks that were deemed to have
 10 a longer shelf life than initially thought.
 11 MR DUNLOP: Sorry, it seems to me that there's two issues
 12 arising out of that from what you're saying, from your
 13 evidence. It's whether there was enough in terms of
 14 supply and then whether the supply that was available
 15 was adequate. Correct me if I'm wrong, but I think what
 16 you're saying -- or you didn't -- when I asked if
 17 members had said had they run out, you didn't come back
 18 to me and say, "Yes, they did". So am I correct in
 19 assuming that GPs weren't running out of PPE but there
 20 were anxieties about the suitability of the PPE?
 21 DR WILLIAMS: I think there will be -- I'll just finish and
 22 hand over to my colleague. But I think there were many
 23 instances where people didn't have a full set of PPE
 24 that they felt met the risk assessments that they were
 25 making or that -- we could see that there were some

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1 environments where a higher level of PPE was required in
 2 some of the hospital secondary care settings and I think
 3 general practice in particular, but I would extend this
 4 to other contractors in primary care, so dentists,
 5 optometrists, pharmacy. I would say that these groups
 6 felt as if — either that the guidance that we were
 7 given round about what PPE was suitable was tailored to
 8 what was available or that — I don't think there was
 9 confidence from the profession that they had, you know,
 10 the right armour on, that they had the right tools for
 11 the job.
 12 MR DUNLOP: I'll maybe put this question to you, Dr Lunan.
 13 If a GP didn't have the right tools for the job, the
 14 right PPE, if it was a more basic mask than was
 15 required, what could a GP do about that, if anything?
 16 Perhaps the answer is "nothing" but ...
 17 DR LUNAN: No, I think it's a good question. There was
 18 variation in the guidance that I guess GPs were reading,
 19 depending on whether it was maybe WHO guidance or
 20 national guidance around what level of protection was
 21 necessary, working in a general practice setting. So
 22 the PPE that we were distributed at the beginning was to
 23 protect us against droplet spread, which is how we
 24 understood that COVID was transmitted at the very
 25 beginning. So that was the fluid-resistant surgical

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1 masks, the ones that you can buy in a chemist, a pair of
 2 gloves, a thin apron but no sleeves, and goggles or
 3 visors. And, as time went on, I think there was a lot
 4 of concern within members that, "Is this the right level
 5 of PPE for the work that we are doing, particularly if
 6 you're examining people who are coughing on you? Is
 7 that adequate protection — if we're seeing people who
 8 don't want to wear a mask and are coming into your
 9 consulting room, does that mean that we have to change
 10 who those people are able to see and maybe see doctors
 11 that are themselves at lower risk of contracting
 12 COVID?"
 13 So there was concerns about the quality, there was
 14 concerns about the quantity and there was concerns about
 15 the reliability of supply, and there were lots of
 16 work-arounds that came about because of that. So
 17 Dr Williams mentioned that often the community would
 18 kind of rise to the challenge and drop in things like
 19 scrubs, they would often drop in things like home-made
 20 masks as well, which we would often wear and sometimes
 21 hand out to patients in the practice as well, if people
 22 didn't have masks themselves, but many GPs actually
 23 chose to purchase their own. They chose to purchase
 24 their own FFP3 masks online, like many members of the
 25 public did, because they didn't feel adequately

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1 reassured that the fluid-resistant surgical masks were
 2 going to give them adequate cover.
 3 MR DUNLOP: And were they able to — I take it there were
 4 sufficient supplies in the marketplace for GPs to obtain
 5 those FFP3 masks?
 6 DR LUNAN: They were subject to the same supply issues as
 7 everyone else because they were going through public
 8 routes, so I guess there would not have always been
 9 a reliable supply of FFP3 masks. It would just depend
 10 on what they were able to order. But they weren't
 11 available through NHS pathways because our PPE was this
 12 other level, this other standard.
 13 MR DUNLOP: So — excuse my ignorance — so a member of the
 14 public might go on to — I suppose I'd better not
 15 mention any names — but on to the internet and use —
 16 find the product on the internet. Is that what GPs were
 17 doing or could GPs go through some specialised, you
 18 know, procurement consortium-type ...
 19 DR LUNAN: No, I think people just bought it online in the
 20 same way that the public would. There wasn't a special
 21 access pathway for GPs who wanted to buy a higher level
 22 of PPE that was considered, you know, acceptable as
 23 deemed by our local infection control guidelines.
 24 I think a lot of people were content with the level of
 25 PPE but some people were really concerned and the

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1 evidence was sometimes a bit conflicting at the start
 2 around how well protected you would be wearing the
 3 fluid-resistant surgical masks. They really only
 4 protect the person that is being seen by the person with
 5 the mask on. They don't protect the person wearing the
 6 mask. It's about protecting other people, so, for that
 7 situation to work, you need both the doctor to be
 8 wearing a mask and the person that you're consulting
 9 with to be wearing a mask as well, and of course that
 10 didn't always happen.
 11 MR DUNLOP: Moving on to a different topic, from
 12 paragraph 39 on, you talk about pharmacies and
 13 prescriptions in the statement. I wonder if I could
 14 just ask you some questions. It's not dealt with in the
 15 statement, but was there a trend towards people going to
 16 see pharmacists where they previously would have gone to
 17 see a GP? And I'll put that to Dr Lunan. Was that
 18 a general trend that you're aware of?
 19 DR LUNAN: It's difficult to know for sure. I know that
 20 pharmacy was really busy. Our community pharmacy
 21 colleagues were amazing during the pandemic because
 22 they — you know, they're also front line, open door,
 23 and they were seeing lots of people who were concerned
 24 about their health. They had a lot of footfall into
 25 practices for people collecting prescriptions. We tried

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1 to help minimise that by taking batches of paper
 2 prescriptions over to them so that they wouldn't have
 3 multiple people coming in with one, they would have
 4 maybe one person from a practice coming in with 20 or
 5 100, depending on how many we'd signed. We don't have
 6 end-to-end paperless prescribing in Scotland so we still
 7 rely on signed bits of paper that need to go from
 8 building A to building B and be collected by person C,
 9 so it's quite contact-intensive.

10 I don't have the figures to hand about whether there
 11 were people seeing pharmacists who would ordinarily have
 12 seen GPs. Some of -- if that was the case, some of that
 13 may have been appropriate because there is a kind of
 14 longstanding background campaign to try and encourage
 15 people to see wider members of the primary care team,
 16 which basically are any clinician working out in the
 17 community who has different sets of skills and
 18 expertise, depending on what the problem is. So we know
 19 that community pharmacists are extremely skilled, for
 20 example, in dealing with minor illness and dealing with
 21 minor skin conditions and giving advice about lots of
 22 different healthcare issues, and it may have been that
 23 people were starting to make more use of that than they
 24 had before the pandemic. So seeing community
 25 pharmacists wasn't necessarily an inappropriate thing.

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1 but it may have driven that change quicker than it
 2 ordinarily would have happened.

3 I think that one of the, again, silver linings, if
 4 you can use that word, from the pandemic was that our
 5 relationships with our community pharmacy colleagues
 6 were really strengthened during the pandemic because we
 7 had to work really closely with them to make sure that
 8 they were safe, that we were minimising footfall into
 9 their buildings, that we were thinking of all the ways
 10 that we could to make sure that pathways were
 11 streamlined, safe for patients, safe for staff.

12 MR DUNLOP: Thank you, Dr Lunan. Could I maybe pick you up
 13 on just a couple of points that you dealt with there?
 14 I suppose the first point, the quicker point, is that --
 15 simply speaking from my experience, is that the local
 16 pharmacy -- there was a queue to go into the local
 17 pharmacy, certainly at the beginning of the pandemic.
 18 Now, I wonder, would that exclude then certain people
 19 visiting the pharmacy, people that may be shielding or
 20 people with mobility problems? Would that perhaps
 21 exclude certain people using pharmacies?

22 DR LUNAN: I mean, I think that the queues were very
 23 apparent and the queues were more pronounced in more
 24 socio-economically deprived areas because that is the
 25 trend across the use of healthcare across the system,

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1 and the queues were partly because of increased
 2 workload, I'm sure, but also because people were having
 3 to socially distance so that the queues were longer than
 4 they would have been.

5 I think that people would have made decisions not to
 6 visit pharmacies because they were scared of standing in
 7 a queue, contracting COVID potentially, maybe being out
 8 in bad weather, so people who had a disability or had
 9 mobility issues or were shielding with more complex
 10 health problems, I would imagine would have experienced
 11 that as pretty frightening in the same way that they
 12 experienced accessing many different healthcare settings
 13 as really frightening, and it's probably one of the
 14 things that delayed people coming forward with health
 15 issues during the pandemic that we were acutely aware of
 16 and worried about. I'm sure that the pharmacists would
 17 have done some work with the people that they knew well
 18 to try and triage people in their queues and at the
 19 front door to make sure that the people who seemed the
 20 most unwell or the most unable to stand in a queue could
 21 be seen more quickly. I don't know what the details
 22 would be around that because it would be more
 23 appropriate to ask them, but I'm pretty sure that would
 24 have happened.

25 MR DUNLOP: Okay. Thank you. Maybe the follow-on question

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1 I'll maybe put to Dr Williams because it's something I'm
 2 sure you're both qualified to answer.

3 Thankfully I'm not particularly familiar with
 4 prescriptions, but, if I understand Dr Lunan's evidence,
 5 it's that a prescription is still a signed bit of paper
 6 essentially?

7 DR WILLIAMS: In Scotland we have the infrastructure for
 8 a message to be sent from the GP practice to the
 9 community pharmacy so that it can be seen what item has
 10 been prescribed, but legally, for that prescription to
 11 be dispensed, there needs to be a bit of paper with
 12 a signature on and for the community pharmacy to get
 13 reimbursement for their work in prescribing -- in
 14 dispensing and supplying that medication.

15 MR DUNLOP: I'm sure we could spend a whole afternoon on
 16 this topic, but in many walks of life electronic
 17 signatures have now become the norm following the
 18 pandemic. Is there any reason why -- and I appreciate
 19 I don't want to open a can of worms -- but is there any
 20 reason why those prescriptions couldn't be signed
 21 electronically, that they have to be still a hard bit of
 22 paper with a wet signature?

23 DR WILLIAMS: So there's two elements and there is an
 24 ongoing programme of work that the digital prescribing
 25 and dispensing pathway or DPDP -- but essentially you

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1 need the digital infrastructure in place and you also
 2 need a change to legislation.
 3 MR DUNLOP: I won't --- this probably perhaps goes outwith
 4 the scope.
 5 In terms of --- I wonder if I can move forward to
 6 paragraphs 57 of your statement and principally 58 as
 7 well. You talk about the changes to clinical work and
 8 you tell us that routine screening was paused. When you
 9 say "routine screening", what type of screening?
 10 DR WILLIAMS: So I suppose we should clarify the definition
 11 of "screening". So screening is an evidence-based
 12 process where you test a certain section of the
 13 population knowing that you are going to do more good
 14 than harm in terms of the results that you --- that are
 15 returned. So there are some specific conditions that
 16 you can look for in sections of the population that you
 17 can then treat --- you can detect at an earlier stage and
 18 there can be more treatment options available at the
 19 point of detection.
 20 So the bowel screening, for example, people will be
 21 sent out a kit to their home that they can test
 22 themselves. Once they're over the age of 50, that
 23 process kicks in. There's a national breast cancer
 24 screening and I suppose the screening that general
 25 practice has been most involved with is the cervical

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1 screening, and I might defer to my colleague,
 2 Carey Lunan, to --- if that's okay, Carey.
 3 MR DUNLOP: Of course. Dr Lunan?
 4 DR LUNAN: Yes. No, absolutely. So fairly early on we were
 5 advised that routine screening would pause. As
 6 Dr Williams was saying, that includes the breast, bowel
 7 and cervical cancer screening programmes. Also
 8 screening for abdominal aneurysms and for diabetic eye
 9 disease. A couple of months into the pandemic, there
 10 was a keenness to try and reintroduce screening because
 11 I think we were all acutely aware that it would be
 12 generating a backlog and potentially delaying diagnosis
 13 of early cancers or pre-cancer conditions for the cancer
 14 programmes anyway, which is what they are designed to
 15 pick up. Also some people are on non-routine screening,
 16 which means that they have a more regular invitation to
 17 come in and get tests done than someone who is on
 18 a routine screening programme where their tests have
 19 been normal previously.
 20 So I think it was May/June time in 2020 that there
 21 were plans to re-open screening programmes within
 22 general practice, which is the cervical screening
 23 programme, the smear test, which is done by practice
 24 nurses in the vast majority of cases, and an agreement
 25 that we would focus, to start with, on the people who

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1 were at higher risk. So people who had previously had
 2 an abnormal smear would be invited in first for their
 3 follow-up smear and, once we'd caught up with the
 4 backlog of people who were waiting for their follow-up
 5 from a previously abnormal result, we would resume the
 6 normal routine screening for people who were on the
 7 normal recall pathway, which was a smear every
 8 three years.
 9 MR DUNLOP: How long did that backlog take to catch up?
 10 DR LUNAN: It probably took a good few months. Certainly
 11 over the first couple of months, I think, routine ---
 12 sorry, non-routine screening, so the higher risk group,
 13 was due to start I think at the end of June, from
 14 memory --- I'd need to double-check the dates now --- but
 15 it was recognised that those smear tests were going to
 16 take longer than normal because they needed to be done
 17 in person, wearing PPE, cleaning between appointments,
 18 all the things that we've talked about already. They
 19 weren't the usual 15-minute appointments back to back.
 20 We had to accommodate a probably 50% reduction in the
 21 amount of cases that we could get through in a normal
 22 working day. But our practice nurses worked incredibly
 23 hard to get through that backlog and then I think we
 24 were able to resume normal routine screening --- I think
 25 certainly by the end of 2020.

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1 There were discussions that we were involved in,
 2 where we were talking about resuming screening, about
 3 whether or not that workload could be shared out beyond
 4 just general practice because of course smear tests
 5 don't need to be done in general practice. That's just
 6 where they've traditionally been done. And we had
 7 wondered about whether we could have a whole system
 8 approach, where we've got colleagues trained in
 9 smear-taking across the wider system within hospital
 10 settings or clinic settings that could maybe help with
 11 the backlog. I think at the end of the day it was felt
 12 that general practice was where the screening should be
 13 done and that's where it was done. And, from memory, we
 14 managed to get through the kind of non-routine backlog
 15 within two to three months, which is pretty phenomenal,
 16 and then managed to get back to more routine screening
 17 by the end of the year.
 18 MR DUNLOP: This might not be a question that you can
 19 answer, but in terms of screening and tests that would
 20 have been done by the GP practice, if that was
 21 delayed --- and we've heard that there was delay --- would
 22 that have led to progression of diseases which would
 23 create more of a pressure on the secondary care, the
 24 hospitals, in the future? I'm just wondering if that
 25 contributes to the backlog that we hear in the press

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1 every day.
 2 DR LUNAN: Yes. I mean, I think we can't know that for sure
 3 but we have to assume that that is the case because
 4 people — there's a reason that, for example, cervical
 5 screening at that time was every three years, because
 6 the evidence tells us that that is the most effective
 7 way to do it. Doing it every three years means that you
 8 pick up enough to make it a cost-effective programme.
 9 So if you're going to delay doing smears, then you are
 10 going to pick up pre-cancers or early cancers at a later
 11 stage, and that was why there was a keenness to try and
 12 get the routine screening up and running as quickly as
 13 possible, with a focus on the people who were highest
 14 risk getting screened first.
 15 So I don't know the exact figures in terms of people
 16 who were picked up with a new cancer diagnosis or
 17 a pre-cancer diagnosis when things opened up again
 18 across the whole of the screening pathway, and of course
 19 we were only doing cervical screening in general
 20 practice — there's also the breast and bowel screening
 21 pathways which had to open up outside general
 22 practice — but I think we have to assume that there
 23 will be some of those new diagnoses that may have been
 24 caught earlier if screening hadn't been paused.
 25 MR DUNLOP: Thank you. Dr Williams, as a very general

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1 question — I'm kind of jumping completely on to
 2 a different topic — but in terms of the impacts felt by
 3 GP practices, are you aware of any difference between
 4 impacts felt within different geographical locations?
 5 I have in mind maybe a city GP practice that's perhaps
 6 in a poorer area, an urban practice that's perhaps in
 7 a relatively affluent area, a rural practice, perhaps an
 8 island practice, where there was varied restrictions.
 9 Are you aware of any kind of differences in terms of
 10 impacts felt by the surgeries, depending on where
 11 they're located?
 12 DR WILLIAMS: Yes, I can certainly speak to the impact in
 13 rural, remote and island areas. General practice in
 14 those settings, the GPs — the practice is very much
 15 a part of the community, so even simple things like
 16 removing the waiting room as an area where people might
 17 meet and speak is — you know, is disruptive to the
 18 local population. I think the populations are
 19 sympathetic to the clinicians that are living and
 20 working there, but, as we described at the start, there
 21 was such profound changes to some of the ways that
 22 things were done — and again I come back to the
 23 emergency medical responder side of things. There were
 24 changes in terms of what — you know, whether people
 25 were allowed to go and do CPR without full protective

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1 bodysuits and masks, and these were things that we
 2 didn't have generally.
 3 So I think some of the ethical dilemmas that were
 4 there, services that we'd previously provided — I think
 5 you've picked up on, you know, the difficulties round
 6 about home visiting and the things that we wanted to do
 7 as general practice but that our risk assessment told us
 8 that this might take — you know, this might expose us
 9 to disease that might then go round the team, and some
 10 very difficult decision-making round about how do you
 11 keep a service going, how do you ensure that the service
 12 keeps going. And these are often, as I say, small
 13 teams, where you don't — in terms of resilience, where
 14 you don't have lots of layers. If one person goes
 15 missing from that team or has to self-isolate or has to
 16 work remotely because they've got symptoms and you
 17 assume that to be COVID or someone develops long-term
 18 problems following an infection, in remote and rural
 19 areas I think it's very pronounced, and it's felt not
 20 only within the team, but, as I say, across the
 21 community. There's — you know, there's a strong bond
 22 in these areas.
 23 MR DUNLOP: I take it you work in a rural practice, do you,
 24 Dr Williams?
 25 DR WILLIAMS: I work in a rural practice in Highland

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1 currently and I've worked in many other rural practices
 2 earlier on in my career, so, yes, I've seen, as I say,
 3 some of the differences between some of the urban
 4 practices.
 5 MR DUNLOP: Dr Lunan, again — sorry, do you wish to follow
 6 up on that?
 7 DR LUNAN: Yes, just on the same question, if that's okay —
 8 MR DUNLOP: Of course.
 9 DR LUNAN: — because Dr Williams and I work in quite
 10 different practices, which is probably quite useful for
 11 being able to reflect on that.
 12 So I worked during the pandemic in an urban deprived
 13 area practice and I think that we're all very aware of
 14 the impact that COVID-19 had on highlighting the
 15 existing health inequalities that we have in Scotland
 16 and the fact that it also worsened them. So I think
 17 what we noticed was, during the pandemic, there was
 18 always a triple whammy of COVID. Our patients were more
 19 likely to get COVID because they were more likely to be
 20 working in front-line jobs — they didn't have the
 21 choice of being able to work from home. They were often
 22 front-line jobs where the prevalence was high, so they
 23 were more at risk and more exposed; poorer underlying
 24 health to start with; more likely to die from COVID if
 25 they caught COVID — four times more likely to die;

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1 higher levels of ethnic minority populations in more
 2 deprived areas, which also gave an additional risk. And
 3 then, when vaccine was rolled out, the vaccination rates
 4 had lower uptake in more deprived areas, which is
 5 a historical finding. It's been seen with every
 6 vaccination programme that we've ever had for lots of
 7 complex reasons.

8 So I think that we were acutely aware that health
 9 inequalities — COVID was following the same social
 10 gradients that we see with many other diseases, but it
 11 felt particularly stark during the pandemic and it was
 12 worsened by things like having to consult remotely when
 13 people were digitally excluded. So if people didn't
 14 have access to data on their phone or reliable broadband
 15 or a private space in their home or they had cognitive
 16 impairment or English as a second language or if they
 17 struggled to, you know, describe the things that they
 18 were worried about, these were all things that made
 19 remote consulting much more difficult in a more deprived
 20 area and I think brought in the issues that we talked
 21 around clinical judgment, in just bringing someone in to
 22 see them face to face and get that sense-check. We also
 23 saw a rise in things like drug-related deaths, in mental
 24 health problems, in safeguarding issues around
 25 vulnerable families and domestic violence rates. All of

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1 those things rose during the pandemic.

2 In the more kind of affluent urban areas, the main
 3 challenges would be that the main risk factor for COVID
 4 was age, and if you live in a more affluent area, you're
 5 more likely to live into old age, so we know from
 6 speaking to colleagues across the country, working in
 7 the suburbs with older, frailer populations, that again
 8 that was incredibly difficult. Different challenges,
 9 having to have very complicated and often very sensitive
 10 discussions with people about their existing health,
 11 what they would want to happen — if they became sick
 12 with COVID, would they want cared for at home, would
 13 they want admitted to hospital, what was realistic to
 14 expect; if they did get COVID, what social supports did
 15 they have. Lots of issues around social isolation for
 16 older people. So there were lots of challenges that
 17 were core to all of us as GPs working across Scotland
 18 and then there were some particularly unique challenges
 19 depending on the demographic of the population that we
 20 were looking after.

21 MR DUNLOP: Thank you. You said a lot of things there that
 22 I wonder if I could pick up on a few of them. I'll list
 23 them and then I'll go through them one by one. You
 24 talked about substance abuse, you talked about
 25 safeguarding, you talked about mental health and you

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1 talked about digital exclusion.

2 I suppose, just doing them in reverse order, digital
 3 exclusion — when we talk about digital exclusion, we
 4 talk about people who obviously may not have either the
 5 equipment or the capacity to use the equipment to
 6 consult remotely. Is that focused on particular groups?
 7 Does that tend to be people that are elderly, that are
 8 frail? Was there a particular people that might have
 9 been more digitally excluded than others?

10 DR LUNAN: I guess the people that we knew were more likely
 11 to be digitally excluded were people who were older and
 12 less confident in using technology, people who had
 13 sensory impairment, so had difficulty with vision or
 14 hearing, people who couldn't necessarily afford the
 15 equipment or the data or the reliable broadband to be
 16 able to access things like Near Me. But we also know
 17 that there were other groups, so people with learning
 18 disability, people with cognitive impairment, so folk
 19 who had previously had a stroke, for example, or who had
 20 other neurological conditions. People who had English
 21 as a second language were also more likely to experience
 22 difficulty around digital consultations.

23 But other things — for example, just being able to
 24 access a private space within your house to have
 25 a sensitive conversation about something that's worrying

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1 you is more difficult if you're living in an overcrowded
 2 home and, particularly if there are issues around
 3 domestic security at home, that felt, you know,
 4 particularly worrying. So there were lots and lots of
 5 things that we needed to be actively considering when we
 6 were speaking to people on the phone or with Near Me to
 7 make sure that this was an appropriate and a safe way to
 8 be assessing someone and consulting with someone. And
 9 the RCGP was involved in writing guidance for GPs to
 10 just help — to sort of sense-check with people, "Does
 11 this feel okay for you?", "Are you able to speak just
 12 now?", "Have you got somewhere private to go?", "Do you
 13 know how to use the technology?", "What would your
 14 preference be?", and we would try to accommodate that as
 15 far as possible, given what was going on around
 16 prevalence in the local area at the time.

17 But I think digital exclusion was a big concern
 18 during the pandemic and remains one because we need to
 19 make sure that, as we recover the NHS and we develop
 20 more hybrid ways of working and more telephone
 21 appointments or video consultations, that they don't
 22 worsen health inequalities because there are many, many
 23 consultations that are more complicated, that need that
 24 face-to-face element, not just to assess somebody but
 25 also to build trust and connection and relationships

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1 with people, which is a big part of what we do as GPs.
 2 MR DUNLOP: Okay. Thank you. One of the other points you
 3 mentioned was mental health, and we see at paragraph 66
 4 of your statement that there was an Audit Scotland
 5 report referred to, which said that accessing mental
 6 health issues [sic] became worse as a result of the
 7 pandemic. I suppose again we could talk about this all
 8 afternoon, but relatively briefly could you explain to
 9 us, if you can, what mental health services weren't
 10 available as a consequence of the pandemic and what
 11 people could do to obtain mental health services, if
 12 anything, during the period March to December 2020 when
 13 you were the chair of the Royal College?
 14 DR LUNAN: So we know that a lot of the third sector
 15 organisations were struggling to be able to see people
 16 face to face, so third sector voluntary charity
 17 organisations that a lot of people got mental health
 18 support from either were not financially viable during
 19 the pandemic or weren't able to staff the service or
 20 weren't able to stay in the premises, so a lot of those
 21 services became unavailable.
 22 In terms of specialist mental health services, a lot
 23 of those went online, so became remote by default, and
 24 a lot of patients with mental health issues often
 25 struggled with that. Not all of them. Some people like

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1 a telephone appointment or a video consultation. But
 2 access to mental health services felt more difficult .
 3 In general practice, it's a big part of our normal
 4 workload, so we see lots and lots of mental health in
 5 normal times. Probably about a third of our
 6 consultations have got a mental health component to
 7 them. But during the pandemic it's estimated that rose
 8 to probably about half of our consultations would have
 9 some mental health element to them, whether it was low
 10 mood or anxiety or insomnia or other issues or more
 11 significant mental health issues, so ---
 12 MR DUNLOP: Can I ask, those issues, were they caused by
 13 effects from the pandemic, whether it be lockdown
 14 restrictions or --- Dr Williams looks as if he might be
 15 willing to offer an answer to that one.
 16 DR WILLIAMS: So aside from the health and social care and
 17 third sector support, people's lives and routines were
 18 disrupted. People experienced financial pressures that
 19 they had never experienced before or uncertainties about
 20 their future work or about their relations or about
 21 their relatives who lived in another place or whether
 22 they could visit their elderly parents or what would
 23 happen if somebody got ill. Some of the things that in
 24 ordinary times might cause you stress or upset or worry
 25 might all come at the same time and might be magnified.

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1 So, as I say, people who had mental health issues that
 2 were coping on a day-to-day basis before, I think were
 3 very much then feeling pronounced effects or I think
 4 there were lots of people who --- where their functioning
 5 became worse or how they felt became worse, I think when
 6 it also appears more difficult to access help that they
 7 would have previously felt able to access, you know, if
 8 there are.
 9 So even if there aren't actual barriers, if there
 10 are perceived barriers or if they aren't confident in
 11 speaking to --- in saying to a receptionist, "I have
 12 depression, it's got worse" --- if people can't navigate
 13 these few simple steps into --- you know, to speaking to
 14 a GP or to another clinician in general practice, which
 15 would ordinarily be most people's sort of first steps
 16 towards help and assistance, then you're looking at
 17 problems out there.
 18 MR DUNLOP: I suppose this takes me on to the substance and
 19 I'll come back to the safeguarding point, but in terms
 20 of substance --- I'll maybe just put this to Dr Williams
 21 because, as a practising GP, I think you can speak to
 22 this. You don't need to be the chair of the
 23 Royal College --- but was there an increase in alcohol
 24 and drug use that you're aware of during the pandemic?
 25 A. Yeah, there was --- and it was a change in pattern and

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1 a change in where people would consume alcohol in terms
 2 of drinking at home rather than going to pubs and bars,
 3 especially when people aren't able to congregate and
 4 they've got a real change in how people are ordering
 5 food and drink and having deliveries. But, yeah, there
 6 are a range of organisations that could document, you
 7 know, the changes in pattern and the harm that's
 8 occurred.
 9 MR DUNLOP: That's the question. A changing pattern in
 10 itself isn't necessarily a bad thing, but when use goes
 11 to abuse that presumably is a bad thing. Did you see
 12 use go from use to abuse, if that's the term?
 13 DR WILLIAMS: So I suppose the fear is the things that
 14 you're not seeing or the people who aren't consulting,
 15 but at the same time you know that sales are going in
 16 a direction that are bound to be causing harm, or by the
 17 time that you see people, they've already experienced
 18 harm.
 19 MR DUNLOP: Dr Lunan, just to pick up the last of the four
 20 points I think you identified. It was safeguarding.
 21 I don't want to spend too much time on this, we have
 22 limited time this afternoon, but you deal with
 23 safeguarding in your statement at paragraph 73 and
 24 identify that GPs play an important role in safeguarding
 25 and deal with family and child and social workers and so

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1 forth. My question is in fairly sharp focus: in your
 2 opinion, do you know if the absence of that during the
 3 pandemic — is it likely to have led to preventable harm
 4 to children and domestic violence or —
 5 DR LUNAN: The absence of the usual organisations that wrap
 6 around, like education, social work, health visiting,
 7 general practice? Is that the question?
 8 MR DUNLOP: Yes. Essentially the role that the GPs play, if
 9 that's taken out the equation, does that increase the
 10 risk that there's harm to children or domestic violence?
 11 DR LUNAN: I think, yeah, the collective responsibility of
 12 all the organisations that are placed to support
 13 vulnerable families, whether it's schools, whether it's
 14 social work, whether it's health visiting, whether it's
 15 midwives, whether it's general practice — if all of
 16 those organisations are less available for whatever
 17 reason because they're having to operate in a different
 18 way during the pandemic, then, yes, that will have
 19 increased harm to families that we were not seeing or
 20 hearing from because they were missing in the system
 21 under very stressful circumstances.
 22 We know that the rates of domestic abuse went up,
 23 for example, and we know that children's mental health
 24 deteriorated during the pandemic and that it was pretty
 25 stark, when schools reopened, that teachers were

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1 reporting concerns about the fact that their vulnerable
 2 children had deteriorated in the time that they hadn't
 3 seen them.
 4 MR DUNLOP: Thank you. Dr Williams, I wonder if I can put
 5 this question to you, and I'm moving on to shielding
 6 now. You deal with shielding under paragraph 81 of your
 7 statement. Maybe just for brevity I can read it out
 8 myself:
 9 "The regulations that GPs worked under were not
 10 straightforward. [The Royal College] felt there was not
 11 good correlation between the list of conditions that had
 12 been drawn up, and those who were vulnerable of becoming
 13 very ill. We objected to the terminology of 'extremely
 14 clinically vulnerable'."
 15 Did the lack of clarity in the guidance cause GPs
 16 difficulties and, if so, what were those difficulties?
 17 DR WILLIAMS: So I should explain, to help inform things,
 18 that clinical record that GPs keep can be a lifetime
 19 clinical record. It can be very detailed, it is
 20 carefully coded, it's curated, and even when patients
 21 move around between practices, we can still have a very
 22 granular idea of procedures that people have gone
 23 through or illnesses that they have had, diagnoses that
 24 they've had.
 25 In terms of the process around about shielding,

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1 I think that started with what model you've got, do we
 2 know who is going to be affected most — who is going to
 3 be at most risk of COVID and most at risk of
 4 complications and serious outcomes, and of course we
 5 didn't know that at the start. So you have a model
 6 which you then need to deploy very rapidly and then you
 7 need to check whether that — whether the right people
 8 were on the list. So along the way, there was all —
 9 there was various groups that were found that were known
 10 about in hospital systems but weren't particularly
 11 apparent from looking at the codes on GP systems.
 12 I think my colleague, Dr Lunan, might be able to add
 13 some more useful information about shielding. I think
 14 she dealt with the start of it.
 15 DR LUNAN: Thanks. Yes, I think that at the beginning the
 16 list that was drawn up of the people who were being
 17 recommended to shield were largely people who fell into
 18 what we call single disease categories, but actually, as
 19 we began to see the data coming out of who was dying
 20 from COVID, it just wasn't as straightforward as that
 21 and it seemed to be that people with particular
 22 combinations of different diseases would be more at
 23 risk. So, for example, if you had obesity and you also
 24 had diabetes and you also happened to be from a certain
 25 ethnic minority background and your age was higher, you

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1 were very high risk, and that wouldn't necessarily have
 2 been picked up in the initial shielding categories that
 3 were announced.
 4 So I think it created confusion in two ways. One
 5 was that there wasn't always a common understanding
 6 between specialist services looking after people with
 7 one illness, one disease, one condition, and generalist
 8 services, ie, GPs who were looking after people with
 9 lots of different conditions, with other stuff thrown in
 10 that makes it more complicated, for example, ethnicity,
 11 for example, poverty or health-harming behaviours like
 12 smoking or obesity — things that make it more
 13 complicated than that. So people would often be
 14 receiving two different shielding conversations, one
 15 from the hospital and one from their GP which created
 16 confusion for patients sometimes. But we did have the
 17 opportunity to add people on to the shielding list if we
 18 felt, in our clinical judgment, that they were more
 19 vulnerable and that they would benefit from the extra
 20 protections that shielding would bring, and that often
 21 just required a discussion with the patient to see how
 22 they would feel about that based on their own risk.
 23 MR DUNLOP: Can I ask a follow-up question? You explain in
 24 your evidence there that you began to see the people
 25 that were passing away from COVID. It wasn't simply

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1 people that were on the shielding list . There was
 2 a range of factors. Obviously we're looking at this
 3 with the benefit of hindsight but what I'm interested
 4 in: as those other factors developed and people said,
 5 "Oh, this is a critical issue", was the shielding
 6 guidance changing to reflect that or was it not changing
 7 sufficiently quickly to reflect that?
 8 I think Dr Williams look as if he's --- I'll let
 9 Dr Williams --- and then perhaps I'll pass it briefly
 10 over to you, Dr Lunan, if I may.
 11 DR WILLIAMS: I think the Scottish Government team that were
 12 working on that might be better able to inform you with
 13 numbers, but I think that eventually they recognised
 14 that --- by being told to shield and by people being told
 15 that they were on a list, it then started off, I guess,
 16 a mindset or behaviours or what people thought --- how
 17 much people thought they needed to limit their
 18 interaction with wider society, and of course a lot of
 19 the background circumstances changed.
 20 So I think over time it became apparent that the way
 21 that shield --- the group that had been told that they
 22 were extremely clinically vulnerable, actually some of
 23 the behaviours that it was then influencing wasn't
 24 influencing them in the right way and, as Dr Lunan has
 25 said, actually there were other --- it was other groups

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1 with combinations that were far more at risk, and that
 2 was being borne out by the death certification process.
 3 MR DUNLOP: I appreciate you said you should put the
 4 question perhaps to those that drafted it, but as
 5 somebody at the front line, I just wondered if you had
 6 a view of whether or not the shielding guidance was
 7 being amended sufficiently swiftly to capture what
 8 was --- these new factors that were important.
 9 DR WILLIAMS: So I don't think there was the technology in
 10 place to be able --- so there was the ability to put
 11 a marker on a large group of people's --- into people's
 12 clinical notes, but this was something that hadn't been
 13 done before, so it hadn't been realised that you can
 14 then easily take that off ---
 15 MR DUNLOP: Just to jump in there --- and I apologise for
 16 jumping in --- but just for lessons to be learned, is
 17 that a lesson to be learned, then, that in a pandemic
 18 there should be a facility for GPs to be able to do
 19 that?
 20 DR WILLIAMS: So I think if you're going to give an
 21 instruction to a subset of the population to be doing
 22 something specific, and that is to be, you know,
 23 especially distanced from normal parts of society, then
 24 you need to understand the implications over time, so
 25 how that person will adapt psychologically. So if you

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1 aren't putting the right people on to that list and
 2 giving them the relevant support, then you're going to
 3 encounter problems. So I think that there was ---
 4 I think measures were taken with good intention but
 5 I don't think that the system responded quickly and well
 6 enough to problems that were stacking up, and that must
 7 have been visible to parts of the system.
 8 MR DUNLOP: Thank you. Dr Lunan, was there anything that
 9 you wanted to add in addition to what Dr Williams has
 10 said?
 11 DR LUNAN: Just a couple of quick points. One, I would echo
 12 what Dr Williams has said, is that shielding was
 13 a really big deal. To tell someone that they were
 14 shielding was quite a frightening thing for a lot of
 15 people and required them to significantly change and
 16 limit their life, so there's --- a huge risk/benefit
 17 decision needs to be made about whether or not someone
 18 needs to be in the shielding group. And I think, as
 19 time went on, we realised that some of the conditions
 20 that were felt to be at high risk of COVID probably
 21 weren't as high risk as we'd originally thought, but
 22 it's far harder to remove someone or remove a group of
 23 people from the shielding list than it is to add them in
 24 the first place because people are anxious then about
 25 coming out of it. So I think that was one of the

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1 challenges.
 2 I think there was recognition of the fact that we
 3 needed to not think in single disease pathways and we
 4 needed to think across something called "multiple
 5 morbidity", so if you've got two or more long-term
 6 conditions running together, you were more likely to get
 7 sick with COVID if you caught it. And I think that
 8 probably two or three months in we began to have much
 9 more awareness of the impact of ethnicity and that began
 10 to get a lot more traction in terms of how we would
 11 risk-assess people.
 12 I think the impact of poverty took longer and
 13 I think that what we need to recognise is that age isn't
 14 a straightforward binary thing. Someone who is 65,
 15 living in poverty, is nearer the age of a 85-year-old
 16 person living in a much more affluent situation. So
 17 there's something about weighting age according to
 18 deprivation so that we think about biological age and
 19 not chronological age when it comes to shielding, and
 20 exactly the same could be said about rolling out
 21 vaccines because many people living in poorer
 22 circumstances never reach old age. So there's something
 23 about adjusting age thresholds, although I appreciate
 24 that's not straightforward to do, but I think that is
 25 learning for next time.

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1 THE CHAIR: Mr Dunlop, you've actually used your allotted
 2 time for these witnesses. If you need more time, we'll
 3 have to have a break for the stenographers.
 4 MR DUNLOP: I will be another five/ten minutes, my Lord.
 5 I promise to be finished before 2.55. However, I think
 6 a break -- I don't think there's a witness on after.
 7 THE CHAIR: No, there isn't.
 8 MR DUNLOP: So I'm entirely in your Lordship's hands.
 9 I apologise. I've just got a few more questions.
 10 THE CHAIR: If you're only going to be five or ten minutes,
 11 I'm sure we could run that through without interrupting.
 12 MR DUNLOP: I only have two topics I just want to deal with
 13 and thankfully Dr Lunan has helpfully basically
 14 identified, the health inequalities. So, Dr Lunan, you
 15 were mentioning there that obviously the people that are
 16 living in social deprivation, a younger person will be
 17 the same as an older person in a more affluent area.
 18 In terms of you deal with health inequalities, were
 19 there particular groups of people that were affected by
 20 COVID more? I don't need to go into detail -- if you
 21 could list the groups rather than -- I don't think we
 22 need to go into a huge narrative unless you think it
 23 would be of particular benefit.
 24 DR LUNAN: People working in front-line jobs who weren't
 25 able to work from home; people who had poor underlying

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1 health, and we know people living in more
 2 socio-economically deprived situations develop diseases
 3 that older people would develop ten to 15 years older;
 4 people who are less likely to be vaccinated, they were
 5 the people that were more likely to get sick and to die
 6 from COVID. That's in a very brief snapshot of who was
 7 more likely to, but obviously I could talk about this in
 8 much more detail.
 9 MR DUNLOP: Thank you. No, no, no, I'm sure we could. What
 10 I would say is we have your statement and your statement
 11 is evidence.
 12 Just finally, Dr Williams, if I can just take you to
 13 paragraph 172 of the statement. You identify that
 14 there's been an increase in private healthcare since the
 15 pandemic which is attributable to kind of long waiting
 16 lists and backlogs. Does the increase in people taking
 17 out or going privately -- does that remove the pressure
 18 from the NHS? Does that enable them to --
 19 DR WILLIAMS: No.
 20 MR DUNLOP: And why does it not?
 21 DR WILLIAMS: So private healthcare is by and large
 22 providing a more limited set of investigations and
 23 procedures, often making use of staff, be they surgeons,
 24 be they nurses, who also have NHS jobs. So I can
 25 understand -- when people are faced with a long waiting

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1 list or, you know, a potentially very long waiting list,
 2 if they're seeking a diagnosis and here is a test that
 3 they could get done without needing that wait, I can
 4 understand the decision. My hope would be for an NHS
 5 that wouldn't have these waits involved, that wouldn't
 6 have these delays that people face. But I wouldn't want
 7 others to think that private healthcare is the solution
 8 to the problems that we currently face.
 9 I think there's certainly -- people look for quick
 10 fixes often, and in some ways, if you get a hip
 11 replacement that, you know, revolutionises what mobility
 12 you have, then that is a fantastic change in
 13 circumstance that you wouldn't want somebody waiting
 14 a couple of years' delay. But it's difficult for me to
 15 speak more widely about. I think the increase in
 16 private healthcare is a consequence of the system
 17 pressures and those who are affluent or have access to
 18 insurance or who are making the choices that something
 19 is necessary are often making sacrifices that I don't
 20 think they should need to make.
 21 MR DUNLOP: Am I correct -- I don't wish to lead you in your
 22 last question -- but am I correct that what you're
 23 saying, then, essentially is that a part of it is that
 24 it's the same medical practitioners who are providing
 25 that care, so if we were to go into another pandemic,

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1 there wouldn't be an answer by looking simply to the
 2 private sector to essentially fill the gap that wasn't
 3 being provided by the NHS in 2020?
 4 DR WILLIAMS: So I think you need to go one step backwards
 5 and look at why some of these waiting lists got longer.
 6 So, for example, for large joint replacements, for hip
 7 replacements, knee replacements, if surgical space was
 8 being repurposed or wasn't able to be used, if these
 9 operations weren't able to go ahead, if the need for
 10 intensive care support round about an operation meant
 11 that it became a completely different risk, as I say,
 12 there are multiple reasons why any pandemic, I think,
 13 would increase certain waiting lists. And the change in
 14 how people have accessed healthcare, in some respects
 15 the sacrifices that people have made when there's been
 16 periods of limited healthcare resource, you know, the
 17 decision-making round about that, you know, is difficult
 18 for doctors and patients alike. I think having a health
 19 system that has capacity, that has reserve, that has
 20 resilience is important.
 21 MR DUNLOP: Thank you. Before I thank you both for your
 22 time, Dr Lunan, was there something -- I saw you had
 23 your pen up but maybe it was just -- I hold my pen as
 24 well. I don't know if there was something you wanted to
 25 add?

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1 DR LUNAN: No, it was just the private healthcare — well,
 2 can I briefly — 30 seconds about private healthcare.
 3 I think that there are lots of people who can and can't
 4 afford to pay for private healthcare that are choosing
 5 private healthcare because they feel they have no
 6 option. But, as Dr Williams said, it's often the same
 7 workforce and often the work will come back to the NHS
 8 for follow-up, where tests are done in private
 9 healthcare systems that wouldn't necessarily have been
 10 done in the NHS because they wouldn't have met the
 11 thresholds for needing tests to be done.
 12 But I think more importantly than that, in the
 13 long-term, if you have these two-tier systems of
 14 healthcare, it removes the collective incentive of the
 15 whole of society to argue for or vote for a public
 16 healthcare system that works well for everyone because
 17 some people are getting their needs met elsewhere and
 18 so, ultimately, that undermines the social function of
 19 the NHS.
 20 MR DUNLOP: Thank you.
 21 Is there anything else that you would like to add
 22 that you think would assist the Inquiry in its
 23 deliberations before I thank you for your time?
 24 DR LUNAN: I think I would just like to say thank you for
 25 the opportunity to give evidence today; that I think

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1 general practice as a profession was remarkably
 2 adaptable and flexible. I was really proud to be a GP
 3 during the pandemic, during really difficult times, and
 4 in many ways it brought us closer to our patients.
 5 I think recovery has been really difficult — a lot of
 6 the media coverage around general practice has been
 7 really difficult in terms of the impact on morale and
 8 we're still working to try and address that, but I think
 9 that the way that we were able to support not just the
 10 medically vulnerable but the socially vulnerable feels
 11 really important and I felt really proud to work during
 12 the pandemic as a GP in the NHS.
 13 MR DUNLOP: May I extend my thanks to both of you and the
 14 Royal College for giving your time freely and going to
 15 the extent of preparing such a comprehensive statement.
 16 We can't essentially do the Inquiry without parties like
 17 yourselves, so I'll extend my thanks to you.
 18 I have no further questions. I don't know whether
 19 my Lord has anything that he wishes to add.
 20 THE CHAIR: No. Just my thanks to both the doctors. I'm
 21 very grateful. That concludes proceedings for today.
 22 Thank you all.
 23 MR DUNLOP: Thank you, my Lord.
 24 (2.54 pm)
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(The hearing adjourned until
 Friday, 15 March 2024 at 9.45 am)

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