Scottish Covid-19 Inquiry

Day 23

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(9.45 am)

THE CHAIR: Good morning, everybody. Welcome.

Good morning, Mr Stephens. You have two witnesses for me.

MR STEPHENS: I do, indeed, my Lord, both representing PAMIS. They've asked to give evidence together as a panel --

THE CHAIR: Excellent.

MR STEPHENS: -- and so we've facilitated that.

THE CHAIR: So it's Ms Graham and -- Ms or Mrs -- Graham and Miller; is that correct?

MR STEPHENS: Yes.

THE CHAIR: Good. Thank you. When you're ready, Mr Stephens.

MS PATRICIA GRAHAM and MS JENNIFER MILLER (called)

MR STEPHENS: Thank you, my Lord. For the record, the respective witness statements for the two witnesses -- their Inquiry reference numbers are, in respect of Jenny Miller, SCI-WT0460-000001, and then for Pat Graham it's SCI-WT0417-000001.

Questions by MR STEPHENS

MR STEPHENS: Could I start, please, by asking you both to confirm your full names? If I may start with you, Pat.

MS GRAHAM: My name is Pat Graham.

MS MILLER: And my name is Jenny Miller.

MR STEPHENS: And you are both content to be called "Pat" and "Jenny" for the duration of this session?

MS MILLER: Yes.

MS GRAHAM: Yes.

MR STEPHENS: Thank you. I'm grateful. Your respective ages and contact details are known to the Inquiry so I'm not going to ask you those. You've both helpfully provided witness statements, organisational witness statements, to the Inquiry. Can I just check you're happy with the content of those as will be supplemented by your oral evidence today?

MS GRAHAM: Yes.

MS MILLER: Yes.

MR STEPHENS: Are you happy for that evidence to be recorded and published?

MS MILLER: Yes.

MS GRAHAM: Yes.

MR STEPHENS: I should also say at the outset that everything you have said in those written statements, along with the accompanying documentation you've provided and the video, which I myself have watched, the Inquiry is grateful for all of that and all of that will be taken into account, so if there's something that features in your statement that isn't mentioned today, please don't worry. It will all be taken into account by the Inquiry.

Lastly, in terms of preliminary matters, can I remind you there's a restriction order in place so please don't name any other individuals when giving your evidence. If it's a staff member, please try to stick to "staff member" or, in your case, Pat, if it was your daughter, you just refer to them as your daughter; is that clear? Thank you.

Those are the preliminary matters. I would like to start, please, if I may -- the organisation you both represent today is PAMIS and I understand that stands for "Promoting a More Inclusive Society"; is that right?

MS MILLER: Yes.

MS GRAHAM: Yes.

MR STEPHENS: And, Pat, your current position is chair of that organisation?

MS GRAHAM: That's right.

MR STEPHENS: How long have you held that position for?

MS GRAHAM: I've been on the PAMIS board of governors since 2015 and I became the chair in 2017.

MR STEPHENS: And what was your previous professional background before you became --

MS GRAHAM: I was a tax inspector with HMRC.

MR STEPHENS: It's fair to say, though, that your own involvement with PAMIS extends quite a bit longer than your involvement with the board; is that right?

MS GRAHAM: Yes, very much so. I have a daughter with a profound learning disability who is now 35 and my involvement with PAMIS goes back at least 30 years to not long after PAMIS was established.

MR STEPHENS: So you bring your own personal lived experience, then, I suppose, in your roles?

MS GRAHAM: Yes, very much so, and I think that the decision that I made to join the board was because at the time I was retiring and my daughter, who had lived at home, was moving into a housing support service and so I had much more free time. And my feeling was at the time that, because I had been and my family had been the recipient of so much support from PAMIS over the years, that it was a really great opportunity for me and my daughter by association to give something back to PAMIS and actually to our community.

MR STEPHENS: I see. Thank you. And how would you describe your role as chair in high-level terms? What's involved in that role?

MS GRAHAM: Well, I guess it's a strategic role in that I provide support to Jenny and to other members of staff, but it's also, I suppose, partly operational in that I'm involved in lots of PAMIS activity, lots of research projects, lots of meetings, lots of discussions with Jenny and other members of staff. I'm involved in a great deal of the broad range of activities that PAMIS is involved in. So I don't know whether that's a traditional board chair role or not, but it's what's really evolved over the years and I think particularly during the COVID period, I was able to support Jenny and the rest of the team in a much broader way than previously, and that's really continued, hasn't it?

MR STEPHENS: Thank you.

Jenny, if I can turn to you, then, your role is as chief executive officer of PAMIS; is that right?

MS MILLER: Yes.

MR STEPHENS: How long have you held that position?

MS MILLER: Since 2015 as well. Yes, I had been on the board previously to that and had been involved with PAMIS since its inception actually, but was absolutely thrilled to get the job.

MR STEPHENS: And what's your previous background before taking on that role?

MS MILLER: So I was an allied health professional. I was an occupational therapist and I worked for NHS Education for Scotland as well. But my early career started with working with people with profound learning and multiple disabilities, so it was great to return at the end of

that career to that post.

MR STEPHENS: So again useful, I imagine, for your current role as CEO?

MS MILLER: Yes, very useful.

MR STEPHENS: How would you describe your role as CEO? What's involved in that?

MS MILLER: Yes, I suppose it is leading a fantastic organisation and supporting and facilitating and enabling the voices of a very invisible community to be heard. So a lot of work is done nationally, working with the Government and with other organisations, but —— yeah, it's been about developing practice, working on research projects, but enabling staff —— I mean, I suppose I have a servant leadership. It's leading from behind, enabling staff to really excel in the fabulous work that they do as well so ...

But the strategy is probably a big bit looking at how we influence and —— I mean, it's about a specific group of individuals, but it is about promoting inclusion, and if we can get it right in our local communities, then people with a profound learning disability become visible and are able to take part.

MR STEPHENS: Yes, you mention that word "invisible" and we will come back to that, I promise you. It's in my thoughts. Yes, I think you mentioned about 30% of your

time was spent working directly with families and then 70% leading your organisation. I think that's what you said in your witness statement about that ——

MS MILLER: Yeah, it is great to still roll your sleeves up and get involved. We get very involved in campaigning. We have a mobile changing place toilet, and so volunteering actually with that means that you're out working with families and being able to see what it's like on the ground really.

MR STEPHENS: Pat, you describe PAMIS as "a unique charity" in your witness statement. This is paragraph 37. Why is that?

MS GRAHAM: Well, it's unique in the sense that it's the only organisation that solely supports people with profound multiple learning disabilities and their families and carers in this country and probably —— from our knowledge of what happens worldwide, it's probably unique in the world. And I think that that gives us a very strong understanding of what life is like for people with profound learning disabilities in Scotland. There are other organisations that will provide a degree of support and a degree of understanding about people with PMLD, but PAMIS —— our exclusive aim and goal is to support that group.

MR STEPHENS: Thank you. We'll come back to precisely what

"PMLD" means again, but you referenced it there, so "profound and multiple learning disabilities", but we'll come back to that.

Jenny, you refer, in paragraph 5 of your witness statement, to a document setting out background information on PAMIS. For the reference, that's SCI—WT0417—000002. Drawing upon on or if you can summarise that document, what would you describe as the founding objectives of PAMIS? That's a question to both of you, but what are the founding objectives of PAMIS?

MS MILLER: So it's to ensure that people with profound and multiple learning disabilities are able to lead healthy and valued and inclusive lives, but we do that through also supporting their families because, if you have a child or an adult with a profound learning disability, it impacts on that whole family life, and I think that's the bit that's often very misunderstood and they're totally intrinsically linked.

So our primary aim, sadly, which was developed 32 years ago, hasn't really changed. It's about hearing the voices of people with profound and multiple learning disabilities and their families, but it's also about enabling communities to include them and it's also about making sure that any policies and strategies that are developed are developed to include absolutely everybody, which is that group. And I guess what we often say is, "If you get it right for that group, you'll get it right for so many other people". But it's that bit about valuing and respecting and ensuring they have a healthy life.

MR STEPHENS: Thank you. Anything you would add to that, Pat?

MS GRAHAM: Yeah, I would say also it's about ensuring that they have a rewarding life because for many people with PMLD, their lives are about care because so many of them have very complex health needs as well. I think probably previously the perception was that for people with PMLD, that was really all they needed, without that fundamental understanding that they have a much greater depth of feeling and comprehension than they are often given credit for.

You mentioned earlier about why I thought PAMIS was unique, and I think one of the unique things about PAMIS is that over the years it's an organisation that's evolved and developed. It started off as a family support service primarily but has moved on massively beyond that. And one of the things that we have innovated and specialised in, as well as our, you know, fundamental -- our founding principles is to ensure that people with PMLD have exciting, interesting lives that

gives them an opportunity to learn things and experience things that other people do and which they previously probably didn't.

You know, there are outdoor activities, indoor -- lots of indoor activities, things that will develop them, arts and crafts and music and culture, you know, festivals, activities in parks and beaches, and all these sorts of things that are exciting because we should all have the opportunity for something exciting and adventurous to happen in our lives, and they are no different and they can derive so much from that, that -- I don't know -- does any other organisation do that, Jenny? I don't think so.

MS MILLER: But they're not simple, they're not easy to facilitate, and it is that level of expertise about understanding how to adapt and develop and the research that's required in order to enable communities to be inclusive. And what we say is communities don't mean to exclude. They just are not always sure how to include people.

MS GRAHAM: Yes.

MS MILLER: So we also lead on research and we take research and make sure that that gets put into practice. So there's been recent research that says actually people's brains develop in a different way from how we thought

and that that early development in the brainstem around emotional and imagination and, you know, consciousness happens a lot earlier. So that means actually lots of judgments that were made about people not being able to live a fulfilling life are wrong, and I think that is now coming to the fore, but it also explains why, for so many people, that lack of expectancy for them to achieve or that lack actually of expecting somebody to live has been a real challenge, and I think we're now beginning to make break-throughs about let's expect people to live a full life rather than just waiting for them to die, which has been quite a dramatic break-through.

MS GRAHAM: Yeah, and I think that's one of the reasons why we -- one example of a thing that we've been trying to take forward is life-long learning for people with profound learning disabilities on the basis that -- well, apart from the fact it's their human right, also they still have the capacity to learn, and they might learn at a different pace and in a different way from everybody else, but why should they not have the opportunities to do things that everybody else does and everybody else derives value from and enables them to live a much better quality of life, just a more interesting life?

MR STEPHENS: Yes, thank you. I was going to ask you about

the core work of PAMIS. I suspect you've perhaps both answered that to an extent at least. Is there anything else you would say about the core work that you do in addition to the things you just mentioned?

MS MILLER: I suppose one other really, really significant important area is that education of the future generation of health and social care practitioners, and actually, during COVID, I mean, we provided extensive practice placements because we were able to give them opportunities. But educating people in understanding not only how to work with people with profound learning disabilities but also how to engage families as core members of their team is absolutely fundamental, and I think we believe very strongly that, if we develop the next generation -- and actually even earlier than that, if we work in schools and with children and young people, we'll develop a workforce but also a community that can be more inclusive. So I think that is a -- education is another very significant part of our role.

MS GRAHAM: Yes. And I guess also that educational element extends to, I guess, the larger organisations in society that will provide those sort of things because what we're often up against are cultural issues that mean that people aren't always open to our ideas and, you know, our suggestions for innovation and so forth, and that's something that we also have to fight to break through. I guess, you know, it's not just our people -- our guys that are invisible. Sometimes we are also invisible, and so Jenny and I do a lot of shouting, don't we?

MS MILLER: Yes.

MR STEPHENS: Politely, I'm sure.

MS GRAHAM: Yes, definitely.

MR STEPHENS: You sound very busy. There's a lot on your plate. What is the size of the team, just so I understand, at the organisation? What are we talking about?

MS MILLER: So we have 20 staff but not all of them are full-time so we are quite small. Most of the staff are involved in programmes or projects, so, yeah, it's quite a small team -- quite a small senior team as well.

MR STEPHENS: You mentioned projects. Could you give an example or an illustration of particular projects that PAMIS is engaged in?

MS MILLER: Yes. So, for example, we have inclusive leisure, so we have a member of staff who works particularly on developing communities to provide inclusive leisure. Multi-sensory story-telling is a really big part of our heritage, I suppose. Telling stories is a lot of what we do, so a programme around

that work. Family support is core. We have funding for that in five areas but we're also developing at the moment a programme of how we can roll out family support in other areas. So it's all based on getting funding in and projects. We've been very fortunate, as Pat said, to have a project at the moment about life-long learning. What we try to do is develop that practice. Quite often it comes from research, develop into practice and then roll it out. I guess the role of PAMIS is to enable other people to do it and then to step back.

MS GRAHAM: Do you want to mention changing place toilets?

MS MILLER: Oh, yes, changing place toilets.

MR STEPHENS: I saw that in your statement.

MS MILLER: So changing place toilets are these larger toilets that have an adjustable height-changing bench and a tracking hoist because actually having your personal needs met with dignity and respect is one of the biggest barriers for people going out into the community. So PAMIS, 20 years ago, started the campaign to get these into every community. We've still only got about 250 in Scotland, but Scotland was the first country to put it into planning regulations, to say it had to come. So we still do a lot of advice and support with architects and communities that are wanting to

build those facilities. But without that, you know, you don't go anywhere or you change your child on the floor of a toilet.

MR STEPHENS: So transformative for those families that are obviously affected, yes. Understood.

You mentioned family support and in your statement you talk about family support directors. We'll come on to the impact on your staff of the pandemic, but what's their role, family support directors?

MS MILLER: So they work -- will only work with families who have a son or a daughter that has profound learning and multiple disabilities, and it is fairly varied. I think there are some fantastic organisations out there, but lots of people don't really understand that unique role of having a child with very, very complex needs or an adult with very complex needs.

So they provide emotional support, a lot of support around transitions, as you move from children into adult services. It's a big black hole and you come from a very -- often very secure service, where there's lots of services wrapped around a child, and suddenly you're into adult services and trying to get appropriate care packages. We've been having debates about guardianship, supporting families so that they still have a say in what their relative does, providing emotional support

when sadly sometimes somebody dies. So, you know, actually the family support starts from birth and goes on well beyond the lifetime of that individual, really picking up because families have so many skills that they can still bring, but that bereavement and loss is quite a unique type of loss as you lose your caring role.

We've also been looking at how we support family carers back into employment, so very, very wide and varied, and families come, you know, with issues. And we provide sort of inclusive leisure, so, you know, over the holidays, there's often clubs, and that's a lovely way of bringing families together to support each other but also to be able to provide purposeful and meaningful and fun activities for their sons and daughters. So it is very varied and at times can be -- I mean, at the moment can be incredibly intense, with, you know, families suffering with their well-being and also, you know, really complex care cases, how do you support a family to remain resilient, you know, throughout that.

MS GRAHAM: I just wonder if it might be worth mentioning at this point what a person with a profound multiple learning disability might be like in a family setting. I guess that would have been -- if we had been able to show the film, that would have been evident, but what that leaves us with is trying to explain -- and probably inadequately in words -- what that entails. So in a family with somebody with PMLD, that person is likely to be non-verbal, will very often be non-mobile and, if they are mobile, that can be very, very challenging because of the level of their learning disability . They're very likely to have complex health issues. They will need 24/7 care. There will be a need to manage medicines because many of them are on very complex medicine regimes. There may for some of them be invasive procedures. There will be moving and handling issues . Many will have severe epilepsy where they'll have seizures on a daily basis, sometimes multiple seizures on a daily basis. There will invariably be postural care issues, particularly for those who are non-mobile, and frequently life-saving care is a day-to-day component of that family's life.

At the same time family carers -- and quite often they're single parent families -- are having to cope with normal everyday life, including caring for other children, maybe caring for other relatives, particularly during COVID, possibly working and managing a home and finances the same as everybody else does.

MR STEPHENS: Yes, thank you. That's exactly what I was going to come on to, as to defining "PMLD".

MS GRAHAM: Oh, right.

MR STEPHENS: No, it's absolutely fine. That's what we're here for, because -- yes, you refer again to a document in your statement which kind of outlines the points you've just made. For the record, that's SCI-WT0417-000004. That talks about the diversity of that group of individuals and that was exactly what I was going to ask you about. It's the human element I wanted to explore.

You've talked about some of the common characteristics -- we can come on to those, but you've covered some of them already -- but it was that flavour I was wondering if you can give of the things that those individuals enjoy doing and what they spend -- I think you both have talked about this to an extent a little bit already today, but that was what I wanted to ask you, just about what activities they enjoy and do because that doesn't necessarily leap off the page and it's helpful to hear from you what that is.

MS MILLER: Well, it's as diverse, isn't it, as you and I?

MS GRAHAM: Yes.

MS MILLER: It is really interesting that for one individual it might be activities -- I always remember going and watching in awe at people catapulting down a snow-slope in a wheelchair. You know, for some young people, they

want to do -- they want that thrill. We've had to quite often think about changing place toilets and the hoist and how that might be used because actually whizzing across a room is really enjoyable. I guess it's all the proprioception that you're picking up. But equally multi-sensory story-telling or being out with friends or -- yeah, I mean it is absolutely diverse, but I guess the trick is being able to make that activity inclusive and accessible. But they -- yeah, it's the sense of humour and the ability to have fun and make people laugh but also the ability to profoundly impact on other people's lives as well. But it is very diverse.

MS GRAHAM: It's very diverse but also it's very, very challenging because for each of those activities that Jenny is talking about, if you have somebody with PMLD in your house, the amount of effort that you have to go to to get your son or daughter, your child, to an event like that is -- it's a mammoth task. That list of things that I have sped through really quickly, each of those things can take many, many hours a day and family carers will spend most of their day caring and quite often a lot of their night as well, which is why -- I guess we'll be coming on to talk about COVID. But that was before COVID, you know, so you add COVID into the mix and it was horrendous.

MS MILLER: Just one other thing to add is also family carers understand their relative and know that sometimes that can -- rhyme, rhythm, repetition, it can take months and months to get somebody to engage in an activity, and I think some of the issues that we have and why we're so keen on education is that sometimes you have to educate fantastic paid carers but who haven't had that experience of understanding that don't just try it once, you need to try it over a number of times, and just because somebody didn't want to go to story-telling one day, it doesn't mean that they won't want to months down the line.

MR STEPHENS: Thank you. We heard earlier about the founding objectives of PAMIS and what those are, and yet it was noticeable in both your statements you described those with PMLD -- and indeed today you've said again about those people being marginalised and invisible. I wonder if you could just say a little bit more about why you think that is or why that is.

MS MILLER: I mean, part of that is absolutely to do with the fact that there are no changing place toilets, so you don't see people wandering around your communities because there aren't inclusive and accessible facilities for them to go to. We've been really lucky -- in Edinburgh we've been doing some work with the national galleries, where they've now got a changing place toilet and they've opened up some of their exhibitions and they've even exhibited some of the folk that we work with there -- their work there. But if you don't have communities that are open and accessible, people don't see that group. And I think, Pat, you'll probably explain a little bit more, but quite often families that have children with a profound disability, their social networks and support all falls away. You know, trying to maintain relationships when you've got such a heavy caring role is really, really difficult, and we often hear families talking about the fact that even their families don't always understand and suddenly they become -- people become either embarrassed or they don't know what to do or how to help. I mean, you will probably be far better to explain that, but people tend to walk away and then, if you're a single parent family, how do you manage to get out?

MS GRAHAM: Yes, and you're much more likely to be a single parent family if you've got a child with PMLD because that is a huge stress on a relationship and often relationships don't survive, and I can testify to that. Yeah.

MS MILLER: Yeah.

MR STEPHENS: Thank you. Jenny, on a related theme,

I wanted to ask you about something you touch on in your statement, about the NHS frailty scale that came in. Just it seemed to me relevant to what we're talking about now, quality of life. I wonder if you could talk about -- you talk about that being a highly stressful time, the introduction of that. Could you perhaps explain what that is and why it was stressful for those with PMLD, please?

MS MILLER: It's really interesting actually. It provokes emotions straightaway. What has been very interesting recently is actually, up until two years ago, if a child or a young person died and they had a profound learning disability, nobody investigated their deaths because they were expected to die, and now that begins to make so much more sense about a frailty scale that was being suggested to be put in place, and I think our anxiety was that somebody was going to make a judgment about who would get treatment if they had COVID and who wouldn't.

Considering now that people -- the whole attitude seemed to be that, "Well, actually, if you've got a profound disability, if you've got cerebral palsy, you're not going to make it", and families spend every day having to, well, you know, take them home and give them lots of cuddles because actually they're not going to survive. A mum the other day said, "Why can't we

just talk about people living rather than expecting them to die?", and people are living far longer lives it now, but that frailty scale absolutely shocked us to the core because we know that people don't always value and, with all due respect, healthcare practitioners don't understand the value that somebody with a profound disability has -- the value of their life and the value of their life on other people.

I think we and families were -- I mean, we were having a lot of calls from people just being so worried that, if their relative ended up in hospital with COVID and, you know, with needing ventilation or having very severe respiratory problems and there was a queue, that actually somebody would say, "Well, actually it's going to be difficult to ventilate that person and maybe her quality of life isn't that great. You know, if we're going to have to make a judgment, then that person won't be the top of the list". I think families and we were absolutely terrified.

Just one example, I had a student that came who had read a lot of medical research and was talking about quality of life but by the end of his placement he realised that a lot of the quantitative data was no good unless you looked at the qualitative data. So he spent time with families, he looked through their digital

passports, he saw films of them at the Edinburgh Book Festival and he realised that, if you were making a decision just based on that clinical judgment, you had missed out all the qualitative data and that actually you wouldn't be making an informed decision. And I think that was our worry, that people weren't making an informed decision. So that was a really scary time.

MS GRAHAM: Yeah, and I think added to that was the really serious concern and fear that families experienced about the lack of acute hospital pathways and the difficulty of making sure that your child -- when I say "child", I'm talking about a child of whatever age -- would be appropriately looked after in a hospital setting, whether that was in an ambulance or in A&E or if they were admitted to a ward, because the thinking at the time was that nobody was being supported. Everybody was on their own. But if you think about somebody with a profound learning disability -- we are always very reluctant to put a developmental age on our people because it's really difficult and doesn't really tell the whole story, but just for the simplicity of the argument, if you were to think about putting a two-year old in an adult's body in the back of an ambulance without any support, in A&E without any support, in a hospital ward without any support from known carers, they can't tell you what's wrong with them, and actually for them to be in that situation there is something wrong with them. They have communication difficulties anyway and to be left abandoned, as some of them were and some of them might have been, without anybody to support them was a horrendous scenario. It was the sort of thing that gave us nightmares and actually I'm sure Jenny would be able to confirm that some people did end up in that position.

We as a family and in conjunction with PAMIS had been fighting with our local authority to have acute hospital pathways put in place, which they declined to do for many years, and particularly during COVID it became so much more important that people with PMLD were looked after properly, and the reason for continuing to delay in getting that sorted out was that there was a pandemic, but failing to realise the irony, being of course that in a pandemic it was much more important, not less important, for there to be appropriate pathways for people with profound learning disabilities or acute communication difficulties, whatever that might have been.

It seems conceivable that the higher mortality rate for people with PMLD can be attributed to the failure to ensure that they're appropriately cared for in hospital

settings and it's not anything that would be really difficult to resolve. It's something that would be quite easy to resolve and, in fact, even if it weren't, it's enshrined in the law and should have been resolved. And that's in my particular local authority area, but I guess that applies across Scotland as well, and that's why PAMIS were supporting our family in doing that. But it was a huge worry and continues to be.

MR STEPHENS: Yes, I was going to ask about acute hospital pathways. Did you have families specifically coming to you with concerns about that lack of accompaniment during the pandemic? Is that something that PAMIS encountered; yes?

MS MILLER: Yes and even with guidance that came out -- I mean, we worked very closely with civil servants at the Government to try and -- because that was an issue that was coming up, that people, one, were worried about what would happen and then, when it did happen, it was really difficult and people -- I mean, just it was interpretations at local levels were different and people -- either their relative was going in without them or they were having to fight to be able to go in. Sometimes that would even change on a shift, that they were allowed in and then they would go out and then the shift would change and somebody would say, "Well, no,

that isn't what the guidance says". There was a lot of different interpretation, but it was a real issue.

MS GRAHAM: Yeah. And I think on the back of PAMIS and PAMIS representations to the Scottish Government, the Cabinet Secretary issued a very detailed letter to all HSCPs and NHS services to ensure that people with profound learning disabilities were supported by known carers in hospital, but actually our experience, our understanding, is that that was pretty much ignored.

MR STEPHENS: Thank you. Just to tie it off before we move on --

THE CHAIR: Can I ask something, and that is because the instruction, if that's what it was, came only in the form of a letter from albeit a cabinet minister, but that's of no legal power, is it? Simply because a cabinet minister says to do something, you don't have to do it.

MS MILLER: Exactly.

THE CHAIR: To make someone do it, it has to be in a statute or at least a regulation.

MS GRAHAM: But of course it was in the statute, wasn't it --

THE CHAIR: I noticed that, that you said that there is a legal duty, but I rather infer from what you're saying that, yes, that was a pre-existing problem that wasn't

being implemented before COVID but was exacerbated, I think was your word, by COVID, which I readily understand. And then you made representations and the cabinet minister admittedly wrote a letter, but, again, as I've already said, that's nothing that is mandatory on the recipient of the letter.

MS MILLER: No.

MS GRAHAM: Yes, exactly and that was our experience. We had been enormously encouraged by --

THE CHAIR: No doubt.

MS GRAHAM: -- the cabinet minister's understanding of the issue, but we did speak to the heads of many HSCPs after that and they acknowledged that they'd received the letter but hadn't realised what the background was and so therefore hadn't done anything about it.

THE CHAIR: Well, I can turn your proposition on its head by saying that, if the cabinet minister appreciated there was a problem, then actually writing a letter isn't the most effective way of doing something about that problem, which is accepted.

MS GRAHAM: Yes. I couldn't agree more.

MS MILLER: I think the letter did say, though, "I'm not asking you, I'm telling you and I don't care who pays for it. You can sort that out afterwards", and we felt --

THE CHAIR: Well, that's no use, with respect.

MS MILLER: But it was a letter that whenever -- what the Health and Social Care Partnership said to us is -- until Pat and I did a presentation, they said, "Oh, we didn't understand why we got that letter", so they hadn't understood the problem. But that again showed the invisibility of our group. We thought, "It's pretty obvious why you got it", and it talked about a specific group, but that that group is so invisible that they said, "Oh, it hadn't dawned on us that that would be ..." -- and it still doesn't dawn on people that it is an issue.

THE CHAIR: Well, it should dawn. I appreciate it's not really for you to say, but it should dawn on a cabinet minister. If a cabinet minister thinks it's sufficiently important to write saying, "This is important, I don't care how you pay for it, do it", that of itself has no mandatory compulsion imposed on it, and if they think it's that serious, you could argue, I would suggest, that they should ensure that it is mandatory.

MS GRAHAM: Yes.

THE CHAIR: Something for us to think about.

MR STEPHENS: Indeed. I just wanted to come back briefly on the NHS frailty scale. Do you recall what the timing of that was and also what the eventual outcome was in relation to that scale because I think we moved off and I just wanted to check that.

MS MILLER: Yes, it was quite early -- I can't quite recall, but it was quite early on because it was when we were meeting as groups with organisations, so I think -- I remember it being very dark, so it must have been early on in, you know, that March/April time because -- I just remember it being a dark day, you know, when we were discussing it. And then it was overridden I think in Scotland really quite quickly. There were a lot of organisations that came down on -- I think the issue was I'm still not sure that that always filtered down, that people were still making those comments. I think we picked up from some families that either somebody had quoted the clinical frailty scale to them in a Scottish hospital later on in the year -- but I think it was pretty quickly quashed. But, sorry, I can't remember.

MR STEPHENS: No, that's fine.

MS MILLER: I just remember it being a very black day.

MS GRAHAM: Yes, in more ways than one.

MR STEPHENS: Thank you. I want to move now on to the impact of the pandemic on your organisation and the services you provide. Pat, for example, you describe PAMIS as an outward-facing charity, providing valuable face-to-face contact and interventions to help families and carers, at least in normal times. You've also said today -- and it's in your witness statements, both of your witness statements and the accompanying documentation -- you describe the complexity of the healthcare needs of those with PMLD and the high packages of care that they require. So the pandemic then hits, what is the impact upon the resources that the PMLD community require when that happens -- you know, health and medical and social care -- what was the impact of that? I appreciate that's a big question, but ...

MS MILLER: Well, it just all stopped overnight. I think I remember you doing a presentation very articulately, saying, you know, that in the blink of an eye everything --

MS GRAHAM: Everything went, yes. And I suppose -- I spoke earlier about what life is like -- very briefly what life is like in a PMLD family, but I think in normal times or non-pandemic times, a PMLD family is based -- what you do is you build a framework and it's a really fragile framework around which, you know, you hang on all the things that you need. That framework depends on input from Social Work and the NHS and allied health professionals and schools and day services and respite and short breaks, housing support and the third sector, and, on 23 March, that framework just collapsed. It collapsed around our ears. And for those with a family member who was still at home, there was no one to ask for support and no one to turn to, and for those who were in a residential setting, it would be months before we would get to see our family members again in any sort of meaningful way, so it was a terrible, terrible time.

So life for a PMLD family is frightening at the best of times and you do what you can to make it as good as you can possibly do, but actually, for those families who had a son or daughter at home, whatever age that was, it was absolutely terrifying because you depend on all those services, not just for general well-being but for physical and medical help and, you know, mental, emotional, cognitive help. All of these things rely on other people. Lots of families have become very, very skilled in providing all of those things, but you still need input from lots of experts and those experts just disappeared. Nobody knew where to find a social worker and it was just gone and it was absolutely devastating.

In my family, my daughter was in housing support so we didn't get to see her for three months, and that was terrible for us, it was much more terrible for her, but actually it was much, much more frightening for all those people who had a family member at home who were trying to look after them and, you know, do all the medical support and all the things that they needed, and keep them moving, keep them active, because often their postural care and just general well-being is dependent on them being able to move. And they couldn't move. They were stuck in houses.

And I wonder -- because we've read the statements from our staff about what it was like, and I wonder if I -- there was something that jumped out at me in one of the statements and I wonder if I might be able -- if I would be able to read that because it would give you a bit of a picture about what it was like in families' homes at that time because -- I guess this must have been slightly later on because she was actually in families' homes, but what she said was, about unpaid carers:

"There was an expectation that unpaid carers would just keep on going. Sadly, unpaid carers are human, like you and me, and are not machines. They just can't keep on going and going and going. There wasn't any acknowledgement of the vital roles that unpaid carers had throughout the pandemic. They weren't recognised, they weren't appreciated, they weren't valued and they weren't mentioned [as read]."

She goes on to talk about what it was like in the families' homes, and she said:

"What was available to families at home was what they had pre-pandemic. That is the bottom line. Lots of young people's postural care requirements are met within their school environment or within their community service environment, such as day services. Many families don't have access to this kit at home, some because they physically don't have room for it, some because they physically can't safely support their young person into a standing frame or side-lying board safely as they're a single parent family. Supporting somebody with PMLD may require a range of specialist equipment as well as resources like gloves, aprons, incontinence pads, feeding tubes, IVF fluid-giving sets. This is all provided in bulk. Often bedrooms and hallways were quite tightly packed with what might be called 'stock'. Many of the families PAMIS support live in social housing so they're not living in particularly spacious accommodation, so even if families had wanted to ensure postural care plans were being carried out, they couldn't, and this came with the knowledge that every day this would impact on their loved one, that this would have a detrimental effect on their posture and possibly their health [as read]."

And indeed this proved to be the case for many families and we know of instances where postural -- individuals' postural care was so compromised that they have died or their quality of life has significantly reduced and it will hasten their death. So it wasn't -- so lots of our people, they may not have died from COVID, and I think that's testament to how well looked after they were by their families, who were absolutely determined to make sure they were removed from as much harm as possible, but within their family homes they couldn't do that because there was nobody to help to support them. And I'm sure Jenny will confirm that people have lost their lives because of that, because of -- you know, many of them have a scoliosis. That scoliosis can move if it's not cared for properly because they don't have the appropriate wheelchairs. It impacts on their internal organs, which eventually are impacted so much that they can't survive. So that journey -- the start of COVID was the start of that journey for many families. Many families are still on that journey now.

MS MILLER: I think the surprise was the fact that -- I mean, we understood it was a unique situation, but it was the fact that everybody walked away. I mean, I am an allied health professional and I had discussions with

somebody at the Government who -- I mean, why did the allied health professions not stand up and say, "Actually we need to carry on seeing these young people"? Because their support usually was -- for young people was in the schools or for older people it was in their resource centres, and suddenly there was nothing there and the families were being expected to do it all. But we know, you know, how important that was for them, but everybody disappeared and they were sent -- you know, obviously there were other priority areas, but actually, again, that invisibility, that we weren't seen as a priority, has had such a huge detrimental impact.

For some families, it wasn't just their loved one with a profound learning disability, it was also the siblings that they were trying to school, they were also trying to work from home. You know, it became a really difficult time and nobody knew how long that was going to last. I remember people thinking, "Well, okay, we'll get on with it", but it went on and on and on and, you know, "We're all in it together and we promise that things will get better", and actually, you know, even post COVID we had an assurance from the minister that, you know, things would get better and that they would get services. But here we are further down the line and people still haven't got back to where they were pre COVID. That group of family carers are still out, you know, alone and managing and –– you know, when you haven't slept for four years probably for some of them.

THE CHAIR: Mr Stephens, I hope I'm not going to say something or interrupt you in your flow. You may be coming to what I'm about to suggest, and if you are, I apologise. Stop me. But all the things you've just described I would have thought might have been anticipated.

MS GRAHAM: You would have thought.

THE CHAIR: Yes.

MS GRAHAM: Yes.

THE CHAIR: Do I take it from that answer that your organisation, for example, weren't asked to contribute to a thought process that might have outlined the possibilities in the event of an emergency such as a pandemic arising of this?

MS MILLER: No, we weren't ever asked about that. We were asked as we went along and we made a lot of particularly early contributions about what we felt should be happening and we did speak very vocally about the fact that there had been a withdrawal of services, but it would be, I suppose –– yeah, I suppose, not to reflect, but I keep asking myself what was it that we didn't do that meant that our voices weren't heard because in the

early days, we were on –– you know, almost on a daily basis, talking to civil servants in the Government, feeling that you'd been heard, but as things –– as other organisations –– I mean, we were small so we were able to do things very quickly, but as other larger organisations came on board, I felt we were drowned out and that group wasn't listened to and it wasn't heard, and those families were absolutely desperate and there was just no –– yeah, but we –– no, we weren't asked about ––

THE CHAIR: You weren't asked, and there doesn't appear to have been any planning?

MS MILLER: No.

MS GRAHAM: No.

THE CHAIR: I'm sorry if I ––

MR STEPHENS: Not at all, my Lord. I'm obliged.

THE CHAIR: You may have covered that in any event.

MS MILLER: No, it's a very useful point for what we would like in the future, actually to be part of that –– well, we want families to be part of that planning process because –– sorry, I'm going to jump in –– but the other thing is these families are absolute experts in infection control. I mean, when we started talking about how we would move out, we went to the families and said, "This is our risk assessment, this is what we're

thinking, can you give us some advice?", because every day, from the moment their child is born, they are thinking about how to minimise the risk of infection control. And we kept saying, "Come and talk to this set of families who have infection control absolutely. Their kids are alive because they've done it so well", but nobody ever came and asked.

MS GRAHAM: Well, we did. But I think it comes back to –– we've mentioned invisibility. I think what this talks to is a real lack of understanding and a lack of will to understand what distinguishes people with PMLD from others.

I suspect –– and I may be wrong about this and I may be wrong to be hazarding a guess –– but I wonder if there was a –– such a fundamental misunderstanding that they were or we were –– our group was lumped in with care homes and were treated in the same –– well, we know, we were treated in the same way as care homes, but that's to fail to understand the –– I guess I'm talking about adults here –– but that's to fail to understand the distinction between an adult with PMLD and somebody who would be in a care home.

Most of our people who live in supported accommodation of whatever description live in homes of their own with their own tenancy in small groups, either

single tenancies, one or two or three, but usually no more than four, and so they were essentially treated in the same way as care homes. It's a fundamentally different type of organisation and they should have been treated as if they were in their own homes. It took a very, very long time for that to filter through. And in the meantime, lots of people who were looking after or whose son or daughter was being looked after in a supported accommodation didn't get to see their families for many, many, many months, sometimes as much as 18 months –– well, not in any meaningful way –– and that's because they were being treated as living in care homes, but it just reinforces our view about our group being invisible, that they weren't treated in the way that they should have.

THE CHAIR: You talk about invisibility and I understand you're using it in a particular sense, but your group, PAMIS, has been on the go for, you've told us already, a long time and I'm assuming –– and I think it's inferential from what you've already said –– that you talked to Government long before COVID. You talked to Government and tried to no doubt educate them ––

MS MILLER: Yeah.

THE CHAIR: –– long before COVID and therefore there should have been an awareness at Government level of the

existence of this cohort of persons that suffer from these issues and their needs. Am I correct?
MS MILLER: Yes, and I think ——
THE CHAIR: You were presumably on a fairly regular basis ——
MS MILLER: Absolutely.
THE CHAIR: —— bringing forward these things and therefore one could argue, I would have thought, that there should have been some anticipation that, in the event of a pandemic, these people would have exactly the sort of problems that you would have if there was a withdrawal of —— I think you said that in the blink of an eye everything went and the framework vanished overnight. That should have been thought about.
MS MILLER: Yes.
THE CHAIR: Is that a reasonable proposition I'm making?
MS MILLER: Absolutely.
THE CHAIR: I want to be clear. Is that a reasonable proposition?
MS GRAHAM: Yes, it is.
MS MILLER: And I think from our perspective there was a group in Government that understood, but it was how that group were then able to influence. I suppose one of the things that people —— you know, you seek to understand —— you sometimes think you know —— that's the bit about the communities don't really understand how to

include. I think that there was a wider Government group that thought they knew who this group were but actually didn't, and, you know, our ask is, "If you're really not sure, ask all those questions, watch that film, make sure you know who you're talking about", because I think what we felt was that there was a small influence within Government but that actually then trying to broaden that out —— and the people that were making the decisions, you know, just didn't understand that there was this sub—group. I mean, even a sub—group within a sub—group. People with learning disabilities are often marginalised, but this group are a totally separate group within that group.
MS GRAHAM: And I think what was ironic was there was a lot of mention at that time about how we should be protecting or how we were protecting the most vulnerable members of our society without any apparent understanding that this group is the most vulnerable group in society and were totally sidelined.
THE CHAIR: Yes, but, remember, one of the purposes of this Inquiry is that at some stage Mr Stephens or one of his colleagues might well be asking someone who represents Government, "What about the profound multiple difficulties and why were they not anticipated in advance?". Is that not one of the things we could

legitimately ask?
MS MILLER: Yes.
MS GRAHAM: Definitely.
THE CHAIR: I'm sure Mr Stephens will make a note of that.
MR STEPHENS: I have. Thank you, my Lord.
Jenny, you said "Government" on a couple of occasions. I just want to be crystal clear. Are you talking about the Scottish Government when you were talking about ——
MS MILLER: Yes, the Scottish Government. There's a group of civil servants within there that work on the learning disability portfolio that we were in immediate contact with when the pandemic happened.
MR STEPHENS: And Pat, since you raised it, we'll come to it, the supported accommodation point because you —— I wanted to ask you about the impact on the families, I suppose. You talked about people being isolated, kept away —— because the two common settings I think you both describe for where people would be helped(?) would be a family at home or in supported accommodation. You've talked about the latter. What were families' reactions to that situation where, as you've described today, they were intimately involved in the care of their loved ones and they were unable to see them? What was the reaction that PAMIS was getting from families? What did they say

about this?
MS MILLER: They were really angry, weren't they, because —— one of the key things is and one of the papers that we wrote is that they weren't just visiting and seeing their loved one there. They actually took part in sometimes very personal care, so they were frontline carers and they were providing that emotional support as well and providing activities. I remember one mum talking about the fact that actually it wasn't about getting in, it was about getting people out as well because they were needing to get out and about and being able to be part of their community, and I know that that, for some people, really —— well, for you, really broke down.
But it wasn't just being —— I think it was absolute desperation, you know, as people got urinary tract infections because some of these very personal care issues weren't being carried out in the same way that a family carer did. I know we had a little sub—group and people were very angry because they just didn't feel that they were being heard.
MS GRAHAM: Listened, yeah. I think it was —— I think maybe at the start we thought, "That's a reasonable thing to do. A couple of weeks, that will be fine. We'll get back to normal". I mean, my personal circumstances are

that my daughter comes home to our house three times a week for, you know, half a day at a time to visit and we take her out, and I'm very actively -- as Jenny said, very actively involved in the provision of her care and consider myself to be part of the care team in my daughter's house and would be considered to be part of that care team by the staff in the house.

That's my circumstances, but that would be reflected across the country with probably -- well, many families, anyway, that we do a huge amount to support the staff. Of course at that time we were no longer able to provide that support -- I mean, apart from the fact that obviously we missed our children, but we were no longer able to provide that support to the care provider, who were on their knees and needed all the help that they could get and we couldn't do that. But also, because they were on their knees because of COVID, they weren't able to provide -- despite their best efforts, they weren't able to provide that same level of support to the people that they were caring for because they were so busy sanitising and cleaning and doing all the things that -- they had to try to find PPE and ... I do remember, in the early days of the pandemic, spending a lot of my time online trying to source various things like soap and gloves and potatoes at one point -- things

that they couldn't get and then driving them up there and dropping them on the doorstep, driving -- taking things up for my daughter and the other people that live in her house as treats, just to try and feel that I was still doing something to help.

But in all that time my daughter was -- her health was deteriorating significantly, physically and mentally, emotionally, cognitively as well. She was tilting over to the side. I'd seen photographs of her at that time. She just withdrew into herself and eventually our care provider decided that her emotional state was such that she had to be allowed to come back to visit us in the family home. And the guidance -- I think that was about three months in -- the guidance changed at that time, enough for them to interpret it in that way. However, I guess we were -- it was three long months before we saw her again because she didn't want to interact with FaceTime or Skype or any of these things, but for many other families that PAMIS was representing, as Jenny mentioned, that wasn't the case and many care providers interpreted the guidance in different ways and -- which meant that families were still, you know -- a year later, still seeing their family member through a window or, you know, on Skype or something like that, whatever, in a garden, in a gazebo,

because of the interpretation of the guidance. And -- I don't know -- if my daughter's care provider could interpret it in a way that meant that we could see her, we couldn't quite understand why others didn't. And we were trying to support families in that and provide them with copies of, you know, risk assessments that my daughter's care provider had provided to ensure her safety.

My daughter recovered emotionally, I think. Physically, she won't ever fully recover. She has to go to a chiropractor regularly and probably will do for the rest of her life because of the damage of the not moving and inactivity over that three-month period. Many others will be in the same position.

MR STEPHENS: Can I ask you if there's a lesson learned there, in your view at least, when you have that piece of the puzzle with families that has been taken out of the equation -- you've talked about the strain on the paid carers who were there -- and this Inquiry has heard before, I think, evidence about, for example, Anne's Law. Is there a lesson learned, would you say, in what happened here with supported accommodation?

MS GRAHAM: Yes, yes, there definitely is. It would have been -- and I think Jenny alluded to this earlier in terms of the care that families take of their family

member. Essentially we, in many cases, have kept them alive for a long time. I mean, that's a responsibility that we take -- every family would -- but we take that very, very seriously. There would have been no reduction in that commitment to our family member because of COVID. In fact the opposite was true. We were not going out. We weren't doing anything. My partner and I were staying in the house. We were having our hour's walk in the park. We weren't meeting up with anybody. But staff, by their very nature, go home to their own families, and so the staff were a much higher risk to our family members than we were and there was no recognition of that at all. So I guess what we would want, in much the same way as the -- you know, in Anne's Law, that we would want to be designated key workers because that's what we were. It would have made it easier for everybody, it would have saved a lot of heartbreak for a lot of families, but also it would have made the lives of paid carers so much easier and so much more effective as well.

MS MILLER: I think one of the other lessons is about being really clear about how to carry out a risk assessment. You know, if the guidance said, "You look at the risk about emotional deterioration and physical deterioration versus the risk of COVID" -- and what we were finding time and time again was that somebody would -- well, one organisation could do that, we were sharing all that information, but we even had -- in one local authority, where one of the family support directors took that risk assessment and worked with somebody from Public Health who agreed it was really important to go in and see somebody and to have that time, and then the next day, when they phoned again to confirm it, it was somebody else -- I'm sorry, it was from Public Health -- but somebody else from Public Health said, "No, that isn't how we do it".

So nobody was carrying out the risk assessments in the same way and actually nobody was looking at the risk of the emotional and the physical deterioration of individuals versus that risk of COVID. I understand it was a difficult time but, yeah, the lessons I think we would like to be learned is how you collectively involve everybody in looking at carrying out a full risk assessment. And the risk assessment that came home from the organisation, I mean, you added to it and then --

MS GRAHAM: Yeah.

MS MILLER: -- it became a very comprehensive piece of work. Yeah, yeah. Sorry.

MR STEPHENS: You've touched on the physical impact, you know, postural deterioration being key amongst that, and

a little bit on mental health. What would you say has been the impact, if any, on the families in terms of mental health? What messages have you had from families?

MS GRAHAM: Oh, goodness.

MS MILLER: Yeah, and it's still ongoing. It was really interesting -- I was just reading over somebody's statement. We had a counselling service and in the height of COVID, actually, families I don't think could even begin to think about what was happening to themselves, so actually numbers of going to the counselling really dropped. But as we began to come out of lockdown the numbers began to increase.

But that impact was awful. People were exhausted. I think, you know, to start with, people felt that everybody was working together, but then, as time moved on, I think that whole issue about not getting access and not understanding about how to get access to your loved one in supported accommodation became an enormous issue and, you know, people became incredibly depressed. They're then, you know, not having any support, no respite, not having -- we did also have cases where there was clear guidance that said nobody's care packages were to be looked at, but I remember a mum who became incredibly depressed and lost all hope because

somebody was threatening to take away what little care package she had or to reduce it. And -- I mean, I think I shared that -- that was a very dark day because she talked about suicide, a suicide pact, because she just couldn't see a way out of it. So it became a really, really difficult time, didn't it?

MS GRAHAM: Yeah.

MS MILLER: It still is, I think.

MS GRAHAM: Yeah, it still is. I think also, without a pandemic being in existence, people who have family members with PMLD tend to have difficulties with emotional well-being anyway because life is very, very difficult, very challenging, and I guess most of us try to have a very positive outlook because, if you had too negative outlook, you probably wouldn't -- you wouldn't survive, and Jenny alluded to, you know, suicide pacts. That's something that isn't -- it might sound shocking when you say it out loud, but actually it's not that surprising and it's not that uncommon because life is -- can be so difficult and so challenging, and then you add a pandemic into the mix, everything is taken away. All the things that make your life viable, make it possible, make it possible for you to work, to spend time with other family members, to go out and do the odd thing, to have the occasional weekend away or whatever -- all of

that was taken away. And those are the sort of little lights at the end of the tunnel that actually make life worth living when you're under that sort of stress and then, to have all of that taken away, I don't know why we didn't have more families where there were much more tragic outcomes. I think -- well, I say I do know why that is. The reason for that is because, if you decide that you can't take it anymore, you're leaving behind somebody who is much -- even more vulnerable than you are or you have to take them with you.

MS MILLER: I think physical well-being was another issue, and we pick that up on some of the webinars we were running on moving and handling because suddenly you were doing all of that physical activity without necessarily the equipment. So we noticed -- and people were putting on weight, so their relative increased in size or -- because they were a child and they were going through adolescence, they grew. So we noticed also there was that physical decline of carers' well-being as well.

MS GRAHAM: But also cognitive decline because, if somebody has a profound learning disability, it takes them a long time to learn things, and actually that's one of the things that families do really well, is to teach people with a profound learning disability to the level of their ability. But sometimes those things can take a very, very long time for them to learn but it takes a much shorter time to unlearn them when you're completely unstimulated and not able to do anything, not able to move. And actually a lot of those skills that they had acquired at great cost to families and great effort will have been lost for all time. And that's really, really, really sad -- you know, when you've put so much effort into ensuring that your child has the best life that they can have, to lose that is devastating.

MR STEPHENS: Jenny, you mentioned webinars and I would be remiss, when listening to your evidence, not to ask you about what PAMIS was trying to do to help these poor families that were -- seemed to be going through a very dark time, as you put it.

MS MILLER: Yes.

MR STEPHENS: I'm interested in particularly webinars, but also I think the digital passport was something that caught my eye. Would you mind explaining what that is?

MS MILLER: Yes. Very quickly we became very techie-savvy, which was quite amazing for some of us, but that whole ability to be able to actually reach out to families -- and because we have a practice development arm, some of our multi-sensory activities we were able to then put online. So very, very quickly we developed an online

programme which brought family carers together actually and brought people with PMLD. We took a lot of advice from experts because we were really worried about whether somebody with a profound learning disability would be able to interact via Zoom, but it was quite dramatic and quite amazing.

I mean, a lovely music instructor that we worked with actually found that in some ways it was more effective using Zoom than it had been, so we began to develop a lot of resources online for families, for people with PMLD but also for those paid carers. But I think almost overnight --

MS GRAHAM: Unpaid.

MS MILLER: And unpaid -- yes, paid and unpaid carers.

We developed some of our postural care resources. That was quite interesting because suddenly postural care becomes everybody's business because, when you have COVID, you're needing to be in the right position, so a postural care strategy that we'd been pushing for years probably was sped forward by about five years because everybody needed to know about postural care, not just our group. So we managed to convert some of the education materials that we had for both practitioners but again for families online and we worked with NHS Education for Scotland to do that.

Moving and handling was coming through the family support as a real issue and so we worked with this fabulous consultant that we'd worked with for years and he ran with us some sessions for families that -- where they could bring their issues. And what we were finding was people were being sent pieces of equipment without being measured for them, you know. And so he was really good at helping people risk-assess before they were using that equipment. But it was a brilliant way of bringing families together. I mean, some of the webinars, you know, we actually had people from across the country, you know, coming and it was a way of sharing.

And then families -- I mean, again, I was reading a member of staff's statement. We were really flexible about how our family support directors worked and for a lot of them actually being able to work in the evening was good for them but it also helped the families, and they used to have these fabulous family chats, just a time -- often 9 o'clock at night, when people had managed to get their loved one to bed, and then they would come and support each other, but also we would share the latest -- what we thought was the latest advice. You know, we'd talk about some of the issues that were coming back. They would feed in to me so that

I could feed up to the Government some of the things that they were talking about. And on a Friday night, we used to have a Friday night virtual disco, which was the most -- and it still is the most popular of pieces.

MS GRAHAM: Still do.

MS MILLER: The digital passport was something that we had developed -- it had been developed by family carers. It's a communication passport that used to be paper and one day a family carer said, "That would be really helpful if it was a digital one". So it's using PowerPoint and it's a flick-through e-book, but it tells you all about the individual and it's written normally in the individual's voice so that they can tell you the things that they like to do, the way they like to be positioned. Being able to show how to put somebody in the right position for their postural care through videos and photographs is so much easier than writing it down.

I think what we were finding was it became more and more useful as people started -- paid carers started coming back because it often wasn't the paid carers that they had before but it was a way of very rapidly being able to give people ideas about how to care but also how to engage with someone. And we made a decision that actually they would be free of charge and we would

provide training to any care group that wanted those because we just felt it was a really, really useful tool. But it also gave people, you know, the opportunity to show who that individual was, you know, what they like doing, you know, who their friends were so ...
MR STEPHENS: And the feedback from families was positive on these initial --
MS MILLER: Yes. I think lots of families said it was a lifeline actually having activities and having something positive to do. You know, we had -- we did the Edinburgh Book Festival virtually, actually, and there was lovely collaboration with the music group and the art group and even doing online art sessions actually. I mean, they've carried on -- and the lovely bit about that was that we were making connections across the whole of Scotland, so suddenly there was somebody in Fife who became really good friends with somebody in Lanarkshire and -- you know, it was really lovely when they all met together when we were unable to go to the Book Festival actually in person. But, yeah, there was a real sense of our community, I suppose, coming together.
MS GRAHAM: Yes.
MR STEPHENS: I wanted to, I suppose, well, finish -- before

giving you an opportunity, as I said -- on how would you sum up, I suppose, a longer-term impact of the pandemic upon the community, as you put it, of PMLD? I mean, what effects or signs are you perhaps seeing or not seeing even now?
MS MILLER: Yes, so it has had a dramatic impact, I think. I mean, you know, postural care is -- again it was led by a family carer a number of years ago, 16 years ago. It's a very, very important way of thinking about how to keep somebody's positioning and their posture safe so that they don't develop scoliosis. I was told the other day that somebody died of cerebral palsy. Well, you don't die of cerebral palsy and you certainly don't die of cerebral palsy if you put the right interventions. Those interventions didn't happen because they didn't have the right input from healthcare practitioners really, and so there are now definitely -- you know, the impact -- people will die earlier because they haven't had that intervention. Some people now aren't able to have the spinal surgery that they would have been able to have and so that physical well-being will have a lasting impact. We said we were very lucky that not that many people died of COVID, but a lot of people will die because of COVID.

Emotionally -- you know, there will be some people,

I know that they feel that they've almost lost their loved one because, you know, they had so little social interaction and that -- all those skills that Pat talked about that took years to develop might never come back. People have lost the communication skills that they had. I think for some families they feel that their loved one in that supported accommodation has forgotten them and that that relationship isn't there anymore.

And for families -- sorry, Pat, I'll let you get in in a minute -- but for families, you know, that whole exhaustion, invisible, not valued, you know, that loss of hope really, you know, it's really difficult, and I know at the moment, you know, we're trying to engage in all sorts of consultations about Government strategy and I'm getting a real sense that people are thinking, "Well, what's the point? You know, when we were so forgotten in a pandemic when we were all supposed to be here together, what hope have we got anywhere else really?". So it's -- there's definitely -- when we're not out of it -- we still don't have people back at day services -- you know, was that an opportunity to close something down or was it an opportunity to really think about how to do things differently? Families are really sceptical about that because at the moment, you know, they're being told, you know, "Your relative can't go

back to day services", so, yes, it's pretty dire -- it's still pretty dire.
MS GRAHAM: I think it's the trauma of what happened, and what continues to be the case for lots of families is something that people will take a long time, if ever, to get over. It's a sort of PTSD without the post. It's a kind of continuing, you know, ongoing stress that people have, and I think -- you know, we talk about long COVID meaning something different, but I think for our families it is a form of long COVID because it's something that they're not going to get over. Whether it's physically or emotionally or mentally or whatever it might be, it's going to be long COVID for them for a very long time to come.
MR STEPHENS: Well, I'm very grateful to you both. I don't have any further questions to ask you. As I said at the outset, the Inquiry is grateful for everything you've provided, the statements, the documentation, the video and of course your oral evidence today, so thank you very much.
MS MILLER: Thank you.
MS GRAHAM: Thank you.
THE CHAIR: Yes. I would like to echo that. Thank you both very much for your attendance. I'm very grateful.
MS MILLER: Could I add one thing about the impact, though,

which we haven't spoken about but I know there is a statement. That impact, if you had a child, if you had a baby -- I mean, I had a daughter who had a baby during COVID -- that was difficult enough, but I think there needs to be a lot of thought put into, if you had a baby with a profound disability or complex disability during COVID -- you know, I know one member of staff worked quite closely with that group -- that is something that we need to be thinking about how we're supporting that group because, you know, that initial support that you might need wasn't there. So I think they're a group that we worry about and I suddenly realised we hadn't mentioned them at all.

MR STEPHENS: Is there anything else you would like to add, Pat?

MS GRAHAM: Yes, there was one thing I wanted to -- because we've been -- you know, we've spent months now writing these statements and speaking to people and reading our staff's statements and other family statements and so forth, and I was trying to think what -- if I had to sum up what I wanted to say about it but I hadn't been able to say anything at all today -- if I hadn't been able to give a statement, I wrote down what I would have wanted to say, and would it be okay to just read that? It will take a minute -- less than that.

MR STEPHENS: Sure.

MS GRAHAM: "It's important to emphasise that people with PMLD cope with all the disadvantages in their lives with bravery and stoicism and still have the capacity to not only derive pleasure and to fulfil their potential but also to bring enjoy joy, inspiration and love to those who have the privilege of knowing them. It's so important to understand that people with PMLD can still have a quality of life because, if you don't understand this, then you can't possibly comprehend the scale and impact of what was taken away from them. Because they couldn't comprehend what was happening to them, many experienced sadness and anxiety and fear and emotional trauma in addition to their physical pain and discomfort and, as so many have no spoken language, they were unable to tell anyone how they were feeling. It's difficult to imagine how that must have felt. And these are precious people who we should be valuing and nurturing but we failed as a society to keep them safe and tragically we let them down. Somewhere along the line, in our fear and our panic, we managed to lose our humanity too and we need to make sure that we learn that lesson for the future [as read]."

MR STEPHENS: Thank you for that.

THE CHAIR: Very good. Thank you again. We'll come back about 20 past or something like that. Thank you very much indeed.

(11.07 am)

(A short break)

(11.27 am)

THE CHAIR: Good morning, Mr Gale this time.

MR GALE: Good morning, my Lord. The next witness, my Lord, is Jane Ormerod. Her witness statement is SCI-WT0456-000001.

MRS JANE ORMEROD (called)

THE CHAIR: Good. Good morning, Mrs Ormerod.

A. Morning.

Questions by MR GALE

MR GALE: Good morning, Mrs Ormerod. Your full name is Jane Ormerod, I think.

A. Yes, that's right.

Q. And your personal details and your contact details are known to the Inquiry and you've provided us with a detailed statement which I've just given the reference to. That statement, to aid you, will appear on the screen in front of you but I think you also have your own written hard copy of it. You are content, as I understand it, that that statement together with the amplification of it that you'll give in your oral evidence today will constitute your evidence to the

Inquiry?

A. I am.

Q. You're agreeable that the evidence shall be published and recorded?

A. I am.

Q. Thank you.

Now, as will be apparent from your statement, you are here to speak as the current chair of Long COVID Scotland?

A. That's correct.

Q. And that's a position you've held for about two years?

A. Yes, that's right.

Q. I think it's quite a busy day for you today because --

A. It is.

Q. -- I think there's to be a debate in Parliament this afternoon or this evening and I think you're anxious that you're able to attend that later today.

A. That's right.

Q. Importantly I think you are able to give evidence to the Inquiry having had a nursing background. Could you just explain a little bit about that background, please?

A. Yeah. I spent 40 years-plus in the Health Service. My professional registration was as a nurse and I worked clinically in cardiac care and cardiothoracics for quite a few years. I was a clinical teacher, a clinical educator, and in the latter part of my career I worked in professional development and practice development.

Q. And has that background assisted you in the work that you've carried out as the Chair of Long COVID Scotland?

A. To some extent, yes. I worked in several leadership roles so that's not unfamiliar to me, although not in the third sector. But working in the Health Service for all that time and then working in the third sector and in a different context, it's not always been easy actually and continues to not always be easy, having had a health background. It's very hard to explain. Working in health is a bit like an inclusive club and working on the other side of the fence, as a patient advocate and patient representative, is very different.

Q. Yes.

A. So it's been a learning exercise and continues to be.

Q. Yes. But, as I think is apparent from your statement, you are now really quite wholly committed to your role as the Chair of Long COVID Scotland?

A. I have. I've been very fortunate. Long COVID Scotland are an advocacy organisation, a charity now -- we became a charity in 2022 -- and I'm in the privileged position of being in the chair and there are, at the moment, seven of us as trustees. We are a small organisation. We all have long COVID. All our volunteers at the

moment apart from one have long COVID. We're not a cast of thousands, we're a small group, but we work hard to advocate for people with long COVID in terms of more effective diagnosis, treatment, support and rehabilitation.

Q. Thank you. Now, you have very helpfully provided the Inquiry with a number of documents, all of which are footnoted in your statement, and we will look at some of the results that you have obtained from the surveys that you've carried out as we go through your evidence, but you are also content that the Inquiry has regard to these documents, which it will --

A. Yes.

Q. -- as we progress with our consideration; is that right?

A. Yes.

Q. You've said that you have long COVID. I don't wish to pry into that unless you are agreeable to doing so and providing us with information about that, but if you are, can you tell us how you contracted COVID, when you contracted it and your subsequent diagnosis with long COVID?

A. Yes, I -- it's four years since I originally had COVID and I think it was probably going to the theatre that did me and I developed COVID. Of course testing wasn't available at that point so it was a diagnosis of

exclusion really. To begin with, I was not hospitalised. I felt particularly unwell though. I had a lot of tachycardia, breathlessness, fluctuating temperature. I did go to the COVID hub in Aberdeen, where I live, and I was just sent home, just to recover, as they put it, and unfortunately my symptoms carried on fluctuating over the next few months and I struggled considerably. I developed a sore throat that lasted for six months. I wasn't to know it, but that was a re-emergence of an Epstein-Barr virus, glandular fever. I didn't even know I'd had glandular fever in the past, but that came out of the woodwork for me and I felt even more ill with that on top of the COVID.

I was diagnosed with long COVID in June of 2020. Getting that diagnosis was particularly hard, accessing my GP was particularly hard, and I -- at that period and after that I was dismissed really as having COVID, I was told I was anxious, it was all in my head and that it would just go away, that I would recover. Well, unfortunately I didn't. And I saw one GP who diagnosed me with long COVID and so that started me on a fluctuation and a journey that I've had over the last four years.

I had COVID again in 2022 and that just made my long COVID worse. I think the hardest thing is the

fluctuation of symptoms. Unfortunately, I still suffer with post-exertional malaise, which is any activity that I do, not just physical, whether it's mental -- any activity that any of us do, I have a kick-back for that. I'll spend time in bed after that. It's very much akin to how people with chronic fatigue symptoms -- and just the same as somebody with chronic fatigue, many people have been dismissed for many years. I think one of the hardest things with long COVID is the dismissal by some people that it exists.

Q. Yes. You do tell us in paragraph 4 of your statement -- and you've repeated it this morning -- that you felt dismissed and minimised by GPs. Could you just give some context to that, please? What were you told?

A. I was told that it was anxiety. I was told that my symptoms would go away, that I was being over-anxious, overly concerned with my health. Actually accessing a GP at that point was very difficult. I had some health problems that I'd had prior to having COVID which resurfaced again during COVID, and prior to COVID I was waiting for a hospital appointment and, as my symptoms became worse, I tried to get the GP to refer me back to the hospital, which -- that took a considerable effort and eventually I was -- after much effort, I was referred back to the hospital, but that took another year for that problem to be addressed.

I think the hardest thing really around the minimisation is there's a fluctuation in symptoms, very often people struggle to express themselves because, for me as well, in terms of brain fog, as people call it, it affects your thinking and your ability to marshal thoughts together, so trying to actually represent yourself in normal terms would be bad enough, but when you're struggling to get appointments with GPs, get seen, get heard, that adds to your anxiety.

Q. Yes. On the question of anxiety, which you've mentioned, did you have a history of anxiety prior to ——

A. No.

Q. —— being infected with COVID?

A. No, not at all. As with anybody, the normal fluctuations of day—to—day life ——

Q. Yes.

A. —— can push you to the edge of anxiety sometimes and further, but no, I didn't. I didn't have any mental health issues before that. I found myself going steadily downhill because of the fluctuating nature of long COVID, the symptoms coming and going, not being listened to, being minimised, I think not only by health professionals but by other people. Even family weren't really sure what was going on and wanted you to be

better, so you felt —— I felt my symptoms were minimised to some extent by friends and family as well as by health professionals. But I think that was all part of the anxiety that you felt and the whole results of having an illness that just doesn't go away and becomes a chronic illness and learning to cope with that.

Q. One other point which again you've made —— you're talking about a fluctuating condition. I think in your statement you also make reference to relapsing and remitting. Are you using those two terms synonymously?

A. Hmm.

Q. Is that one of the difficulties that those who suffer from long COVID —— and I think we see that —— have information that many do —— that, put crudely, there can be good days and bad days?

A. Oh, absolutely. I could have a couple of good days in a week and I think, "Oh, perhaps it's going to go away" or "Perhaps it's receded into the background for a period of time", and I'll perhaps do a bit more. I'll press myself to do more, just normal activities, and then I will have a kick—back from that. I will feel ill, unwell. I'll feel as though I've got the flu. I'll feel cold, feel hot, feel sick, have to go to bed because I feel too tired to carry on with what I have to do in the day.

Q. I think it probably goes without saying that that is going to have a considerable impact on your day—to—day life.

A. Absolutely. I think for any of us with that sort of a picture —— and not everybody has that picture, not everybody has post—exertional malaise —— but if you have something that comes and goes and if you're in a relationship with somebody, they have to cope with that. If you have kids, and many of our members are in the age group —— it predominantly tends to impact on women, although not exclusively so —— they're in the age group of 35 to 60, 55/60, they have jobs, they have to hold employment together, they have a home to hold together, so it's not surprising that it impacts on their relationship with their partner, with their kids, with the wider family who struggle to understand what's going on.

Q. And again, because of the age demographic that you've referred to, there is obviously —— and we'll come to this in a little more detail as you're giving evidence —— but there's obviously an impact on the person's ability to work?

A. Absolutely. I think we have a good proportion of members who are not able to work anymore as a result of having long COVID. It really does depend on the type of

employment that they do. It depends on if they have an employer that is sympathetic, who understands about long COVID. And, to be honest, the knowledge of long COVID amongst the wider population is not good. People think you just get a bit tired and that's it. They don't understand that it impacts on your whole life. And from the work point of view, if you are trying to go to work, most people who try to go to work, the only way that they can do that is to do a period of work and then go to bed when they get home. That enables them to hold the job down. If they can't hold their job down, then we do have members who have lost their jobs, who can't pay their mortgage, have had to give up their house. We have quite a few members who work in the Health Service and, as you can imagine, trying to work in a clinical capacity, 12—hour shifts with long COVID, it just doesn't fit.

Q. Well, I think I should indicate to you, Mrs Ormerod, that in the course of the next few weeks we are going to be hearing from a number of organisations representing healthcare workers and one of the issues that will be raised in their evidence will be that relating to long COVID, so we will be hearing it from specific witnesses in those areas.

You've obviously put a great deal of work into preparing your statement, for which we are very grateful, and you've come here today to give evidence. Given your condition, has that been a bit of an ordeal for you?

A. Yeah. Just travelling to Edinburgh -- well, getting prepared and travelling to Edinburgh, delivering a statement today, being here, yes, I'll have a considerable kick-back from today and -- yes.

Q. Thank you. You say that your experience resonates with many of the members within Long COVID Scotland, so do you gain any comfort from knowing that you're not alone?

A. I've made many new friends and colleagues from working in Long COVID Scotland. It's useful. You have a point of contact and a fount of knowledge really because people with lived experience are the experts about their condition. So it's useful to be with other people although, to be honest, many of those people I've only ever met online, in a virtual environment. It's only this year that I've started to meet people in a face-to-face capacity. So we've conducted our business virtually until this year probably.

Q. Do I take it from your position as chair of Long COVID Scotland and with your background that you've gained and carried out a lot of work and acquired a lot of

information about long COVID as you've progressed?

A. Oh, without a doubt. I mean, one of the benefits of being in the group, as I've said, is meeting other people, but we've also networked and continue to network with other groups nationally. There is a bigger English long COVID support group, there's a Welsh group, an Irish group, and internationally as well we network, and I wouldn't say we meet regularly internationally but we keep in contact. I mean, I'm doing a presentation next week to an American group at the request of them with another colleague as well because they want to know what's happening in Scotland. So we share our information. We don't hesitate to ask if we need any help from other groups.

Q. With that amount of research that you've done and information that you've acquired, just one thing that occurred I think from the outset of the representation of long COVID groups and this Inquiry is consideration of whether long COVID could have been predicted. Do you have a view on that?

A. I think given other -- the existence for many years of other post-viral conditions, such as ME/CFS, Epstein-Barr -- they've been well known about for many years, how they arise. I wouldn't say that they're well treated and the people that have those illnesses have

been subjected to the same sorts of things that we have as well.

Q. When you say "the same sorts of things", does that range from general scepticism to outright antagonism?

A. Absolutely, yes. I think that hits the nail on the head. And, you know, in terms of that, then it should have been predicted that infection with the COVID virus, SARS-CoV-2 -- we should have been able to predict that something like this would happen, and pandemic preparations surely will have been rehearsed and that may have been included in that rehearsal, so why were we not better prepared?

Q. Right. Can I just ask you a little bit about Long COVID Scotland, its structures and its aims? We can read about these in your statement and I'm not going to go through it in great detail, but you're a volunteer-led charity, as I understand it, and I think you've mentioned that since September 2022 you've been a registered charity.

A. Yes.

Q. Do you receive funding from anyone?

A. No. No, we don't receive funding.

Q. And you've explained the structure of your group and your membership and we can read about that. One of the things you've mentioned is that you seek to advocate to

get your voice heard by the Scottish Government and you've worked with -- to establish partnerships with various organisations, including the Scottish Government, also the Health and Social Care Alliance Scotland, Chest, Heart and Stroke and various researchers from universities. That's in paragraph 14 of your statement.

Can I just ask you a little bit about your relationship, particularly your relationship within the terms -- within the timescale that this Inquiry is confined to, which is to the end of 2022 -- can I ask you a little bit about your relationship with the Scottish Government?

A. It has always been a struggle. A struggle getting heard, recognised, accepted, I think, as a serious group and not just a virtual group, a Facebook group -- but as a recognised group, advocating for people with illness.

Q. You're on the other side of that. What's your impression as to why it's been a struggle?

A. I think there is perhaps a view that people with illness should be heard but only so much and kept in a place, not treated as equals. I mean, we would look to have services developed in a co-productive way. We are looking to work as equals, to inform the development of any service that might involve patients with long COVID.

Actually, whilst Scottish Government might say that they work in that sort of a way, in a co-productive sense -- and I know there's a whole dimension of co-production from patients at one end, working as total equals to health professionals or researchers or whatever, and then at the other end patients just -- it's a tokenistic thing, and I think we are somewhere perhaps not even in the middle of that -- and I think that's because it's quite hard to do that, to work in a true co-productive sense. It means that more effort has to be made to hear what patients have to say, more effort has to be made to include them in all meetings, in discussions about service development, in actual developing a service. It is quite hard to do. It's not impossible but it is quite hard to do and it requires a change, I think, in attitude and culture, which I'm not sure that Scottish Government are willing to go the whole hog with that.

Q. Obviously I prefaced what I asked you by confining matters to the period of our remit in this Inquiry. I think I have to ask you: have things improved since?

A. A little, and I say glacially slow in the sense that there is a Long COVID Strategy Network which was established in 2022 -- I think, if I'm correct, 2022 -- and there is a lived experience group within that

network. When it was first established, there were only two of us with lived experience on that group. It's a lived experience group. There were only two of us with long COVID, myself and Helen Goss. We're both on that group. Unfortunately the numbers of people on that group with long COVID haven't increased. In fact they've decreased. There's only me at the moment. So within the Long COVID Strategy Network, there is only -- I think there's myself and there are a couple of professionals now with long COVID that have come into the strategy network.

Q. Who else is on that strategy network?

A. They are professionals from the health boards, from Scottish Government, project managers from Scottish Government. It's a range of people who are working to deliver on what the network -- the strategy network is hoping to achieve, and that's the establishment of services in the health boards.

Q. Do you feel that it would be either necessary or appropriate for there to be a greater voice of sufferers on that network?

A. Oh, without a doubt. I mean, I've been arguing for that for the last two years, looking for a panel, a patient panel, to be established. Communications are not good. The flow of communication back and forth from the

network to the boards, from the boards to the network, to patients, it's not satisfactory. Patients don't know what is going on, and I am just one person. I can't communicate with everybody.

Q. You mention in paragraph 16 of your statement a long COVID summit which occurred in 2021. Can you tell us a little about that, please?

A. Yeah, we hosted a long COVID summit. It brought together a range of people who had an interest in developing services for people with long COVID; ourselves, Chest, Heart and Stroke, the Healthcare Alliance, Scottish Government. A range of patients were involved.

Q. What was its outcome, if I can put it that way?

A. We produced a mind map of everything that patients were speaking about in terms of what they thought were important to them about developing a service for people with long COVID, and the idea was that that would inform the development of long COVID services moving forward into what was the establishment of the Long COVID Strategy Network.

Q. I think this is what you talk about in paragraph 18 of your statement. You say that there was:

"... an ... event [which] we organised to feed into discussions with [the] Scottish Government ..."

Was it of assistance in either initiating or continuing discussions with the Scottish Government?

A. Both, I think. I can't say that we didn't meet with Scottish Government. In those early days, actually, we had more regular meetings than we have now with them and that work informed meetings that we had with Scottish Government about how we could inform the development of services.

Q. And you obviously would have at that point -- and presumably it continues on -- having views as to the level of care and services that are necessary?

A. Oh, without a doubt. I mean, from the beginning of this work up until the present day, people with long COVID have been very clear about what they want, and they want long-COVID-informed services, ie --

Q. And, put simply, is that what is happening?

A. No, not in its entirety.

Q. Where are the deficiencies?

A. The deficiencies are around accessibility, equality, accepting that Scotland -- you know, health boards are in different bits of Scotland and what fits in one health board might not fit in the other in terms of geography and access. However, we have always maintained that there should be some core tenets to the provision of a long COVID service:

a multi-disciplinary -- the availability of a multi-disciplinary pathway that people can access; a clear system for diagnosing and treating long COVID.

Now, it's fair to say there are some elements of that available in some health boards and it's taken two years/three years to get to the point we're at now, where -- I think the minister spoke earlier in the week about how many health boards had a long COVID service in situ and I think it's all but two of the health boards she insisted had services available. We would maintain that what is available is not accessible. It's not meeting the needs of people with long COVID. If it was, why would people still be saying that they can't access services, that they don't meet their needs? People are having to go for private care because they cannot access, either through their GP or indeed through any other route, a service that will help and support them.

Q. Thank you. One of the points that you make, had already made and continue to make throughout your statement is the difficulties that you personally and your members have had in being heard in, first of all, obtaining appropriate diagnosis and, thereafter, obtaining care and treatment. Have you given thought -- I'm sure you have -- as to why there has been that difficulty in being heard?

A. I think, as is often the case, if people don't understand something or they don't have enough knowledge of what it is that people are seeking either information or help about, for some people it's easier to just dismiss it.

And I think particularly for health professionals, for some health professionals anyway, it may be a sign of weakness that they don't know what it is that people are asking them about, whether that's about treatment or a certain drug to do with long COVID. And along the way, I think one of the things that I've had said to me is that -- I've had a number of things said to me. I think I've alluded to a couple of them already.

Q. "Get out and exercise".

A. Yeah, that's one. The other is, "Well, there's no research on long COVID. We don't know anything about it". Well, we actually do. We know a lot more now than we knew two years ago. There are good trials, robust trials, that have been done around drugs and treatment.

Q. I think we'll hear from Dr Taylor this afternoon, and one of the papers that she will refer to is a paper in The Lancet on the efficacy of metformin, which is a diabetes drug, which I think has a -- I've forgotten the precise percentage, but I think it's in the 40% efficacy in treating long COVID.

A. Hmm.

Q. You're aware obviously of that?

A. I am indeed.

Q. You've talked about perhaps -- I don't want to use this pejoratively -- but ignorance on the part of certain members of the medical profession. There is also, obviously, a public perception. You've mentioned friends, possibly family members, who have a particular perception. Does that perception or has that perception changed over the period since 2020?

A. For some people it may have. I think, you know, the more information, the more there is in the press, on the TV, about long COVID, people speaking about what long COVID means for their lives, then that may influence some people. However, for many people COVID has gone away. You know, they think it doesn't exist anymore so therefore how can you have long COVID if COVID doesn't exist. We don't have any strong Public Health messaging around COVID or long COVID, we don't have any strong Public Health messaging around masking, around ventilation, so people just think it doesn't exist.

Q. And probably certain of the statements that have emanated from people in power may not have assisted.

A. Absolutely.

Q. I wonder if, just completing this section on the -- we've perhaps touched on a lot of other matters, but on your organisation, if you could just go to paragraph 29 of your statement and indeed to paragraph 30, and just so that we have -- for both the Inquiry's view and also for public consumption, could you just read out paragraph 29 because it tells us what your members want.

A. "Our members are very clear about what they want; 'people with Long COVID need to be listened to and lived experience needs to be at the heart of solutions'. We need space and structures to be created so we can inform processes and action, for example a stakeholder panel."

Q. Thank you. You also mention in paragraph 31 the Scottish Government producing a document, "Scotland's Long COVID Service". Can you tell us a little about that, please, and its significance?

A. We hoped when that document was produced that it would lay the groundwork for the development of services, and, in fact, I mean, Scotland's Long COVID Service informed the development of the Long COVID Strategy Network and we were hopeful that services would be quickly developed in the health boards, that lessons and information around what was happening in the rest of the UK and in England, who were a little bit further ahead than ourselves in terms of developing services and thus had some idea of what might be worth persisting with and what was working -- that we would be informed by that and it would help with the development of services here.

We didn't see a lot of that. There was a reluctance, I would say, of the likelihood of learning being acknowledged and influencing what we were doing here. A little of that got a bit better further down the line, probably more in the last year and a half, but we certainly thought that, "Okay, services will now be developed in health boards and we will see patients able to access care and treatment". As part of the network, there was an education strategy because one of the issues -- and we've already spoken about -- is education of health professionals, particularly round GPs, who were being faced by a lot of people trying to speak to them about long COVID. And we've always had a lot of feedback from our members that, amongst the GP population, it was very varied in terms of their knowledge and understanding of long COVID. Despite the fact that there were a couple of guidelines -- a signed guideline written about long COVID care, many of them didn't know anything about it, and in fact our members were taking a copy of that and handing it to their GP so that they would be better informed, and that was only one of a number of things that members were able to hand

to GPs.

So we were hopeful that the strategy network would inform education of health professionals; we would see services develop. It didn't happen as fast as we hoped it would --

Q. Has it happened at all?

A. Pardon?

Q. Has it happened at all?

A. It has happened. Some of it has happened. Money was made available as well and to be allocated over -- we thought it was three years, but in fact it's four, and that ends in 2026. That money was made available for the development of services within health boards. Much has been made of that money being spent and in fact some of that money hasn't been spent because of the difficulty of engaging staff within health boards, so things happened glacially slowly and they still happen glacially slowly.

Q. Thank you. Now, you go on at paragraphs 34 and following of your statement to give some information about the emergence of long COVID. We can read what you say there, but, in paragraph 34, there's one point I'd like to explore with you. You say that, "Despite the high number of people being hospitalised", and I presume that's with COVID itself, "Government advisors said

there was an expectation that most people would experience milder symptoms and could expect a full recovery". Are you putting that forward as a criticism of the initial advice or is it simply a statement and that events that have happened subsequently have cast doubt on that?

A. I think it is probably a criticism based on -- you asked me the question earlier about what we should have known might happen as a result of a virus like this. There must have been some sort of picture around what might happen, how this would pan out, and, sure, some people would be in hospital, but I think it was very much promoted that the majority of people, if they got COVID, would experience milder symptoms and could expect a full recovery. That was pushed for a long time and I still think to some extent that is pushed.

THE CHAIR: That would be a clinical question, wouldn't it --

A. Yes.

THE CHAIR: -- because you did say earlier on that, on the basis of other viral illnesses, there was known to be residual or long-term effects and therefore we could no doubt hear evidence from appropriately qualified clinicians as to (a) if that was true -- I'm not for instance suggesting you're telling untruths -- but (a)

if it was true, (b) what the incidence of it was and so forth and so on.

A. Yeah.

MR GALE: Thank you, my Lord.

You have provided us with the definition of "long COVID" as provided by the World Health Organisation. I think we can see that. I'll simply read it out for you:

"[It's] a condition that occurs in individuals (adults and children) with a history of probable or confirmed SARS-CoV-2 infection. Diagnosis is usually three months after the onset of COVID-19, with symptoms that last for at least two months and cannot be explained by an alternative diagnosis."

You've also provided us with some very helpful information about long COVID and, again, I'll just read this for you:

"[That it affects] multiple organs and systems within the body, including respiratory, cardiovascular, neurological, gastrointestinal, and musculoskeletal systems."

The symptoms, which I think is something that we probably all in the general public are aware of -- but there are some common symptoms.

"[These] include fatigue, breathlessness and cognitive dysfunction. Symptoms may also be new following initial recovery from illness. People experience fluctuations and relapses of symptoms that majorly affect everyday life."

Now, two documents that you've produced to the Inquiry and you've referenced there are surveys that your organisation carried out. One is entitled "Impact of Long COVID" and the other is "Issues with Employment for People with Long COVID". We'll look at some of the points that you take from that in a little.

I'd like to look at some points in the section headed "Our experience of Long COVID symptoms". I should say that you explain the analysis of the surveys that you've carried out in paragraphs 41 to 43, but in paragraphs 44 and following you talk of "Our Experience of Long COVID".

You provided us with some statistical data, which is obviously very helpful, and what you say is that, in October 2022, the ONS estimated that 2.3 million people, so 3.5% of the UK population, self-reported long COVID symptoms and, proportionately, if one takes that to the population of Scotland, then it would mean that at least 175,000 people in Scotland are living with long COVID. Do you think that's accurate?

A. No, not at all, for various reasons. Self-reported

long COVID symptoms -- the whole thing around testing or not testing, that was always a very challenging thing in the early days, people being believed if they weren't tested or -- so the self-reporting thing of long COVID was viewed negatively, not by us but by other people, I think. There's no doubt that more people, I'm sure, have long COVID than the numbers there present, and I think that applies today, much more so today, because we don't test and we're not reporting numbers of COVID or long COVID today.

THE CHAIR: I think what you're saying -- I take your point entirely, but self-reporting -- I'm no statistician, but my understanding is that statisticians are always suspicious of self-reported pools -- let's call them that --

A. Hmm.

THE CHAIR: -- and we've got to be very careful about data of that nature, and I suspect that -- I don't know. Perhaps Mr Gale intends to do so -- but if we had the evidence from a statistician, we could get some insight into how reliable or unreliable such figures were.

A. Hmm.

THE CHAIR: Is that a fair comment on my part?

A. Oh, very much. Yes.

THE CHAIR: And I stress a lay person's comment in relation

to statistics --

A. Absolutely.

MR GALE: Thank you, my Lord.

I think you also indicate that 73% of people who self-reported with long COVID had symptoms lasting at least 12 weeks and then nearly half of those people, well, 44% in fact, had symptoms more than a year after that, after first becoming unwell. So in terms of the length of residual effects of long COVID, is it quite common, in your experience and with your access to the people that are within your group, that one can be looking at symptoms that are lasting more than a year?

A. Oh, very definitely. Yes.

Q. Now, I've asked you a little bit about relapse and remitting and fluctuating, and I think we can see that both in paragraph 48 and also in paragraphs 55 and following. Just so that we do understand, is the relapsing and remitting nature of the condition something that is common within the cohort of people within your group?

A. Very common. In fact I'd say everybody I know with long COVID, it's a relapsing, remitting condition.

Q. What is the effect of subsequent infection?

A. For me and I know for many other people it makes it worse. It makes the other symptoms you have worse and

that may be worse for a while and then it may improve or, for some people, unfortunately, it makes them much worse and people go on a decline really after having a subsequent infection.

Q. You again have provided us very helpfully with some of the common symptoms and perhaps you've expanded on what I think you've described as the "top five symptoms" which you say are "almost universal". This is in paragraph 51. Then you go on to talk about other symptoms which, beyond the common ones, include difficulty sleeping, chest pains, irregular heartbeat, joint pains and anxiety. There are some more perhaps nuanced symptoms that you describe in paragraph 53.

A. (Nods).

Q. Also you do mention -- I think it's in paragraph 50 -- that most of those who have been afflicted with long COVID contracted it during the first wave. Is that what is the information from your group?

A. The survey was -- information from the survey that we -- that people who completed the survey felt they contracted it during the first wave, before testing was available.

Q. I'm particularly interested in what you say at paragraph 59 -- and you deal with it in more detail later in your statement, but it's perhaps a useful point at which to talk about it here -- and that is the impact on mental health and well-being. You talk about the ongoing symptoms of anxiety and depression. Now, we will hear from Dr Taylor about patients with anxiety and depression. What I take from her statement is that these are largely people who do not have pre-existing mental health issues. So, from your perspective, you've mentioned you've had anxiety, you obviously know other members from your group who have had anxiety and presumably depression, do you know -- is it possible for you to say or speculate as to where that comes from?

A. For me, personally, it was -- I had a number of things going on in my own life at that time as well. My husband became ill at the end of 2021 -- he was seriously ill, so I had that as well as my own illness. But I think generally it's around not knowing if you're ever going to improve, if your condition is going to get better, if you're going to recover -- not knowing any of that and being, I think, dismissed by people who perhaps don't believe what you say when you talk about your symptoms. So I think it's a number of things that contribute to anxiety. I think anybody with any chronic health condition knows what the impact of having that is on your day-to-day life and how you cope with that. You can't help be anxious about the future and the impact on

your family and the people you love of an illness that really for people with long COVID knew very little about.

Q. We are obviously, in this Inquiry, mindful of our obligation to identify areas of inequality, and in paragraph 60 and following in your statement you refer to the impact of long COVID on women. I think you've already said that there is a preponderance of sufferers of long COVID who are women.

A. Hmm.

Q. You've indicated some of the problems that women have experienced and have reported. Could you just indicate what they are?

A. I think -- I mean, in chapter 60 we were speaking about 50% of women said they experienced flare-ups or worsening symptoms with menstrual cycle or menopausal symptoms since developing long COVID, and in fact that wasn't -- up until that point, it wasn't anything that our members spoke about in great detail. We asked the question and that's the answer we got. And around about that time, probably a short time afterwards, we had some contact from a couple of researchers who were looking at problems with menstrual cycle and menopausal symptoms in more detail with people with long COVID, so I think it was starting to be more spoken about and brought out

into the open, and indeed, since then, it has been acknowledged that that is a major problem for women.

Q. And you take the matter slightly further in paragraph 62, where you say:

"... there is an urgent need to better understand the [inter-relationship] between long COVID and their reproductive health to develop treatment plans and to reduce further risks to women's health."

A. Yes.

Q. Do you know if that research and that understanding is developing?

A. I think it definitely is developing. I mean, we kept in touch with those researchers and, yes, that is developing. How it has influenced clinical practice, I can't say in any great depth that I know much about that at this point.

Q. Now, the next quite lengthy section of your statement deals with various impacts and you supplement each of these with quotations from the surveys that you've carried out. That's, if I may say, very helpful --

A. Thank you.

Q. -- because it's given context to what is said. Obviously, when the Inquiry comes to look at this in more detail, we will be looking at other areas of the research -- of the surveys that you've carried out, so

I'm not going to take you through these in great detail, but these include, as you've numbered them, "Demoralised by illness", and you give a quote from that. You give -- the "Impact on our working lives", you give an instance of -- an example of "The impact on family life and relationships".

Can I just ask you, however, a little bit about "Long COVID in Children" because that's one of the areas where you've provided us with some further information. One of the points you make in relation to children is that experiences of long COVID can lead to social stigma. Can you explain that, please? It may be obvious to you certainly but perhaps you can just explain it.

A. I think there's a combination of things for children and their parents, and that's around them not being able to go to school -- one thing -- mixing with their peers. For parents, it's almost -- well, it is becoming perhaps a full-time carer for a child. The parent themselves may have long COVID. There may be other children in the family. So there's a whole range of things around how that impacts on the child and the parents. And then there is the thing of being believed by health professionals and trying to access services and care, and, to be frank, care for -- I've said a lot about care for adults or the state of care for adults with long COVID. The state of care for children with long COVID in Scotland is behind that of adults in terms of there being a recognised pathway for care provision. What is going on in different health boards, I don't think that's well known for children. So, yes, that is not good and the impact of that on parents and children who are trying to have some life, live their lives, it's just horrific. I say that as a parent myself. My children are grown, but I just think it is a horrific thing to have to deal with.

Q. Yes. Again, I don't want to go through these in any detail. You go on to talk about the need for better Public Health messaging. You go on then to "Living with a myriad of unpredictable symptoms". The recognition of the chronic nature of long COVID, you've touched on that. You then go on to talk about accessing care and treatment through a GP. Again, this is something you have alluded to and you say that, in paragraph 78:

"People with Long COVID often report frustration at accessing care and treatment through GP practices."

Is that because of what you've termed "the lottery" as to whether GPs understand long COVID?

A. I think that is part of it. The other thing that is part of it and some might say it's a hangover from the

pandemic, that COVID in general is the access -- the ability to access a GP, and some of our members have found that -- still find that very difficult, as well as, when they actually get there, whether the GP understands long COVID. And whether they're willing to work with the patient to look at what the care they require is another thing. It's not a predictable thing. It is a lottery.

Q. This is again something you go on to, particularly in the section on "Improving care and treatment pathways" at paragraph 85, and it has at its root, I think, the multi-systemic nature of long COVID. So if you go to your frontline of health professional, your GP, with certain symptoms, there then becomes a question as to: if you are going to be referred further for investigation, to whom are you going to be referred? Is that a problem?

A. It is. It is a problem -- can be a problem. Many people, myself included, as you've very well described -- you know, the multi-systemic nature of it means that there may be a referral required to cardiology, to respiratory, to ENT, to reproductive health, and many of those services themselves are getting to grips with what long COVID means as well, particularly -- I mean we have had instances -- still do

of -- but at this point, when we wrote the survey we're speaking about, the results of that was that people were requiring -- I'll give an example of cardiology -- a referral to cardiology and the GP making a referral and cardiology just sending it back, saying, "Well, that's nothing to do with us".

Q. Yes.

A. "We don't deal with patients with long COVID".

Q. To use a word that we perhaps hear quite often -- and you use it in paragraph 85:

"There is a need for all patients to receive a long COVID holistic assessment of their physical, cognitive, psychological, and functional abilities so that they can be referred to the right specialist help."

A. Yes. I think what we have always looked for is a multi-disciplinary hub or focus for care, accepting that there's a requirement to have specialist treatment accessible within that, and that has always been a challenge.

Q. Right. One other point I'd like to ask you about is "Underlying Health Conditions and Long COVID", which you refer to in paragraphs 91 and 92. Again, this is probably something you've already touched on but I was particularly taken with the quote from your survey which you give at paragraph 92. Perhaps you could just read

that out, please.

A. "COVID has affected every part of my life for the worse. From being a fit & healthy professional geologist working around the world, an ultra-runner, with an active social life and a regular volunteer, I was too ill to work at all for over a year, and I'm now only well enough to work half-time from home, my income has reduced, and my long term employment depends on my employer continuing to enable me to work remotely, which I have no guarantee of."

Q. You've provided us with quite a lengthy section of your statement on accessing care and, again, time is slightly against us so I'm going to actually just take that as read, but I am going to ask you about the impact on mental health and well-being, since this is a particularly important section. So you repeat at paragraph 105 that negative or unsupportive comments can come from many sources.

A. (Nods).

Q. And they may not be particularly directed at an individual, I suppose; is that right? You also talk about:

"The feelings of social ostracism, rejection and devaluation are likely to affect emotional wellbeing negatively."

A. (Nods).

Q. Can you give a little context to how people with long COVID do feel socially ostracised?

A. I think feeling socially ostracised emanates from the fact that we feel -- I've said there, we feel left behind. People have moved on, COVID is over, therefore people don't have long COVID. People don't like to be reminded of what it was like during the pandemic, and long COVID and people speaking about long COVID, asking people to wear masks, talking about ventilation, it reminds people of that period and they don't like it, and that includes friends and family. They just want to move on and get on with their lives, and that's understandable, and so do we. But for us, for many of us, I think, because we are left with compromised immune systems very often, it means we can't get on in the same way as other people do. We need other allowances and precautions to be taken for us to have a life, like everybody else wants to have.

Q. Can I take you finally to the section on the employment survey that you carried out, 2022? It's paragraph 107 and following. Again, I don't want to go through this in detail because we can obviously read it. You give the figure there of:

"... 82% of people identify as female indicating

that Long COVID disproportionately affects women."

And I think that's in accordance with what you've said. I suppose one of the difficulties in relation to employment is there needs to be an acceptance by an employer -- if it's an employment situation, there needs to be an acceptance and a willingness to be flexible by the employer; is that right?

A. Yes.

Q. One of the points you've made in paragraph 112 is that, from the survey that you've carried out, you've come to the view that long COVID and its symptoms fit within the description of "disability" under the Equality Act 2010 and that reasonable adjustment should be made where possible to support workers returning to employment. Do you know if there are any proposals in relation to categorising long COVID as a disability under the Act?

A. It's my understanding that some work is underway in that respect. I'm not sure how far it has got but I know it is underway.

Q. You also tell us at paragraph 115 that nurses and teachers with long COVID face unique problems regarding registration and updating their skills and qualifications --

A. Hmm.

Q. -- and I think you then give a quote from a nurse who

was seeking to renew her -- I assume a "her" -- her registration as an RGN.

A. Hmm.

Q. Again, as I've indicated, we'll hear from the Royal College of Nurses in due course.

Finally, and with a little haste, Mrs Ormerod, "Recommendations for the future". Again, we can read what you say, but accepting for the purposes of your evidence what you've said there, is there anything further that you would like to say to the Inquiry at this stage before you leave us?

A. Thank you. I would like to say that there is an insistent claim from Scottish Government that money allocated for long COVID services in 2021 has been well spent and that services have been developed and people's needs have been met, and the allocated money for long COVID services development equates on average to £12 per person with long COVID. We know that some of this money has not been spent and, although some services have been developed, it's clear they're not meeting people's needs and they're not easy to access.

Two recent reports, just in the last couple of weeks, from Chest, Heart and Stroke and the Health and Social Care Alliance, have also validated those claims from our members as well. So I suppose I would say the

Scottish Government might be better placed to ask, "So what might we do differently? How can we move forward?".

We're also told that funding may cease in 2025. What will happen then? Will services go back to the same as they were before? Will long COVID services, as they are, be absorbed into existing services? And this is all within the context of long COVID -- it being predicted that 200 million people may develop long COVID in the next decade.

So we have a huge challenge and it's just how we look at it differently, and we're very clear about what we want. We want to be listened to and for lived experience to be at the heart of ongoing solutions. And that can only happen with a commitment from Scottish Government to a dedicated plan to ongoing funding for the continued work of the development of long COVID services.

Thank you.

Q. Well, thank you very much, Mrs Ormerod.

My Lord.

THE CHAIR: Very good. Thank you, Mrs Ormerod.

A. Thank you.

THE CHAIR: 1.30, I think, Mr Gale.

MR GALE: Yes, my Lord. It's Mr Stephens again.

THE CHAIR: Mr Stephens. Very good.
(12.51 pm)
(The short adjournment)
(1.30 pm)
(Proceedings delayed)
(1.44 pm)
THE CHAIR: Right. Good afternoon, Mr Stephens.
MR STEPHENS: Good afternoon, my Lord. This afternoon we're expecting to hear from Fiona Loud of Kidney Care UK, and this witness is going to be giving her evidence remotely.

MS FIONA LOUD (called)

(Evidence given via video-link)

THE CHAIR: So I see. Good afternoon, Ms Loud. Can you hear me all right?
A. Good afternoon, my Lord.
THE CHAIR: Oh, you can. That's good. Splendid. Right, you're going to be asked some questions by Mr Stephens.
When you're ready, Mr Stephens.
MR STEPHENS: Thank you, my Lord, and for the record, the witness statement Inquiry reference number for Ms Loud is SCI-WT0426-000001.

Questions by MR STEPHENS

MR STEPHENS: Firstly, Ms Loud, can you see and hear me okay, before I start?

A. I can. Thank you, Mr Stephens.
Q. Can you confirm your full name, please?
A. Yes, I'm Fiona Caroline Loud and I am policy director for Kidney Care UK, a patient charity.
Q. Thank you. Your age and contact details are known to the Inquiry so I won't ask you for those. You've already provided a witness statement. Can I just check that you're content for that statement and the oral evidence that you're giving today to constitute the evidence that you would like to be before the Inquiry?
A. That is correct. Thank you.
Q. And are you happy for that evidence to be recorded and published?
A. Indeed I am. Thank you.
Q. Okay. Now, I'll say at the outset that everything that you've said in that statement, even if we don't touch on it today in oral evidence, will be taken into account by the Inquiry and I will also give you an opportunity at the end, if there's anything that you think I might have missed, to pick up on then.
A. Thank you.
Q. Finally, before we move into the detail, just to remind you there is a restriction order in place, so please do not name any other individuals when you're giving your evidence. If you're referring to a staff member, refer

to them as that rather than name them specifically. Is that clear?
A. It is, and thank you for that.
Q. Great. Thank you. Now I think you said already, but your role is policy director at Kidney Care UK; is that correct?
A. Yes, indeed.
Q. How long have you held that role for?
A. Since 2013 -- summer 2013.
Q. And what does that role entail?
A. So that role entails taking all the information and the evidence we receive from people with kidney disease and using that to campaign for better treatment for people with kidney disease.
Q. Thank you. Prior to that you were a director of the Kidney Alliance, I think you say in your statement, which was representing kidney charities across the UK; is that right?
A. That's right, yes. So that was a number of patient and professional charities across the country.
Q. And your previous professional background was ...?
A. My previous professional background was in IT, where I was originally a programmer and then a project manager, then a people manager.
Q. And how did you come to be involved then with kidney

charities?
A. I came to be involved with kidney charities because of what happened to me. So while I'm director of policy for Kidney Care UK, I'm also -- I have lived with kidney disease and I had to stop work for a number of years because I suffered kidney failure. I have a genetic condition and I spent five years on dialysis before receiving a transplant from my husband, who I probably can't name, 17 and a half years ago.
Q. So you bring that lived experience to your role then as policy director?
A. I do indeed, yes, and many of our staff are in a similar situation, although not necessarily all of them.
Q. I want to ask you now about the organisation itself. The organisation you're representing today is Kidney Care UK. That's a kidney patient support charity?
A. That's right. We're a UK charity. We used to be known as the "British Kidney Patient Association", but we changed our name in 2016. We still do the same things though. We are there to support everybody with kidney disease and their families too so that they are able to be supported in all aspects of their life which aren't the NHS.
Q. And that's a UK charity, so registered both in England

and in Scotland?
A. Yes, we are registered in Scotland as well as England.
Q. Therefore your organisation offers services across the country; would that be fair to say?
A. That would be fair to say. We offer counselling, we offer patient support and advocacy services and we offer our other grant, financial and information support services everywhere in the United Kingdom.
Q. In terms of the size of the organisation, then, just to get a clear picture, how many staff does Kidney Care UK have and what's the geographical spread, if you like?
A. Yeah, we have about -- I think it's about 77 people now. When I joined there were ten of us, so you can see the input, the organisation has grown, and not all those people are full-time. Some of them are part-time. And in Scotland -- I was just counting just now -- we have five members of staff currently -- yes, we have five members of staff.
Q. I suppose, breaking those down slightly further, your statement refers to, I think, patient support and advocacy officers as well as counsellors. What are their respective roles?
A. So our patient support and advocacy officers, who are throughout the whole of the United Kingdom, their roles are to support people locally with any of the questions

or queries they may have about their condition, so that could include assisting them with getting benefits, going to tribunal with them, if they need further support. It could include helping them to make a case with some issue on housing, for example, or it could include advocating for them around things to do with treatment or employment, for example. So a wide range of things that people who are affected by kidney disease and especially late kidney disease and kidney failure may need further help with. They can also help to direct them towards our grant services or our counselling services.
Q. Thank you. In terms of I suppose the size of the task that you face, I'd be interested to know for the population of Scotland, for which this Inquiry is obviously principally concerned, how many in Scotland, if you know, are living with chronic kidney disease, for example?
A. So -- I mean, across the whole of the United Kingdom we estimate there's about 7 million people living with kidney disease, but that's at all stages. In Scotland the estimate is about 607,000 people with all stages of kidney disease, looking likely to rise over the next few years. Of that number, about 273,000 have the later stages of the condition, which is often referred to as

"moderate to advanced kidney disease", so a large number of the population.
Q. Thank you. Moving on then to the impact of the pandemic upon your organisation, I think you note in your statement, I think you marked the beginning of the pandemic by reference to a parliamentary event that was due to take place.
A. Yes.
Q. I think it was World Kidney Day -- is that correct? -- on 12 March 2020.
A. That's absolutely right, and in fact, in a strange irony, tomorrow is World Kidney Day 2024. So, yes, for World Kidney Day 2020 we had an event planned at Westminster, and that was the day on which we realised we couldn't possibly go ahead with that and we had to call up all the patients that were going to be attending and tell them not to go, and that was the day I personally decided that I wouldn't be going out anymore because it became obvious that the risk to people with kidney disease was just growing by the minute and we didn't know how much it was, but we just had to be really, really cautious as we started to see the pandemic was beginning to spread.
Q. I think you yourself say in your statement that you were immunosuppressed so you had to stop working; is that --

A. Well, I carried on working, but working from home, yes. So that's -- when I say, "we stopped", I meant myself as well. So I think 12 March is probably the last time I went out for a long time because -- so some people, like myself, who are immunosuppressed -- because that stops your precious donated kidney from rejecting from your body. You have to take tablets to stop that. They're called "immunosuppressants" and they give you a greater risk of catching infection, so you always have to be aware of that risk. But with a new and unknown risk to people like us, we -- I certainly got home that night and said, "That's it. I'll work from home for now", and I didn't go back out again for months and months.
Q. What changes did you have to make as an organisation to your ways of working in light of what happened with the pandemic?
A. So, Mr Stephens, what we had to do was we had to rapidly deploy our members of staff home. We had to buy laptops for people. I already had one because I worked -- I moved around the place quite a lot for my job anyway, but we had to buy laptops for all of our staff, including our admin staff, who would have normally used a machine in our head office, which is in Hampshire, and then effectively close the office down, although we did

of course leave room for the post and someone would come in from time to time to check the post. But we had to completely change the way in which we worked and how we talked to people.

Q. I think crucially for a charitable organisation, what impact did the pandemic have on -- in terms of your fundraising?

A. So much of our fundraising, in common with many other charities like us, will include community events, so people might choose to say, "We'd like to raise some money for you, to help your counselling work, your advocacy work", and that might be cake bakes or the London Marathon or something else like that. And of course all of that had to rapidly -- well, had to stop. So for our fundraising team, in common with many other charities, that was a real challenge, and they had to get very creative to think of other ways to do that because I should say that patient demand increased enormously because of people wanting advice, people feeling very anxious and many other things about the incoming disease and what that would mean to them. But we had to get very creative in terms of thinking of other ways to do things and -- things that people could do in their back garden, running up and down the stairs or other such events, to raise funds and awareness for

the charity.

Q. Thank you. And given what had happened as regards fundraising, what was the impact upon staffing in the charitable sector as a whole? We can come on to kidney care specifically, but what did you notice generally about staffing as a result of what was happening with fundraising?

A. So generally across the charity sector I noticed that some charities had to make quite a difficult decision, which was to let some people go. I can't tell you who all those people were because that wasn't what we did. But I did notice that because obviously a number of people we'd been involved with were really actively helping with those fundraising types of events and -- so I did notice that in terms of a change in the way some organisations worked. But then some, like us, deployed to the frontline with providing information, continuing to provide telephone services and other ways of counselling, and we all adapted very quickly to using initially Zoom but also Teams.

Q. Did your organisation lose any staff or make use of furlough, for example?

A. We -- I don't think we lost -- I don't think we had to let anybody go, but, I mean, during that time a couple of people did leave anyway, just through natural

attrition. We had to use furlough for not that many people -- I mean, perhaps three or four people I suppose -- I can't remember the exact numbers now -- and for part of that time. So those would have been people perhaps who had young children who needed to stay at home or were sharing care with their partners as well, so tried to do a bit of -- continued some work but also had to take some time on furlough and use the Government scheme to support that.

Q. I think you also say in your statement that you tragically lost a colleague, the chair of your organisation, in around March 2020; is that right?

A. Well, we actually lost two colleagues. In fact one of them -- in fact it wasn't March. That was December 2020. So our chair, [redacted], who was a very well-known, very highly respected kidney doctor -- so in fact he died in January 2021, just before he was -- just before the vaccinations came along, and a few months after that I lost another colleague from our team, who was a person with kidney disease as well.

Q. I just need to ask you to stop for a minute.

THE CHAIR: You mentioned the name of the doctor.

A. So sorry.

THE CHAIR: I point out he's dead. I don't mean that

rudely, but I'm not sure if that makes a difference.

(1.57 pm)

(A short break)

(2.01 pm)

THE CHAIR: Can you hear me, Ms Loud?

A. Yes, thank you. I'm back.

THE CHAIR: Not at all. We have taken -- you, as you appreciate, inadvertently, I'm sure, mentioned the name of the late director of your organisation.

A. Yes.

THE CHAIR: We have excised that from the record being kept --

A. Okay.

THE CHAIR: -- and we've told the people in the room that are listening that they mustn't repeat that.

So I appreciate fully it wasn't your fault. Easy mistake made.

A. Apologies, my Lord.

THE CHAIR: No, not at all.

A. I'll start that again and I will just not use any names.

THE CHAIR: Thank you. Mr Stephens.

MR STEPHENS: Thank you, my Lord.

Ms Loud, can you see and hear me okay before I start asking questions again?

A. I can, yes. Thank you.

Q. Thank you. I'll move on, if I may. I wanted to ask you now about just the topic of guidance actually in the context of moving activities online for your organisation. I think you describe in your witness statement the organisation's website becoming the most important window into what the organisation was doing and also that you became a leading source of information on COVID. How did that come to pass?

A. Yes. So, as I explained, we deployed home very rapidly and we realised from the volume of questions that we were getting that people with kidney disease -- and that included people at all stages of the disease -- had many, many questions and they wanted to know what was happening, what should they do, where should they go. And we rapidly got to work with colleagues, medical colleagues, and pulled together our first page of information, which just explained that there were some risks to people with kidney disease from COVID, that we didn't know much yet and that it would be advisable for people to stay away from others if they possibly could, and started to create a kind of set of things that people should consider as they -- well, as they went about their business or didn't go about their business. That included defining who might be at the highest level of risk. So if you were at a later stage of kidney

disease, if you had a transplant, if you were on dialysis -- which is an option for some people to keep them alive and so it's a form of treatment -- and so we listed out all of those things as clearly as we possibly could and published them online.

We realised that people found that information very valuable, so we made it our business, particularly myself and my colleagues and our policy team, with medical colleagues, to put together the best quality of information we could, so partly informed by what was going on, partly informed by what Government or the various NHS organisations were saying and partly informed by the many questions we were receiving through our helplines, social media, emails and so forth about what to do and what risk people were under. So that information grew and grew and it became NICE, and then the MSC, the Scottish Medicines Consortium, went on with that as well, recommended it as a good place for people to look if they had questions about chronic kidney disease or kidney disease overall and COVID-19.

And we must have updated it -- do you know, I can't remember -- sometimes it was twice a day, depending on the new information we got. And if you can imagine, gradually the information started to build, but sometimes information would come from NHS or

governmental sources and it didn't necessarily apply to people like us, people with kidney disease, or it needed a greater level of understanding to put it into lay terms. So that was the point at which we might have to embark on conversation with the relevant health department or Government department or doctors, nurses, whoever, to understand what that meant in terms of people with kidney disease. And it was -- I call it sort of a labour of love after a while because it just grew and grew.

In fact just yesterday we updated the information again, so we still have that as a live source of information. Now it's all about the next vaccines, a reminder of what you do if you do get COVID and what treatments are available to you. But at the very beginning we were just starting to put together the range of advice and the guidance that might be there for you. And at the very, very beginning, people didn't know very much at all, so it started sparsely but it grew and grew and grew, and the quality of it was hugely improved by our readers, our contributors, and of course all the teams at Kidney Care UK combining to get that published as regularly as we could.

We also know that our readers liked it because they told us all the time, and they also pointed out if we

made a mistake, got the day of the week wrong, something like that, and that was both a challenge but really motivational as well because it made us work as hard as we possibly could to give the best quality of information you can because, in an information desert -- and I know it's a bit of a theme of our submission -- is that we didn't feel the communication was perhaps as clear as it could be to the many people with kidney disease about their risks and what they could do about that and what treatments would be available to them, if any, through the pandemic.

Q. Thank you. As a UK charity --

THE CHAIR: Just before you go on, Mr Stephens, you mentioned in the course of that rather long answer, Ms Loud, NICE. I think that's the National Institute for Clinical Excellence; is that correct?

A. That is correct, yes, and NICE worked with the MSC, the Scottish Medicines Consortium, to produce some rapid guidelines on COVID-19, which we input too as well, and that was -- the reason I referred to that, my Lord, was that they actually named at some point our information as being a good place to refer people to for the latest up-to-date information.

THE CHAIR: I just wanted to get the acronym into the record. Sorry, Mr Stephens.

MR STEPHENS: No. I'm obliged.

Ms Loud, you said earlier, of course, it's a UK charity, the organisation, and you're providing services across the UK. You also mentioned in your answer there the numbers of sources of information on guidance that you were receiving and having to act as a conduit for, I suppose, for want of a better word. I wanted to ask you just the question: how straightforward did your organisation find the task of providing this information on COVID to those with kidney disease, kidney issues?

A. So I do have to say that it was a challenge, trying to pick our way through the information as it appeared or ask the questions to try to get to the right information, and, as I said, it literally started with who should be on the shielding list or, as it became known in Scotland, the "highest risk list". That's where it started, to try and understand which people with kidney disease -- was it all stages of kidney disease, was it people with transplants, was it people on dialysis, was it all of those, because if you were at that point on the list of people who would be advised to shield, there were certain things that would go with that to provide you with a level of protection, although -- albeit the protection was partly provided by just staying in your house and not going and talking to

anybody else or seeing anybody else. So it was quite the challenge and to deal with the different nations and the fact that information came out at different stages from the different nations as well was also quite challenging.

So in Scotland -- sometimes we had to get the information from England and then understand whether the same information would apply in Scotland, but, likewise, sometimes the Scottish Government would volunteer -- once we'd made our links fully with them about this, would then give us some information that was coming here in Scotland and how it applied to people in Scotland as opposed to the rest of the country.

So we would, within that information source that I've just described, that grew -- grew later and then had to be rapidly re-organised to become easier to read -- we would say, "Here's this announcement about shielding or tiers", or something like that, "In England it's like this, in Scotland it's like that, in Northern Ireland and Wales ...", and so on, so that people in each of the nations would get the generic information about, perhaps, "Stay isolated. Do some shielding", but then the specific information that may apply to the different -- may apply in Scotland about -- as time went on, where you could travel to, how far you

could go away, which tier you might be in and so forth.

Q. You mentioned shielding and we'll certainly come back to that in due course.

A. Yes.

Q. I think you also said in your witness statement on the subject of guidance that you conducted a number of surveys of those users of your services. I think the phrase you used at paragraph 54 of your statement was that people "didn't know where to look". I think you also make the point about a difference in perhaps terminology between, say, England and Scotland. Is that right?

A. Yes, that's right. We ran three different surveys through from the mid- -- probably for about a year from 2020 to 2021 and we received 2,500 responses overall. And, through those surveys, one of the key things was about lack of communication. There was information about mental health support, which I can come on to as well, but in answer to your question about lack of communication, people did not know where to look because, if they hadn't received a letter directly or an email communication -- which at first nobody received anything for a period of time. They just knew that this thing was there and it became obvious -- and I can explain why in a minute -- that people with kidney

disease would be quite vulnerable to the condition -- they knew they were worried so they started to look about the place. They asked their doctors, they would ask their kidney consultants and, of course, they would ask a charity like Kidney Care UK, "What do I do? What should I be doing?". And it was the challenge -- quite the challenge to get that information to people in a way that they could understand, that they would know what applied to them and would be able to take a sort of informed risk-based assessment about what they could do. Would it be to shield completely, to go to work and for how long should that apply and also what should members of their family do as well, because we're all individuals who are -- you know, people -- not just people with kidney disease but we have families around us as well, so we had a lot of questions about what -- should people see their families, should they see their grandchildren, should they give them a hug, all of those sort of questions.

So some of them were very -- you know, there was a lot of emotion in that as well as just trying to see through the facts and the news as it came up and work out "What did that mean to me?", and that was something we felt, through our information, it was something we should try our very hardest to be able to produce, but also to challenge different authorities to make it as clear as possible. As you say, Mr Stephens, having different terms in different countries at certain times made that quite difficult.

Q. So is there, do you think, a lesson learned there -- looking back on what you've just said about different tiers, different approaches taken in the four nations, et cetera, et cetera, and given what you've just said just now on terminology, do you think there's a lesson there?

A. I think there's a lesson about communication. I think there's a lesson about working with charities like ours, who are very close to the population, if you like, specialists on the people that we're working with and representing, but also a lesson about consistency because, if someone is listening to the main news, they might hear one term that only applies in that country and a different term in the other country and the different tiers. In fact, when I was going back through all this for today, I thought, "I can't believe we used to have all these different levels and tiers and things", because I'm sure it made it more difficult for everybody, whether it's public services provision, medical provision, that we had so many different kind of strategies and there was a lack of consistency around

the place.

So I think it would be very helpful learning from the very difficult things that happened in the pandemic to try to adopt some levels of consistency in terminology and to invite charities such as ours, you know, to work with on the communications. I should say that did start to happen but I think it could have been a lot more timely and made easier with a little more notice and a bit more involvement about what does this actually mean to somebody affected by this directly.

Q. Thank you. I'll move on now, then, to ask you about the impact of the pandemic upon those with kidney issues at that time. But first, prior to the pandemic, how would you have expected those people with developing kidney disease to have been dealt with? You touch on this in paragraphs 70 and 71 of your witness statement. What would have been the status quo prior to the pandemic?

A. So prior to the pandemic, if somebody has -- well, first of all, if somebody has high blood pressure or diabetes, they should be getting an annual check and that annual check should include a kidney check, so that is one of the ways in which somebody with chronic kidney disease would be identified. And if that person's kidney disease was then seen as going down, you know,

deteriorating, they would then be referred to a specialist hospital, where they would be seen by a kidney doctor, and then, over time, perhaps left in primary care or maybe stay with the hospital. And if they're unfortunate enough for that to be genuine kidney failure, they would then be taken into specialist care, as in looked after by their hospital for their appointments, and then eventually they may have to go on to dialysis, the transplant list or be fortunate enough to get a transplant or some people may pass away before either of those options were relevant to them.

Q. Would you have expected those people to have been given a choice, for example, as to the form of dialysis and the place of dialysis if that was required pre-pandemic?

A. People should -- first of all, they should be picked up in a timely way, so if there is a decline that can't be addressed they should then have those choices, absolutely, and whether that is dialysis at home, whether that is dialysis in a hospital and whether it's dialysis through your tummy or through your arms -- there's different ways to receive that dialysis. But I would emphasise that it's a life-maintaining treatment.

Q. So during the pandemic, then, I think you observe in your witness statement, paragraph 79, that it was safer

to have dialysis at home during COVID but there was a problem with the obtaining of the surgery to enable people to have that. What was that problem? Could you explain that?

A. So, yes, vascular surgery -- so in order to get the dialysis at home, you would need a level of surgery in order to have the access in your tummy or the access in your arm to the dialysis treatment itself. So trying to get those surgeons to be able to give those choices, some of that was a challenge as well. So that's what I was referring to there, is that while home dialysis would have been safer because you had less need to go out to the hospitals -- just to contrast that, if you're on dialysis, that would be three times a week in hospital for sort of four to six hours at a time, with a journey there and back again, whereas dialysis at home would involve less exposure to other people.

So as with all the things that I've been talking about, there was a bit of a variation on where and how you'd be able to get that access to that surgery, so it wasn't entirely clear to us what happened with home dialysis apart from the fact that there was ultimately a lower level of COVID-19 in people at home, and so that choice may have been affected, as indeed would have been the numbers of people approaching dialysis or being picked up sooner -- because they would have needed care for their kidney failure sooner, they perhaps weren't picked up as soon as they could have been because of the impact of the pandemic.

Q. So, if I've understood you correctly, then, if people were still apprehensive about visiting healthcare places due to COVID, you make the point that those needing dialysis would have had no choice but to go to the hospital and the consequences of that if they didn't would be fatal, would be renal failure; is that right?

A. Well, that's right. If you have kidney failure and your kidneys have actually failed, dialysis is life-maintaining, so you do need to maintain that treatment on a regular basis.

Q. Are you aware of, if you know, how many people died through COVID that were receiving dialysis that were having to visit hospitals? Do you know the answer to that?

A. Yes, I do have some numbers on it. I'm just going to refer to one of my papers, if that's okay, because I've got to get the numbers right.

Okay, so in the first -- between 26 March and 14 April, the UK Renal Registry received notifications of 1,173 positive COVID results from people on in-centre. That's in-hospital dialysis patients. That

represented 5% of the total population on dialysis.

This is a published report from the UK Renal Registry and, as it says, it is "very sad to report to you that the seven- and 14-day mortality at that time was between 11% and 19% [as read]". So you can see that that was -- you know, in those early days, it was quite devastating for people with kidney disease. If I may add to that, with permission, that was across the whole of the UK. I have actually just put out some specific numbers from the Scottish Renal Registry for a slightly different period of time, which was up to 22 September, I think it was from a -- I'll give you the earlier date in a moment -- and they reported 120 cases with 30 deaths.

THE CHAIR: These dates are all in 2020, I take it?

A. That's all in 2020, yes.

MR STEPHENS: Thank you for the clarification as regards Scotland. As you're aware, our remit is obviously looking at the Scottish Government's response to the pandemic.

A. Yes, that's right.

Q. Can I ask you also whether the pandemic had any impact upon the frequency of which people were receiving dialysis?

A. Indeed. So in some hospitals, but I would say that --

not so badly in Scotland, but in some hospitals there had to be a restriction in the amount of dialysis people could give and some people were moved to twice a week dialysis rather than three times a week dialysis because of the ability to care for everybody, to provide adequate isolation for those who were COVID-positive, who had to be moved into a different -- into different units or segregated, if you like, to COVID-positive and COVID-negative people undergoing dialysis. So, therefore, for some periods of time, across particularly 2020 and again in part of 2021, some people had to receive less dialysis than would have been ideal. But I do have to say that in Scotland I don't have a note of people -- of that happening to them in Scotland, but overall that was not a great experience for some people on dialysis.

Q. Thank you. I think you also talk about, in your statement, the delivery of home dialysis equipment. How, in your experience, was that affected by the pandemic restrictions?

A. Yes, I do indeed. So if you are dialising at home, you would need to receive regular tubes, boxes of fluids, lots and lots of reusable stuff, and that would have to be delivered to you. So in a couple of cases that were reported back to us, but I can't tell you where in the

United Kingdom that was, we heard from very frail patients who said that the delivery drivers were not prepared to bring the equipment into the house, so that caused them a problem, which we had to speak back to the dialysis company manufacturers and delivery agents about trying to get all of that heavy stuff into somebody's house in order to provide a level of assurance for the drivers but also for the patients, who would be anxiously waiting for all that equipment, because if you don't have your renewables and your supplies, you can't run the treatments.

Q. You also touch on the issue of procurement and the availability of equipment in your statement at paragraph 110. I think the phrase you use is it "became a huge problem". Can you explain why that was an issue?

A. Yes. So alongside the existing population of people who are dependent on dialysis to stay alive, with kidney failure, COVID-19 had a nasty effect on the -- as well as on the lungs, on the kidneys of a number of people who had COVID. Again, just to be clear, this is in 2020, so it's building up sort of March/April 2020, and in fact some of the data shows that 28% of people affected by kidney -- sorry -- affected by COVID needed dialysis mostly in intensive care units. What that meant was that there was quite a stress on the materials. You know, I've just talked about the materials for home dialysis. Well, these would be materials that the hospital would be using to -- the hospitals would be using to deliver their dialysis.

And there was, you know, a global demand for these products. In fact a note I have here is that the global demand for those products tripled when -- as the pandemic really took over -- took off in Italy and in America, in New York particularly, I remember at that time. And because of that lack of equipment, we had to -- we, Kidney Care UK, raised that with the NHS very, very urgently, and eventually, after a couple of weeks a decision was taken of procurement and distribution to be made across the whole of the United Kingdom because otherwise there could have been a situation where hospital A was in desperate need, ordered all the stuff and then, by the time you got to hospitals B or C, there was nothing -- there wouldn't have been anything left for them.

So by introducing a national procurement and distribution system across the United Kingdom, the equipment was able to be shared appropriately across the country so that nobody would actually lose out, and some new protocols were put in place as well and some additional training for staff so that they would be able

to provide the type of dialysis necessary for people who had acute kidney injury, which is when your kidneys suddenly go down and you very quickly need dialysis treatment. That is different to when your kidneys have failed as part of your chronic kidney disease over a longer period of time.

But, as I said, COVID-19 had that particular effect on kidneys, particularly at the beginning, and it really did need a level of -- an additional level of dialysis treatment to keep people maintained in the intensive care units. So that was something that we were both extremely concerned about but wanted to be able to give reassurance to people who were actually on dialysis for their persistent chronic kidney disease that their supplies wouldn't be affected by the fact that additional equipment or similar equipment was needed for people with acute kidney injury, exacerbated by COVID-19.

Q. Thank you. So on that question of procurement, then, and sufficiency of equipment being available, is that something that you think should be handled differently, could have been handled differently?

A. So I think, again, it's another reflection on the pandemic and it was managed -- later on it became okay, but then I don't think we had quite that acuity. So if

we can see that particular organ support systems are going to be challenged by an infection -- so we saw lungs, the need for ventilators, and then the kidneys as well -- people should learn from this and be able to, if at all possible -- just as we needed PPE, we needed other forms of protection -- to understand that there will be -- this type of treatment could be needed and to deploy some of the learnings we had here, which was sharing across the country, which was training for more staff, and there were also introduced additional techniques, whereby people could be given -- I talked about the dialysis in the tummy, the peritoneal dialysis. There's a technique -- you can do that urgently as well as through the needles in the arm, so that technique was also identified to give continuous renal replacement therapy for people.

So there's about equipment, there's about training and there's about, you know, smart purchasing and distribution approaches as well. And all of those things I think are something to reflect on -- and in terms of innovation as well, because those products aren't made in the United Kingdom, and that was one of the particular things, that they had to be gotten from other countries quite often.

Q. Thank you. And finally on this segment, what was the

decision taken during the pandemic with regards to kidney transplants? What did you notice in terms of the rate or frequency with which they were being undertaken during the pandemic?

A. Yes, so a kidney transplant is a gold standard treatment for somebody with kidney failure. If they are suitable and well enough to be able to receive a transplant, you can receive a transplant from a living donor. I mentioned earlier that was how I got my transplant, from my husband, and that's about one-third of all the transplants. The remaining two-thirds will be from deceased owners, and people are incredibly grateful for that gift of life.

When the pandemic started, really got started, transplant doctors, kidney doctors, were quite concerned because they didn't know what effect having a transplant would have on somebody with kidney failure in terms of their additional COVID -- additional COVID infections or COVID risk because you may -- as I explained earlier, if you were taking some newly immuno- -- some drugs to suppress your new kidney rejecting, that could make you, like a baby, sort of extra vulnerable to COVID, but that of course has to be balanced about the risks you have of having to go to dialysis all the time and perhaps being next to other people who also have COVID and that level of infection, so -- plus our staff, many of the kidney transplant type staff, would be ICU staff who had to be deployed into saving people with COVID in the intensive care units.

So over that -- especially over that first year, a number of the transplant units closed or really slowed down the numbers of transplants they were able to make, only giving them to people who were at the very, very highest risk -- so some heart transplants went along -- or people who were perhaps at very, very low risk, some perhaps younger people who could be eligible but were considered just to have a less high risk if they received a transplant. The overall effect of that meant that the numbers of people waiting for transplants, we still haven't recovered. We're at the highest list -- sorry -- the highest number of people on the transplant waiting list than we've been for -- I think it's nine years now.

So the two transplanting units in Scotland, in Glasgow and Edinburgh, actually did really well. They continued doing some level of transplantation, whereas other units in England had to virtually close. But nevertheless overall, with living donation, because you have two people involved with that in terms of the donor and recipient, and deceased donation, because of the way

in which staff were deployed as well, and the unknown risk of somebody newly transplanted getting COVID or indeed if the donor themselves had had COVID and deceased, meant that the transplant system slowed right down and people missed out as a consequence of that unfortunately.

Q. What, therefore, is your view on the decision that was taken? This is something you cover in paragraphs 101 and 102 of your statement, where you talk about the Scottish Government's response:

"... took a decision [as to] whether ... to pause transplantations except in [the most] urgent [of] cases."

A. Yes.

Q. You then go on to say in paragraph 102:

"Whereas it was sometimes considered, and you will agree or not agree with this, that people who were on dialysis could wait and therefore they would just be waiting on a transplant. This for some was a real risk to life."

Can I understand what your view is, then, on the decision that was taken, whether you think it was right, wrong, somewhere in between? What's your view?

A. I think it's really hard now to look back because, at the time, we didn't know -- we didn't know enough to

balance out those risks and what we now know is that there is a level of -- there are ways in which transplants can be done quite safely, and that's what happened in the later years of the biggest part of the pandemic. But at that time I think some policymakers considered that, "Well, people were being treated. They had dialysis. They could carry on in that way". But we heard from many, many patients, many people waiting and hoping for a transplant, that -- I think there were two things: one, they did understand that the staff were absolutely taken up and they understood perhaps why a transplant wouldn't be right for them at that very moment, but they also didn't know what their situation was. So were they still listed? Had they been temporarily suspended from the waiting list because of the overall COVID risk? And a lot of people came to us with great anxiety about all of that.

So I suppose -- if you ask me now, I suppose we would say that people -- more people could have been transplanted during that period, but in the middle of that I think many people understood -- felt that -- they were so supportive of the NHS staff and what was happening in the transplant units that they did understand that for a period of time. But the communication with them about their risk and about

whether a transplant would have been right for them and whether they should be suspended from the list, that could have been improved. So it's back to that and I think people -- because it came back quite slowly and we had a bit of variation in different parts of the country, I'm still not quite clear what the best thing was to have done with that. But I do think communication could have been better and I dare say that some people -- you know, their opportunity to have a transplant was certainly delayed for a period of time and that's never good. But perhaps we had no choice.

THE CHAIR: Just to remind you, we're getting time-critical, Mr Stephens.

MR STEPHENS: Yes.

THE CHAIR: Sorry.

MR STEPHENS: Finally on this, Ms Loud, you also talk in your statement about the monitoring or check-ups of those who had already received kidney transplants. I think you yourself say that you didn't see a kidney specialist for two years.

A. That's correct.

Q. Again, is that something that your organisation was informed of as happening regularly or was there -- what was the position during the pandemic as to those having their health checked, as it were?

A. So through our surveys, through —— we had I think 11 question time webinars as we called them —— through all those different routes, we had lots and lots of communication with people, like myself, who had transplants and the ability to get a check—up was really variable throughout the country. So some people were able to get their check—ups locally, their blood tests locally ; some people weren't. I wasn't able to get one locally because there was no link between the IT system in my local part of the country and the part of the country where the transplant hospital is , so there was a bit of a —— that was an issue in terms of how IT works and I think some people missed out for that reason.

We did introduce —— "we" —— the NHS introduced much more virtual monitoring —— sorry, virtual meetings and appointments with doctors and patients, and that was a welcome way to approach it but that doesn't necessarily replace a blood test. So I think, again, providing a joined—up IT system, being able to get local blood tests so that that monitoring could continue, even during a period like this , so you don't actually have to go to a hospital where there may be a major infection and wait there for a blood test, that could have been much, much better.

Q. Thank you. Could I move on to shielding, which is

something you've mentioned briefly already but I'd like to just touch on it in a little bit more detail. When those deemed most clinically vulnerable were first asked to shield from March 2020, were those on kidney dialysis included within that list ?

A. No, they weren't. So people with transplants were asked to shield , but, initially , although there had been a press conference when —— and I can't remember whether it was Chris Whitty or someone else said that the list of people who would be asked to shield —— and I think it was around those two days when lockdown —— the initial lockdowns were announced in about March 20 something, wasn't it , 2020, they mentioned people on dialysis, and then, when the shielding list came out, people on dialysis were not on that list .

Now, in Scotland, there was a difference and initially the shielding list showed people on dialysis. However, within 24 hours, people on dialysis had disappeared from the list . I had quite a lot of communication with medical staff in Scotland about whether they knew what was going on and why dialysis had been taken off the list and no one was ever able to give me a straight answer. So I do think that is one of the learnings from the pandemic, is that people on dialysis —— because I've already explained that people

on dialysis could die —— were very vulnerable —— just as people with transplants were, of course —— but people on dialysis were very vulnerable to COVID infections and they did need to have that level of protection from shielding . And it wasn't indeed until October 2020 —— so that's from March to October 2020 —— that people were not specifically named on the shielding list as —— you know, it didn't actually say, "This list includes people on dialysis ".

Q. You've stated that those people on dialysis were vulnerable. Do you consider that something that should have been understood and known at the time when shielding was introduced or not?

A. Yes, I absolutely do that. I do consider that. In fact that excerpt I read to you from the UK Renal Registry report, reporting from those first three weeks of the pandemic about numbers of people getting COVID and also, unfortunately, sadly levels of people passing away with it has well reflected that. And we did work with our medical colleagues to find ways round how people could be listed as shielding and in a number of cases it was the doctors and the specialists who wrote to their patients to say to them, "You should shield. You are able to shield".

But because —— you know, if it doesn't say your

condition on a public list that you see, then people can lose out, and people did lose out because they would have not been able to receive the food boxes, for example, for which they would have been eligible had they been on a shielding list , and I know that if you're going to hospital three times a week, you can't shield entirely but you could —— there were areas in which people could have been provided additional protection for at that time, which were employment protection, as I say, access to food —— to shielding boxes or just supermarket priority deliveries , for example. Those would have been things that people could have had and they didn't have at the beginning, and it was only a little later in October when guidance was officially changed, but there were nevertheless many doctors and specialists who did write to their patients and explain to them that they could be considered as shielding and that should happen to them.

Q. Did your organisation make specific efforts to contact the Scottish Government when those on kidney dialysis were not on the shielding list to begin with?

A. We did, yes. We made a number of contacts with the Scottish Government and via both MSPs and directly with the Health Minister and we received some guidance back about people on —— being on something —— I think it was called "level 7". So there was six -- I can't remember if it was called "level 7" or something else. But there were six kind of categories for which you could shield and level 7 was for people who felt that they should be on the shielding list but weren't named on the shielding list, but that meant you had to know that you could qualify on to a level -- as a level 7 through that route, and of course not everybody would have been able to read that, not everybody -- read it -- would have seen that information, and unless they'd received a letter directly from their specialist, which some people would have done but some people didn't, or unless you were very directly connected with a charity like ours, putting out all the differences in all these different levels and the different ways in which you could qualify as shielding, then you could well have missed out.

I think that is something we'd really like people to learn from, that there is really a vulnerability in people on dialysis as well as people with transplants to infections like this because that's what the data shows us.

Q. Thank you. I was struck by the use of your language. You talked about "ways round" being found if you weren't on the shielding list to begin with, for example,

contacting a GP. What does that suggest to you, if anything, about the consistency of how people ended up on the shielding list?

A. Well, that unless you were in a specifically named category, for those other people, you could miss out and so there was a lack of consistency there. And also what we found was that, if the letters come from GPs, not every single GP would have the full set of information about their patients and their status, and that was probably part of the reason for the inconsistency we found, in fact, throughout the country with people who could have been shielding or perhaps should have been shielding but weren't given the advice and support to do so until it became explicit in October 2020, following a lot of campaigning and some new information that came from something called the "QRISK Analysis" from Oxford.

Q. You mentioned earlier in your evidence about communication more generally, when we were talking about the guidance available across the board, but if I can ask you specifically in relation to shielding, how would -- what would be your assessment of the quality of the communication that was given as regards shielding from the Scottish Government?

A. I would say that the communication that came from the Scottish Government, when people received it, was good.

It was clear and on occasion they listened to some of the things that charities like ours were saying and we got some good feedback about that information, but not everybody got that information and that would be something that, you know, as I said, there is some regret on as well. But I would also say that not everybody received -- as I say, not everybody received that information in good time and there could have been improvements in the way in which it was publicly delivered.

On occasion we were told there was some new guidance coming out, which we very much appreciated -- so the Scottish Government would write to us and say, "This is confidential but the First Minister is going to say it", but we may only have had a couple of hours or an evening to learn about it. So in that instance there was no way for us to feed into it. It was just for us to accept it and place it on to our website and share it with those that we were supporting.

Q. You say there that people didn't receive the information. Can I ask why you think that was?

A. I think because sometimes people weren't on the right lists, whether -- and so sometimes it would be a specialist who would write to that person because they knew that that person, say, was on dialysis, but it

might be that somebody had very late stage kidney disease and perhaps it was thought that the GP should be writing that letter instead and maybe the GP didn't have the most up-to-date information. I think there was a -- there's been a lot of discussion about lists and people having different lists and not necessarily being able to use those lists to write to all -- to get all the different people. And we worked with some MSPs and others to ask questions but it did seem that a number of people -- and we heard this through our Scottish advocacy colleagues -- that people who would have expected to be written to were not being written to or being written to much later than others and we don't know what the difference in that was, but it was probably to do with admin.

Q. So when you say in paragraphs 63 and 64 of your statement, "we tried to improve shielding lists", and the Scottish Government did eventually make those improvements, is that the improvements you're talking about, improvements to these lists? Is that what you mean?

A. That is correct. That is what we were trying to do and that is what we were writing letters to the Health Minister for, sending out briefings on and hearing back from patients with their huge concerns.

And I do remember one of my colleagues -- you know, some of our own colleagues being very, very upset hearing from people who were just -- who themselves were so upset because of not being able to get hold of food, really, really worried about their jobs. These were the impacts of people receiving -- not receiving the information they needed at the time in which they needed it, despite the massive efforts that we all made to either change policy and, once the policy had changed, to get to see that through, so people were getting the information and the vital support they needed.

Q. Thank you. I think you've given a few suggestions already, but is there anything else you'd like to say on lessons learned, specifically as regards shielding, things that you would like the Inquiry to consider?

A. I think it would be really helpful for the Inquiry to consider why people on dialysis were not initially put on the shielding list, to consider sharing information -- and we very much appreciated the information that was shared with us from Scottish Government and the Listening Ear -- but actually perhaps to work with us a little bit more openly so that we can do more sharing of that and further information to make that as rich and as easy to understand as possible. And I suppose overall for

people to -- policymakers to understand that there was always going to be, unfortunately, an additional vulnerability for people with kidney disease to an infection -- a pandemic infection such as COVID-19. But at the same time obviously I do wish to give some thanks to our medical staff and all the systems that did their best, but that doesn't mean that we don't think it could have been improved in some of the ways I've just suggested.

Q. Thank you. Ms Loud, I don't have any further questions for you. Just to reiterate my thanks for your evidence and the Inquiry will obviously take into account everything that's in your witness statement, even if we didn't cover it today in oral evidence. Was there anything else finally you would wish to add that would be helpful for the Inquiry to hear before we conclude your evidence?

A. I think there's a couple of things, if I may. Is it okay for a couple of minutes?

MR STEPHENS: Yes, of course.

A. I know you talked about time. Is that okay?

THE CHAIR: I actually called critical time rather too early. I apologise for that.

A. Okay. Thank you. I just wanted to be clear on that.

Okay, so just a few things. We talked about the

reduction in dialysis sessions. There was something else, which was about eating and drinking bans during dialysis because units were so concerned about people -- if you imagine they're sitting on a machine for several hours, next to somebody else sitting on a machine for several hours, with needles going into their arms, so they can't move very much. So some units, but I can't give you exactly which units for obvious reasons -- but some units we heard reports back that people were not able to -- were banned from eating and drinking during dialysis. For some people, who perhaps lived in difficult social circumstances, sometimes that will be their only opportunity to eat or they might have been given a sandwich on their dialysis session and some patients are quite at risk of malnutrition. So not being able to eat or drink during dialysis was something that we heard quite a bit about and, in the end, some units did adapt their processes to advise that people could take their mask off, have something to eat and drink and then put their mask back on again, for their own comfort and support as well. So that would be one thing to think on.

The next thing was about challenges of transport to and from dialysis, six journeys a week. We actually heard quite a lot from patients during that time that

they thought their transport experience had improved, and that was because, because of the risk of infection, eventually individual -- well, smaller transport vehicles were used, which meant that, rather than having to wait while a little coach -- a van would go around and perhaps collect four or five people to go on to their dialysis and go to the hospital -- collect them from their homes, take them to the hospital -- that, because of transport risk, over time people would be able to receive just one -- a lift just from one person in the taxi or the transport as well, so it was a curious reflection on something that people often marked quite badly in the annual patient reported experience measures. So the individual transport, while perhaps not possible at all times, was much more timely, and that helped their own experience of getting there and back, so that was something interesting to think about.

And that people on dialysis themselves told us through our various surveys that they needed more care and more communication from their teams and they needed additional mental health support. We haven't talked about mental health support very much at all, but I think it's probably quite reasonable to expect that, if you are asked to shield, if you know there's an infection that can really affect you, especially in the times before vaccination, that your mental health might be affected. And I have to say the Scottish Government did do a couple of surveys to look at the impact from that and in its messaging did try to offer people ways in which they could address that. But I think facing that upfront would have been something for the Inquiry to think about as well -- in fact, the longer-term impacts of that.

I suppose finally on that point, which is -- and it's probably out of -- tell me if it's out of scope for today -- I have talked a little bit in my evidence about vaccinations and people being able to access their vaccinations in a timely way, and we did get some support from some MSPs because we needed to -- once the vaccinations became available at the end of 2020, there was a further push for people on dialysis to be able to receive the COVID vaccines. And, at first, people with transplants were prioritised but people on dialysis also needed that prioritisation, and I think that would be a further lesson to learn, is that, because people were exposed to others, they did need to have that prioritisation, which eventually came -- it took a bit of a push -- to receive their COVID-19 vaccinations.

And -- I said "finally", but there is a further

point in that, despite the vaccinations that people received, there remained a group of people, even now, after having received many vaccines for COVID, who are not able to produce the same antibodies as everybody else and for them there does remain, thankfully, a range of treatments that they can receive.

I think that that message perhaps isn't as clear as it could be, although I checked the Scottish Government website. It's still on there, that there are treatments available for people who remain additionally vulnerable to COVID, and while we encourage people to take their vaccines as they're offered and their boosters as they're offered, that there are these additional treatments available for them as well and they should be aware that they're still there and, again, messaging about all of that just needs to be as clear as possible because, for some people, the impact on their mental health of having had to shield -- some people are still shielding because they're still concerned. There remains -- even though this is part of perhaps a sort of learn to live with COVID, but there does remain a risk to them from COVID and still it's prudent to know what the advice is and that there is treatment -- there are some treatments available to support people who contract it.

So there's -- sorry, that was rather long. Apologies. But there's still some lessons to be learnt. Some of that we've described in our evidence and I hope that what I've said today is able to kind of contribute to what was a very emotional time for us, it was a very challenging time for us, and that we did and continue to do and promote the best possible risk-based communications and prioritisation for people who have a level of vulnerability to something like COVID-19 and that we can learn those lessons for future pandemics and minimise the risks, minimise the mental health impacts and be more forward in prioritising people with kidney disease. Thank you.

MR STEPHENS: Thank you very much for those additional points. Thank you.

THE CHAIR: Thank you indeed, Mrs Loud. Very good. About 15 minutes.

MR STEPHENS: Yes.

THE CHAIR: Very good. Thank you.

(2.52 pm)

(A short break)

(3.06 pm)

THE CHAIR: Good afternoon again, Mr Gale.

MR GALE: Good afternoon, my Lord. The next witness and the final witness for today is Dr Claire Taylor.

DR CLAIRE TAYLOR (called)

THE CHAIR: Good afternoon, Dr Taylor.

A. Good afternoon.

THE CHAIR: When you're ready, Mr Gale.

MR GALE: Thank you, my Lord.

Questions by MR GALE

MR GALE: Dr Taylor, your full name is Claire Taylor, is it? Your personal details are known to the Inquiry, your age and your contact details. You've provided the Inquiry with a statement. The reference for that statement is SCI-WT0562-000001. Just for further reference, there is a document that is footnoted in Dr Taylor's statement, and that is an excerpt of an article from The Lancet, a paper from The Lancet, from October 2023. Its reference is the same start, but it's 000002. If we have time, we may look at that, probably fairly briefly, with Dr Taylor in her evidence.

Doctor, you've provided a statement for the Inquiry and we're very grateful to you for that. I think you are content that the statement, together with your evidence today, is your evidence for the Inquiry to consider and that you're content that your evidence is recorded and published?

A. Yeah.

Q. You're a medical practitioner and your academic and

professional qualifications are set out in that section of your statement headed "Background". We can read those. You have a Honours degree in neuroscience from Edinburgh University and a degree in medicine from Dundee University?
A. Yeah.
Q. You have a background as a general practitioner and I think you've practised in various locations in Scotland over the years. When the pandemic began almost -- well, exactly four years ago, you were working as a GP both for a local health board and for individual practices; is that right?
A. Yes.
Q. Now, you're here, Doctor, to provide the Inquiry with your experience of treating patients with long COVID, so I'd like to understand how you came to be involved with the treatment of long COVID. But before I do that, can I just ask you to go to the end of your statement and to paragraph 146? So that we have a little flavour of what you're going to say, you say that, "no other doctor is doing what I've been doing for several years now", and that's in the context of long COVID?
A. Yeah.
Q. And you say:

"... I must have seen the most patients in Scotland

with Long Covid ..."
A. Yeah.
Q. You've said you've never been consulted on any decision-making and I think you found the exercise of providing this statement for the Inquiry quite informative because you've said that you've "been asked more questions in this interview than I've ever been asked before".
A. Yeah.
Q. So, with that perspective, the information that you're giving to this Inquiry is, can we say, probably the most comprehensive account of treating patients with long COVID that you have given --
A. Yeah.
Q. -- in public?
A. Yeah.
Q. Thank you. Now, just in relation to your background and how it assists in your treatment of long COVID, at paragraph 12 of your statement you indicate that in October 2020, so we're into the pandemic, you applied for a job working for the ME Trust, and can you explain why you did that?
A. So I had done various specialties throughout training and as a doctor and I was particularly interested in people who had symptoms of what appeared to be

a rheumatological disease, inflammatory disease, but bloods were normal and patients -- but they were very unwell, and ME is one of those diseases. So when this job came up in 2020, I was already seeing people who had had COVID who had not recovered and thought it would be a good job for -- a good fit for me and to see if I could help these patients.
Q. And the work that you were doing for the ME Trust, I think you tell us in paragraph 13, was for a year.
A. Yeah.
Q. And you were working one day a week online --
A. Yeah.
Q. -- and looking at the overall condition of patients?
A. Yeah. So even though it was online, there's still a lot that could be done. Actually a lot of these patients couldn't access NHS care. This was through a charity, obviously, but they couldn't access NHS care because they're housebound, a lot of them. And when you're housebound, if you're then sent an appointment for, I don't know, a cardiology appointment at the hospital, that could be a major -- major difficulties in accessing that care. So I could take a full history, go through what medications people were on, and I could get them to do some simple tests at home and get the results back, and from that make a plan to try and improve their

condition. So quite a lot could be done, even though it was online, and there was a long waiting list.

This had existed -- before I obviously did that job, somebody else did that job, but it originally had been a hospital and over the years it had been downgraded into a service where people could consult online. But years before it had been set up by [redacted], who is now retired.
Q. That's my fault. I should have mentioned, Doctor, please don't mention any other names.
A. Okay.
Q. I'm sorry. We'll just have to pause for a moment.
(3.13 pm)

(A short break)

(3.17 pm)
THE CHAIR: Right. All sorted?
MR GALE: Yes.
THE CHAIR: Good. Thank you. On we go, Mr Gale.
MR GALE: Doctor, we were talking about your involvement with the ME Trust. When you applied for that job and thereafter when you had it, were you also seeing patients, in your capacity as a GP, who had symptoms of post viral infection from COVID?
A. Yes. So I had a mix of patients. I had patients who had maybe had ME for a long time and then I had patients

who had had COVID, who weren't getting better, as they'd expected, and had looked to see what was available and saw me either with the ME Trust or in my own practices. They would seek me out. But, yes, lots of patients in 2020 and into 2021/2022.

Q. You tell us at paragraph 15 that you noticed that ME patients and those who had COVID had quite similar autonomic and allergic problems as part of what was wrong with them. Can you just explain what "autonomic" means?

A. "Autonomic" is a word that is similar to "automatic", so your body does something that you don't have to control, like your heart beating or -- you're not consciously aware of that, and it can be connected to your brain and the signals between those are autonomic.

Q. And what were the similarities?

A. There was a higher prevalence of a condition called "postural orthostatic tachycardia syndrome" --

Q. That's PoTS, I think.

A. PoTS, yes -- and that was very obvious to me, very early on, that these patients shared PoTS in common and also that they were more likely to be allergic to things -- randomly they could be allergic to things. Their immune systems were overreacting to things they wouldn't usually and they also had post-exertional malaise, a lot

of them. So in common there was these particular features.

Q. Right. Now, you had also -- I think we can see this in your background -- you have some experience of cardiology and also rheumatology; is that right?

A. Yes.

Q. Were you able to bring those experiences to bear in relation to these patients?

A. Yeah. So I supervised what's called tilt testing in Dumfries and Galloway, it would be about ten years ago now --

Q. Can I just pause you there? Can you tell us what tilt testing is?

A. So tilt testing -- PoTS is when the blood in your body should -- when you stand up, it should go up to your brain and that should happen automatically, and if it doesn't, the blood is not getting to your brain and your heart rate speeds up. And one way of testing it is with a tilt test, where you attach somebody to a bed and you essentially tilt it up and you watch what happens to the heart rate. It's fairly niche to be supervising those tests and it just happened on one of my rotations I was supervising, so I knew about PoTS, and I would say that it's not as well known about in medicine as it should be or could be. I already knew about this condition and

recognised it very quickly.

Q. In relation to those people who are presenting symptoms post COVID infection, was PoTS an issue?

A. A massive issue.

Q. I think you've given an indication of I think 80% of your patients -- you identified that as an issue with them.

A. Yeah, and the prevalence in research papers would be between 40% and 80%, depending on what group of patients you're looking at post COVID. But certainly the patients that I've seen, most of them have PoTS that hasn't already been diagnosed, so they've often had it since they've had COVID and it's not been diagnosed in these patients.

Q. Right. You tell us also at paragraph 19 that you attended your local health board meetings on what to do about long COVID and gave your own perspective. Now, just before I ask you some questions about that, the term "long COVID", when did that start to assume prevalence in medical parlance, if I can put it that way?

A. So the term "long COVID" was coined by patients mid-2020 --

Q. Right.

A. -- and there are other terms used in medicine. "Post

acute COVID syndrome" is one of them, but "long COVID" has stuck, as it were, as I would say the term --

Q. It's a simple term.

A. Yeah, it's a simple term that I think everybody understands.

Q. Yes.

A. Yeah.

Q. Okay. So you were providing your own perspective at health board meetings and you tell us that you were cautioning that physiotherapists and occupational therapists were burning out. Can you explain why that was happening?

A. So patients were referred -- and every health board is different -- the one I was in, the patients were referred directly in from their general practitioners. So they might have had some blood tests, they might have had a chest x-ray. What they hadn't had was a full physical history, examination and investigations by somebody who knew more about long COVID than they did, and physiotherapists were trying to work with people who had PoTS, who every time they stood up their heart rates doubled and they couldn't do the rehab they were being asked to do. That's very difficult for those physiotherapists because they could recognise the problem but there was nobody there for them to ask for treatment or advice, so they were essentially trying to rehabilitate people with the rehabilitation model who needed more medical input first.

Q. And you tell us that you were met with the comment -- which I think is probably apocryphal, but you've given it -- "People just need to exercise".

A. Very common --

Q. Who were you getting that response from?

A. So from other doctors, that these patients weren't trying hard enough, that they just needed to get back to what they were doing and build it up and they would be fine after that and they didn't need anything else.

Q. At that time and in your view, was exercise beneficial to patients who were presenting with these symptoms?

A. No, because we know from ME and the change in the NICE guidance in 2021 that exercise was taken out of the NICE guidance for these patients, graded exercise, because they found, when they re-examined the studies, that it wasn't beneficial and could be harmful. And given many of the long COVID patients, about 50% of those, meet the ME criteria, that they were unlikely to not only not benefit but for it to be harmful without it being properly supervised and, you know, individualised plans for people. So it may not be the case for every single patient, but certainly for at least half of them it

could be potentially harmful.

Q. So, as a piece of generalised advice, to effectively get out and exercise was not particularly helpful?

A. No.

Q. And I think you say that this has since been confirmed in studies. You haven't given the details, but you've obviously seen these studies.

A. I have. I've seen -- the most recent one is in about one-third of patients that they studied, there was muscle necrosis, which meant that the muscles were breaking down and dying after exercise, and it was about two weeks for those muscles to regenerate.

Q. You do tell us -- and don't worry about naming this individual in the next paragraph because it's an individual who is well known -- you were at an awards ceremony for Long Covid Kids and you say that you're one of their champions.

A. Yes.

Q. We'll come to long COVID in children at a later stage in your evidence, but at that ceremony you spoke to the then Health Secretary, Humza Yousaf, who is now First Minister obviously, and you gave him certain advice and information. Can you tell me what you told him?

A. So we had a chance before the ceremony to mix and I said

that the model that we had for long COVID patients wasn't working and wasn't going to work, which was the model of sending people to physiotherapy and occupational therapy without a medical person involved in that, and he listened and said, "We should have a chat some time properly about it".

Q. And did that subsequently happen?

A. So I did have a chat with him, with Helen Goss of Long Covid Kids, and she and I both put the same point across in the meeting in 2023. But it was a proper meeting to talk about the model of healthcare and also about the dangers of COVID and what it can do to the blood vessel system. So we also discussed that and my concerns about the effect on the population of repeated COVID infections.

Q. Now, with this basis of experience, you set up your own long COVID clinic and we can read about that. First of all, why did you decide to do that?

A. So having attended health board meetings and tried to put across that I felt that having a doctor that knew about conditions like this -- and, having worked with the ME Trust, I felt I had that experience -- to see if that worked better, when the money was awarded in 2022 for health boards, there just wasn't the money for the area to employ a doctor to do that. At that point

I realised I'm either going to just not do any work at all on this at all or stick to my own practice where I might have, you know, half a dozen/a dozen long COVID patients and that's it. The only other way to do it would be to set my own clinic up and see what happened. So I just sort of did it and thought, "I'll see what happens", and very quickly booked up for six months fully with patients desperate to be seen.

Q. How was your identity made known as somebody who is providing this service?

A. I think it was mainly patients telling other patients, you know, "I've seen this doctor and she can offer more than ..." -- I've never advertised my services. It's just sort of known that I can -- I have my long COVID clinic, I also see ME patients there, PoTS patients, and I have this clinic and patients find me.

Q. The clinic is private; is that right?

A. Yeah.

Q. How does that sit with your general philosophy towards the provision of healthcare?

A. So I grew up in a household where we probably couldn't have afforded to go to private healthcare and I wrestled with it a lot because I really believe in the NHS and free healthcare for all, but it was either nothing or offering something. So in the end I thought, "Well,

maybe I can do this and maybe the NHS could learn from this and maybe I could help implement it". But doing nothing, to me, was worse than doing something. But, no, it didn't sit well -- it doesn't sit well, but currently still it's the only way I can provide those services.
Q. You personally have had COVID several times?
A. Yeah.
Q. How many?
A. Six.
THE CHAIR: Excuse my breath, but that's an awful lot. It seems so high. Ignorant --
A. I think occupational hazard.
THE CHAIR: Is that what it is?
A. Yes, it's part of it, I think being a doctor, and we were around a lot of COVID.
MR GALE: I'll come to symptoms of COVID in a little with you and we've heard -- I know you are aware -- we heard from Mrs Ormerod this morning about symptoms, so we will look at that in due course. But can I just ask you from your perspective what effect treating patients with long COVID has had on you? And I'm not talking about being repeatedly infected with COVID --
A. Yes.
Q. -- just upon your ability to do it.

A. So the effect on the patients?
Q. No, on you.
A. Oh, on me. So I do all of this on my own and I don't have much administration support. I have very desperate patients who are about to lose their jobs, who might have to retire early, who need support, so I'm supporting lots and lots of people all at once. So, yeah, it's -- I've taken on a lot, I would say, as a person.
Q. You do touch on this at paragraph 129 of your statement, and this is in the context of mental health impacts. You do talk about the need to protect your own mental health.
A. Yeah, so --
Q. How do you do that?
A. I'm very lucky in that, because of social media, I've managed to make connections with other doctors who are interested and want to learn about long COVID and to help people, and so I have lots of people that I can speak to and -- that I hadn't met before I started working with long COVID. So there's always somebody at the end of the phone. Especially if you've had a very difficult case and you work on your own and you might have had a -- you know, an upsetting consultation, there's always somebody that I could speak to.

Q. I think that's possibly the point I'm wanting to get from you, Doctor, is that some -- as you put it, some of the horror stories that you hear are clearly very distressing and I'm just interested as to how you cope with those.
A. I think I cope with it because I'm a doctor and I need to help them and that's my -- that's my job. So as a professional, that's my job, to help these people in their time of need.
Q. How many patients do you see a week?
A. So it's around 16 per week and they need a lot -- I need an hour with each person to see them.
Q. And what does a consultation with you involve?
A. So it can either be in person or by videolink, and I do a full history of, you know, before somebody had COVID, what their life was like, the symptoms of COVID, what they've had since, any investigations, examining them, checking if they've got PoTS and then going through a treatment plan. So it usually takes about an hour and then they get a letter back to their doctor, their GP, with what we've talked about and a plan and sometimes referral on to other people.
Q. Right. So you -- well, you don't refer back. You report back to the patient's GP?
A. Yeah.

Q. Will the patient have come to you with a diagnosis of long COVID or are you the provider of that diagnosis?
A. Most of the time they have a diagnosis from their doctor and they've been on waiting lists for NHS services and are still waiting or they've decided they want to see me because they've heard about me. But, generally, they've got a diagnosis. Some people, it turns out to be another diagnosis, so that's part of the job as well, is making sure they've definitely got long COVID. But I would say most people have the diagnosis or are looking for confirmation of that diagnosis sometimes too.
Q. Are you in a position, having made a diagnosis and I suppose depending upon the nature of that diagnosis, to offer treatment to that patient?
A. Yes. So there is -- although none of the guidances that we have have treatment in them, there are treatments for some of the problems that the patients have, like PoTS, like the hyper-immune -- so their immune system being overactive. There are treatments from other conditions that we can draw from. You know, there's treatment for fatigue in MS, for example. We can draw from that. So there are treatments that we can use. They just aren't in the national guidelines yet because they were made a couple of years ago and they've never been updated.

Q. What about referral to specialists? Do you do that?
A. So you can refer from private into the NHS. That's in the NHS constitution. So it would be depending -- most of my patients don't have much money so they're not the usual people that would be accessing private care and they don't have the money for lots of referrals and tests. They don't have private insurance. So if they, for example, are having chest pain, then I would refer to a cardiologist and say, "Could you please investigate this chest pain? In particular, make sure it's not this" or "Have they got myocarditis?", for example. Sometimes the GP will do it but I try to do as many as I can. Some specialists haven't accepted those referrals because they are from a private provider and not NHS.
Q. One of the things we heard from Mrs Ormerod this morning was one of the difficulties in a GP referring on a patient with, as she put it, a myriad of various symptoms is to identify the specialist to whom that referral should be made, and she used the word, "This does not allow for a holistic approach". Is that something that you recognise?
A. Yes, so like -- I said, if they've got chest pain, cardiology; they're short of breath, respiratory; neurological symptoms, neurology. And these

professionals don't tend to communicate with each other and what you get is patients that go to different clinics after a different length of time with a, "It's not this, it's not that". That's usually the outcome, is, "It's not this, it's not that". Not everybody gets all of the investigations that I think they should have. So, in relation to chest pain, for example, they might just get a phone call and that's their appointment and not have any investigations done, so they come back often no further forward than they were at the start of that.

So there isn't one person or a group of people working together, looking at that one person and what might be causing their symptoms, and some of the things that can cause chest pain in long COVID can be serious. So there can be blood clots, there can be inflammation of the heart. So it's not -- you're looking for serious outcomes of this disease, and without people communicating together, the cardiologist might say, "Well, it's not myocarditis", but then you might have the question, "Well, is it a blood clot?", back to the different specialty.
Q. Okay. Sorry, there was one point, and it's my fault. I should have asked you about this earlier. Paragraph 11 -- you don't need to look at it -- but you

do mention there that you sit on an advisory group for long COVID run by the World Health Network.
A. Yeah.
Q. Can you just tell us a little bit about that?
A. So the World Health Network has a group of doctors like myself who are interested in COVID and long COVID and we meet every two weeks to discuss research. We are currently writing a paper on treatment and we've given public talks on it for the public if they're interested, and we've done a variety of public things for people to learn more if they want to.
Q. I think you specifically mention that it's an apolitical organisation.
A. Yeah.
Q. Is there any significance in saying that?
A. I think they just present the science as the science is. That is what I mean by that. There is no --
Q. There's no overlay?
A. No. What we present and what they present is what the science is telling us, and that's what's presented to anyone that's interested in learning more about it.
Q. Okay. Can we turn to some of the specifics of long COVID? Now, Mrs Ormerod, this morning, in her statement, provided us with the World Health Organisation definition of long COVID. You would be

aware of that. Is that the accepted definition of long COVID now?
A. It is. The only differences you sometimes get with definitions is the length of time.
Q. Right.
A. (overspeaking - inaudible).
Q. So the months referred to.
A. Yes, so the ONS study that was monitoring long COVID was four weeks, for example -- ongoing symptoms post four weeks. Then we've got three months for the WHO. So I think they accepted it's usually three months, I would say, if somebody's not better in that time, that you can call it "long COVID" because a proportion of people will recover in the first few months.
Q. Right. One thing I'd like your thoughts on -- and it's something that we've addressed with a number of witnesses but I'd like your thoughts on it -- and that's the scepticism that surrounded long COVID, particularly in the early days of the pandemic and which may still exist. As a medical practitioner with a degree of expertise in treating long COVID, do you have any comment to make on that?
A. I think this is a -- comes from what's happened with ME/CFS, over the years of the history of it being psychosomatic, eg it's in somebody's head, and I think

it's a follow-over from that because it's similar, it's post-viral -- a lot of ME is post-viral -- and for many, many years patients have been treated like they either haven't done anything to help themselves or they're not really that ill or it couldn't possibly be that bad or people think they're the type of person that would get that sort of disease. So there's a lot of stigma around post-viral illness and it would have been highly expected from the SARS-1 incidence that lots of patients wouldn't recover.

Q. You mention stigma on at least one occasion in your statement. I now can't actually find where it is so apologies, but you do mention it.

A. Yeah.

Q. Is that stigma a difficulty, first of all, for patients themselves?

A. Absolutely. I think it causes them problems with work, it causes them problems with accessing healthcare, with maybe friends and family, and, if you look at the way long COVID is written about in the media, depending on who is writing it, you can see that, that they are not taking it seriously, that these patients are extremely unwell and can't do the things that they used to do. So definitely for the patients, I would say having a diagnosis of long COVID can be very difficult for

them.

Q. Is the stigma still the same now as it was, say, two years ago?

A. I think it's still the same, yeah.

Q. We heard from Mrs Ormerod this morning -- she referred to the stigma in particular in relation to children.

A. Yeah.

Q. Now, I know you don't treat children or you don't treat anyone under the age of 16 --

A. Yeah.

Q. -- but, from your own perspective and your own knowledge, is the stigma attached to children with long COVID particularly damaging?

A. Absolutely. I might not treat them until they're 16, but I've got their history when I see them at 16 for maybe the last couple of years of their illness and they've had the same thing said to them. Patients will tell me what they've had said to them; "I've been told that I need to just get back to doing what I was doing". But they can't get back to what they're doing, which might be school, for example, because they're too unwell. And in that age group, telling these children that they just need to try harder when they've had a virus that has multi-system effects and then nobody has treated those multi-system effects I think is

particularly damaging for them and their trust in healthcare.

Q. Thank you. Can we look at some of the symptoms, please? And, again, we had the benefit of Mrs Ormerod's evidence this morning -- I think you were aware of it -- and so she described some of the symptoms. You describe them at paragraph 44 of your statement, and I'd like to look, please, at the first three of those. The first is extreme fatigue.

A. Yeah.

Q. It may well be that I suppose post-exertional malaise is attached to extreme fatigue -- that may be a manifestation of it -- but how do you categorise or characterise "extreme" when you're describing fatigue?

A. So with ME/CFS there is a severity scale but there isn't for long COVID. However, the most extremely fatigued patients I have could maybe tolerate 10 seconds of talking to somebody for a whole day. The most extreme are in darkened rooms. They have to cover their eyes for the light. They can't get out of bed to go to the toilet. That's the level of fatigue people can have. You have a spectrum of people who might be mildly fatigued in that they are not able to do what they wholly used to do before COVID, but most of my patients would fall into the category of housebound or nearly

housebound or bedbound.

Q. We'll come to housebound because you have a section on that, but post-exertional malaise, PEM --

A. Yeah.

Q. -- we've heard some evidence I think -- there's reference to it in Mrs Ormerod's statement -- about people feeling so fatigued that, after putting a pan on the cooker, they forget about it or they're unable to go back to switching it off. Is that an instance of post-exertional malaise?

A. I would say slightly different. So post-exertional malaise can develop immediately or in the next one to two days after activity --

Q. I see.

A. -- whereas that would be their cognitive --

Q. That's cognitive.

A. -- a cognitive problem if you're forgetting. But the post-exertional symptoms can last for several days after an activity.

Q. I think in your statement you say that, for some people, PEM can even be triggered by talking or sitting up.

A. Yeah. So I would -- you know, anybody with long COVID who gets post-exertional malaise -- and what tends to happen is they get COVID, they're not getting better and then they might try and go back to work, for example, and they find that they might manage that day they've done and then they're in bed for three days afterwards and they don't know why they've suddenly not been able to manage a day at work, for example. But for others it can be -- you know, for these very severe patients, as simple as sitting up can actually make -- everybody will get a different experience of post-exertional malaise, and some patients tell me it feels like they've been poisoned, other patients tell me that it's like having the flu and for others it's just they cannot do anything. The energy systems of their body isn't working properly, down to the cellular level.

That's -- what it has in common with ME is that these patients -- in most of the ME diagnostic criteria is post-exertional malaise, as having to have that to have ME. That's why about 50% of long COVID patients meet the criteria for ME because they have this post-exertional malaise.

But "malaise" is a funny word to describe it given just how unwell people can feel and it isn't tiredness. I think what I gather from it is like their entire body is dysfunctioning and, you know, if you got it today, you might take yourself off to hospital type of level, but they know now what they've got wrong with them, and in the early days they might have went to A&E, saying,

"I don't know what's happened to me. My heart rate is 160 beats per minute. Why is my heart doing this?", and then they've learned over time that this is part of their payback for maybe doing something the day before.

Q. I think you do mention in your statement that one of the concerns you have is about the nomenclature of "fatigue", somebody describing what somebody has -- who has long COVID as having "fatigue", almost to the extent that that expression tends to diminish its significance; is that right?

A. Yes, it's very difficult, the word "fatigue", because it may be taken to mean being tired but it isn't the same tiredness that people get because they've had a busy day. It's this person might wake up as if they haven't been to sleep. And I've heard it described as -- you know, as if you've not slept for a week and just woken up. So I think the term "fatigue" is a difficult one, although there isn't really another one to put in its place, but, you know, in this context it doesn't mean tiredness.

Q. Now, the point you make on that is at paragraph 89 of your statement, and this is where you're dealing with issues that are difficult to treat, but I think you make the point that "fatigue" is a terrible word for this condition --

A. Yeah.

Q. -- and you believe deliberately used to make it seem less serious.

A. Yeah. If you look -- we have to look back at the history of ME/CFS to see why the term kept changing. So it started out as "ME" and then it was replaced by "chronic fatigue syndrome" and then later on -- there have been lots of campaigns over the years. Now most people would use the term "ME/CFS". But chronic fatigue syndrome, on its own, there is a history of why that happened, going back into the 1990s/early 2000s, and certainly it appears to be that it was to make it seem like it wasn't a disease that might stop you from being able to work, for example.

Q. I think again in this context you do express the view at paragraph 90 of your statement that you "believe most patients have got inflammation at some level in their brain and the fatigue part, it's not tiredness, it's an actual inability to meet the set amount of energy required for daily activities as a human". Can you explain what you're saying there and how that can be tested?

A. So there have been tests done on inflammation in the brain, many, many research papers, and the tests that we use in clinical practice such as MRI scanning will not

usually show this up. But there was a study done by a private group in America who looked at PET scanning and they also looked at the blood vessels in the brain, and they found that, in the long COVID patients, in about a quarter of them, that they had inflammation in multiple areas of the brain, doing multiple functions.

There have been studies that look at the population and, since COVID, following up these patients, who were just -- in the UK Biobank, it's a biobank of patients -- a drop in IQ. There's been grey matter loss. We know that COVID can affect neurons. So I think if we extrapolate what we know from these studies, although we can't currently put that person through a scanner, we know from the research that they do have inflammation in research study.

Q. Right. I'm going to move on to cognitive dysfunction now. I've probably confused matters by talking about putting a pan on a cooker, and that's a more cognitive dysfunction than post-exertional malaise, but -- or in my case, probably disinclination.

A. To be fair, if you've got post-exertional malaise, you're more likely to leave the pan on the cooker.

Q. Cognitive dysfunction, how does that manifest itself in the patients that you're seeing?

A. Many of my patients have to bring notes to appointments, write everything down, so they can't actually remember their own medical history. They will tell me about how they are trying to function and they can't find the words they're looking for, so they'll word-search and they'll give the wrong words for things. And I would say that, even just watching a patient, if you're on video, you might notice at the start of the call they're talking normally and by the end their face has just dropped and they just can't remember and they get really frustrated because their brain just isn't firing properly.

Q. Is there a treatment for that?

A. There isn't a treatment for inflammation in the brain as such in long COVID but there are medications that help to reduce inflammation and in some patients simple things like antihistamines have helped with those symptoms.

Q. You say at paragraph 92 in relation to cognitive issues that they're "very hard to treat" and you make reference to the use of a referral to neuropsychologists, who "do ... detailed assessments but there are long waiting lists so most people haven't seen [them] even after 4 years".

A. Yeah, and that's to characterise which bits of their function they've lost because they might have

a responsible job where they may need to have that function to do their job, for example. Most people haven't had that done and you can -- the other way you can sometimes treat cognitive issues is by treating their PoTS because you're talking about blood going to the brain. If blood's not going to your brain, you're not getting enough oxygen to your brain, you're not getting enough nutrients to your brain. That's another way of doing it.

But if we have virus still in the brain -- and we don't know yet what we're dealing with here -- how do you treat that? And we don't have answers to those sort of questions still. And detailing what patients have with a neuropsychologist at least allows them to -- for example, if they need benefits or work adjustments, to say, "These are the bits that I can't do". And currently all they have is -- what they can tell people is that they're -- you know, they can't order their work or they can't remember to take the pot off the cooker.

Q. You make an interesting point at paragraph 92 that some people who have cognitive issues may be reluctant to admit to them.

A. Yeah. I mean, if you think about people's livelihoods -- and they may not be able to do their job if they've got cognitive issues, so it ties in with

livelihood and being able to support -- people supporting their families.

Q. It may be useful to talk about some of the examples of extreme fatigue that you've encountered and perhaps we can do this under reference to that section of your statement under the heading "Bed bound patients".

A. Okay.

Q. Now, you've, I think, already mentioned that there are patients -- and you put it by saying that they may be of all ages -- "who cannot tolerate any noise, or light, need a commode for the toilet, need tubes for feeding", and their carers come to you to obtain advice, I suppose. So within the cohort of your patients, how many people fall into that sort of category, that they can't tolerate noise or light?

A. There's many that have light and noise sensitivity but the ones that are bedbound and not able to tolerate it at all is probably about a quarter of what I see. So it's not the majority, but there is -- you know, I probably see more than anyone else of these unfortunate people who can't tolerate it at all, but a lot of long COVID patients will have light and noise sensitivity as part of their illness but not need to be in a darkened room as such. But these people, I would say probably about a quarter.

Q. You describe it in paragraph 66 as a "living hell" for a lot of those patients.

A. Yeah. I don't know how they bear it, especially when they don't have very much support or input. I don't know how their carers bear it because it's not just a few weeks, it's not just a few months. It's years and years and they don't know if they're going to get better.

Q. You do give one specific example, which I think perhaps brings out some of the extremity perhaps of the difficulty for people with this condition and for their carers in paragraph 69, and you talk about situations where people may have parents in their 70s or 80s and are dealing with adult children who are in -- have long COVID to the extent of being bedbound. You give the example that those parents may have to hold bags to the bed so that the patient can defecate into the bag. Is that something you've come across?

A. I have a number of situations of what were independent adults who were working, had their own house, have had to move back with their parents, who are elderly, because they've lost their job with long COVID, their condition has got worse, they haven't had any help, and resulted in these sorts of situations where they are too unwell to get up from the bed and their parents do have to help them go to the toilet in the bed. And I've seen some of these people —— I don't often speak to these patients because they're too unwell to speak to me, but their parents, who are doing this often in their 70s, sometimes in their 80s, are completely broken doing that.

THE CHAIR: Can I ask a question which at one level is extremely simplistic. You said earlier on in your evidence that many patients consult you either face to face or online, they've heard about you by word of mouth, they have perhaps —— I think in fact you said they've seen general practitioners who have either sent them to a specialist for an inappropriate specialty or have declined to refer them to a specialist.

Now, I can understand that. That all makes sense. But what you're describing in paragraph 69 is people who've got really very extreme symptoms on any view, and I would have thought —— this is the simplistic part of my question —— I would have thought people with symptoms as extreme as that would have been seen not only by GPs, frankly, but would have been referred to —— and of course I don't know what the appropriate specialty would be —— but an appropriate specialty or a specialty who would at least willingly look at them.

A. What often happens is that they get unwell very quickly

and then they can't get to those appointments and there aren't teams that go out to see them. So it might be that they should see neurology, for example, but how do they get there? How do they get the scans when they can't stand any light and sound? So if they have a gradual decline, they might have seen the specialties, but if they've very quickly declined, there isn't a service that goes —— takes them.

THE CHAIR: I understand that, but if someone had symptoms as extreme as that, particularly I would have thought if they came on suddenly, they can either themselves or whoever is with them phone 999, frankly.

A. So often they will have presented over and over again to A&E with their symptoms and I've said elsewhere in the statement that they might be told they've got anxiety, that they —— you know, that's the problem, they can't possibly be this ill, and I think there's a lack of understanding in medicine just about how unwell people can be.

You could admit somebody to hospital for investigation and some of these patients have. However, many are concerned that they'll get worse being in a hospital environment because they're going to need a side room, they can't stand the noise. The noise to these people is excruciating. Their brains are so

sensitive. So they might be in a position where, even if they were offered, "You could go to hospital for a week and have a number of tests", that they wouldn't want to go because it would be too painful.

THE CHAIR: Right. Sorry, Mr Gale.

MR GALE: Thank you, my Lord.

I'd like to ask you a little bit about your patients and, just to be clear, please don't mention any names.

A. Of course.

Q. You wouldn't ——

A. No, I wouldn't.

Q. —— in relation to confidentiality, but please don't. Just in relation to your patients, you say at paragraph 48 that your patients don't come to you with one symptom, they're coming with a full package of symptoms.

A. Yeah.

Q. Is that the standard presentation to you?

A. Yes. So you can define "long COVID" as "persistent symptoms after a few months", but what I see isn't one symptom, it's everything. The fatigue, the post-exertional malaise, the headaches, all of it. It seems to be, if you get one of these things, you tend to get more than one thing.

Q. At paragraph 50 you say:

"The story invariably starts with [the situation] pre-COVID ..."

And you give a quote:

"I was well and doing lots of exercise. I was working in a job full time and then I got COVID and then I didn't get better."

A. Mostly that's what I hear. I've heard it hundreds of times over, the same opening sort of statement of what's happened to them.

Q. And so far as pre-existing conditions are concerned, I think one of the things again we've heard is that —— certainly in some of the comments that have been made about those people with long COVID is that, "Oh, well, you must have something wrong with you and this is why COVID has exacerbated your condition".

A. Hmm-hmm.

Q. What do you respond to that?

A. Certainly at my clinic that's not what I see. I see people who generally haven't been on any medications or had any health problems. Maybe they might have had a bit of mild asthma or hay fever, but certainly not what I see in my practice is people who have had pre-existing conditions that COVID has made worse.

Of course it is possible to have a pre-existing condition that COVID makes worse, but the actual, as you say, package of long COVID, the multi—system —— the people I tend to see are people who were well beforehand and didn't really know that this could happen to them with COVID because they were told it was mild and they were unlikely to be hospitalised or die. And I'm not sure that most of these people realised that this could happen to them because they were previously well.

Q. Mental health is an issue I'd like to ask about. Paragraph 51, you say very few of your patients have any previous mental health issues or are on any medication when they come to you and you then develop this at paragraph 127 of your statement and you say:

"I genuinely don't think most of them have very deep mental health issues but I think they have a fear of being told that they are mentally ill as the cause of the illness."

A. Yeah.

Q. So probably two different perspectives there. One is patients coming to you with long COVID, and they generally, as I understand what you're saying, are not patients who come with previous mental health issues?

A. Most of the time not. I always explore how people are coping with their illness, given it's a multi—system illness, and they generally haven't had any previous mental health issues. And often, when they went to

their doctor to say they've had COVID, they've not got better, they've got X, Y and Z symptoms, are told, "Well it's anxiety", and they will sometimes be diagnosed with anxiety when they don't have anxiety, they have PoTS, for example.

As time goes on, I think the illness gets harder to deal with —— you know, patients who have been unwell for four years, coping with that, and I think that it would be natural in that position to, you know, struggle with motivation or how —— your moods and how you're feeling when you've got a disease that people don't understand and there's no help for. But, generally, what comes to me is people who were working, had lots of activities, social life and weren't mentally ill, but they do often get then told they have a mental illness instead of long COVID. Eventually, when they don't get better from that, then they get a diagnosis of long COVID.

Q. Right. Just in terms of the gender of your patients, you tell us at paragraph 54 —— and Mrs Ormerod has already made this point this morning —— that this is a condition that appears to predominantly affect women.

A. Yeah, so any of these diseases that are what we would say "inflammatory", so the immune system overreacting, are more common in women. We know that when people are pregnant, that they may well get a relief from their

symptoms, for example, in conditions such as lupus. So we know that there is an effect of hormones on these types of diseases and we know that women are more likely to get these types of diseases because of their —— partly because of their hormones but also because of their gender, that there is something about women that is more likely to have an auto—immune/inflammatory—type disease.

Q. All right. I think you also say that, with the scepticism that may exist in relation to long COVID, there may be another element to that, which is misogyny.

A. Yeah.

Q. Is that something you've come across?

A. It is. I've had patients tell me things that have been said to them by members of the medical profession and I do think some of it is misogyny, being told that it's because of their —— because they're a female, because of their age, that they've got this imaginary illness, and often the people that do this don't try to hide it from the patient. They're very frank with them. And there's a lot of patients who —— I will see them and something that's been said to them maybe four years ago, it's still stuck with them, like, "I was told this by this particular ..." —— such as, "You know, you're this age. You've just put on a bit of weight. You just need to go

and do some exercising and you're ... you know, I see a lot of women ..." —— they'll be told that they see a lot of women like this in this age group.

Q. Yes.

A. Yeah.

Q. You also indicate at paragraph 57 that, in terms of age, most of your patients are between 20 and 50, so that puts them into the working category, I suppose, and clearly —— and we heard a good deal from Mrs Ormerod and one of the documents that she's provided to the Inquiry about the effects that that has on the ability to work and the necessity to have employers who are sympathetic towards the condition that somebody has.

A. Yeah. It just hits right in the working age group and employers will be mixed in their response. So there are some very good employers who are still employing their patients —— their employees and my patients with reduced hours, for example, but there are other ones who have lost their jobs, and some people are only, you know, a couple of weeks of income to homelessness. You know, not everybody's got, say, things or a back—up, not everybody has got income protection, most people probably do not, and they are hanging on by a thread, some of them, to their livelihood for their children.

The study in doctors, one in five doctors with long COVID can't work, and there's lots of headlines recently about the increase in people who are not able to work -- look for work. So if you follow the pandemic from 2020 and the numbers of people not working, it does correlate with the increase in long COVID. Obviously there's other reasons why people don't work, but I think, because it's so prevalent in that age group, that it has a huge impact on employment.

There will be elderly people with long COVID who never get diagnosed with it because they will potentially get more forgetful, decline -- I've seen it in my own patients in general practice -- decline, and it looks like old age but actually they've had COVID and never got better from that COVID. So they're probably not diagnosed and the -- what's interesting about long COVID is that with ME you don't tend to get as many people up to about 50. It tends to hit people younger in life, sort of teenage years and their 20s, and with long COVID it seems to affect a whole spectrum, up to an older age than what I see with ME. But I suspect there's many not diagnosed in either side of those groups.

THE CHAIR: Can I just remind you, you've got 15 minutes left, Mr Gale.

MR GALE: Yes. Thank you, my Lord.

Just if I can take children and teenagers briefly. As we've established, you don't see patients under the age of 16 but obviously you do see patients who have had long COVID as a child and then graduated, as it were, to seeing you. You do tell us at paragraph 58 that there's "a lot of children [who] are told [it's] in their head", but they may have been in bed for a few years before you see them.

A. In bed, yeah, absolutely, and I've managed to give them treatment for PoTS, got them out of bed and got them back to some education or what -- something that resembles, you know, a normal life.

Q. So far as recovery is concerned, I think you do indicate at paragraph 102 and following that teenagers make the quickest recovery.

A. Yeah.

Q. Can you identify a reason for that?

A. I don't know if it's to do with their physiology, so our bodies change as we get older, our immune systems change, but the most dramatic recoveries I've seen are teenagers who I have treated for PoTS and dampened down their immune response and they've had extraordinary recoveries. And they may have had no treatment for several years and it seems such a waste that that treatment couldn't be instigated by any doctor several

years before and saved the suffering that they've had for those several years.

Q. Briefly, you do and have produced for us a paper from The Lancet on "Outpatient treatment of COVID-19 and incidence of post-COVID-19 condition over 10 months", and reading very short from that, because we can look at it in detail, this was something that was produced in October last year and the interpretation of the trial that was carried out was that outpatient treatment with metformin, which I think we all know is a drug normally associated with the treatment of diabetes, this reduced long COVID incidence by about -- is it 41%? -- "with an absolute reduction of 41%, compared with placebo. Metformin has clinical benefits when used as outpatient treatment for COVID-19 and is globally available, low-cost, and safe".

A. Yeah.

Q. Is metformin something that you prescribe for some of your long COVID patients?

A. So this is more looking at prevention of long COVID, but at the moment -- and it's been the same for the past four years -- we have a reactive style of responding to COVID. So if somebody gets COVID, it's essentially -- in the beginning we're told, "Wait until you're blue and then go to hospital", and still we don't have much

treatment at the time of COVID. So if you get COVID and there's a drug here that may -- it probably needs some more work -- but may reduce your risk of long COVID by nearly half, 50%, would that be something you might want to take? And at the moment -- and there's going to be other drugs like that that already exist. That's why we do research studies.

A very small per cent of the population have antivirals. They also reduce down the risk of long COVID. So what we're doing is we're letting people get long COVID and then we're not treating it once they've got it when there is potentially preventable medication for them.

Q. Thank you. I can bring your evidence to a close, Doctor. You provided us with a section on what we need and I think, in our discussions, I think we've probably identified that most of these elements come with a cost in financial terms. But one of those that I do want to ask you about is what you say at paragraphs 143 and 144. Perhaps you would just read those out, please?

A. "But most of all, we need to stop telling people that it's psychological because we have enough research to know it's a physiological illness.

"Education is important so we need to stop telling people with Long COVID that they need to just try harder or exercise to get better -- because that is adding to stress on top of what they're already going through."

Q. Dr Taylor, thank you very much. Is there anything further that you would like to talk to us about?

A. I think I would just like to add that the risk of long COVID is still there and the recent Canadian study suggested that by three infections your risk of long COVID is 38%. What we don't want is a population full of people who are unwell like this, who are suffering, who can't work, who are losing houses and not aware that that risk is still there.

So I think we need to do more work -- and this especially applies to children in schools, for example -- of ventilating buildings to a standard whereby COVID is taken out of the air. We need to have -- you know, people who are, you know, obviously unwell with it not attending school.

The prevention of long COVID is really important and I think the reporting of long COVID and the reporting of COVID, we should remember that it is still a dangerous virus and, although it's not killing people in the same numbers that it did before, it is primarily disabling people and I think it's just worth that we are still aware of that and there's a lot of work to be done aside from fixing patients that are already unwell, to prevent

more cases.

Q. There's one point, I'm sorry, I should have asked you. It relates to a matter I discussed briefly with Mrs Ormerod this morning. We've heard from a number of both representatives and witnesses that post-viral syndrome of some description might have been anticipated with COVID. Do you have a view on that?

A. Yes. When I first heard about COVID early 2020, my first thought was, what's the case fatality rate? That's natural to wonder that. Then my second thought was, what are we going to do with all of the people who don't recover? Because the SARS 1 patients didn't have a good level of recovery. So I think we could have anticipated not the exact number, which we think is around 10%, one infection, but there's some arguments either way, either side of that. But I think absolutely we could have foreseen quite a lot of people who would be disabled by the virus.

MR GALE: With that, Dr Taylor, thank you very much.

A. Thank you.

THE CHAIR: Yes, indeed. Thank you, Dr Taylor.

A. Thank you, my Lord.

THE CHAIR: With that, we'll close it for the day.

MR GALE: Till tomorrow, my Lord.

THE CHAIR: We'll be back at 9.45 tomorrow. I think -- no,

it's not you.

MR GALE: I have a day off.

THE CHAIR: You have a day off. It's all right for some, isn't it? Thank you very much. Very good.

(4.23 pm)

(The hearing adjourned until
Thursday, 14 March 2024 at 9.45 am)

INDEX

MS PATRICIA GRAHAM and MS JENNIFER MILLER (called) 1
Questions by MR STEPHENS 1
MRS JANE ORMEROD (called) 63
Questions by MR GALE 63
MS FIONA LOUD (called) 105
Questions by MR STEPHENS 105
DR CLAIRE TAYLOR (called) 156
Questions by MR GALE 156

A

abandoned (1) 25:4
aberdeen (1) 67:4
abilities (1) 99:13
ability (11) 19:10,11 52:25 53:22 69:6 71:22 98:2 131:5 141:5 169:25 196:11
able (75) 5:7 6:22 7:8 8:12 11:4 12:9 16:14,24 19:8 25:8 26:22 33:6,11,12 38:4 41:22 44:12 45:11,14,18,19 53:3,4,22,24 54:5 55:17 56:15,23 58:19,20 61:21,22 64:17,19 71:24 75:8 85:10,25 96:16 108:22 124:9,25 128:9,20 133:22,25 134:12 135:4 136:7 137:7 141:7,8,19 142:22 143:24 144:3 145:8 148:6 149:4 151:10,16 152:10 153:13,17 154:4 155:4 162:7 179:23 181:3 183:14 186:24 187:1,17 197:2
absolute (3) 38:22 44:15 199:13
absolutely (29) 5:17 8:25 12:13 18:2 19:7 20:20 23:3,19 32:13,21 35:8 38:8 39:5 41:5,16 70:16 71:4,23 75:5 83:25 91:2 111:11 127:18 139:11 143:14 177:17 178:14 198:9 202:16
absorbed (1) 104:7
academic (1) 156:25
accept (1) 147:17
acceptance (2) 102:4,6
accepted (5) 28:20 76:15 173:13 176:1,11
accepting (3) 80:20 99:16 103:8
access (20) 34:8 50:17,18 80:23 81:2,13,16 85:11 91:10 96:24 98:1,2 103:21 128:7,7,20 144:10 153:13 159:16,17
accessibility (1) 80:19
accessible (5) 19:9 20:23 21:5 81:11 99:18
accessing (8) 67:15 68:17 97:17,21 100:12 159:21 173:5 177:18
accommodation (8) 34:20 39:24 40:9 43:15,20 47:22 50:19 59:7
accompaniment (1) 26:11
accompanying (2) 2:21 31:4
accordance (1) 102:2
account (5) 2:24 3:1 106:17 150:12 158:12
accurate (1) 89:24
achieve (2) 11:7 78:17
acknowledged (3) 28:13 85:6 95:2
acknowledgement (1) 33:22
acquired (3) 53:5 73:25 74:16
acronym (1) 120:24
across (22) 19:4 26:6 45:9 55:11 57:17 107:17,20 109:3 110:19 114:8 121:4 130:8 131:10 133:14,21,22 135:9 146:19 167:10,20 188:18 195:13
action (1) 84:12
active (2) 33:4 100:5
actively (3) 45:3,4 114:13
activities (15) 5:3 10:4,5,7 16:15 18:17,23 19:14 44:8 53:24 57:10 70:20 117:3 183:20 194:13
activity (8) 4:25 19:8 20:5 52:14 68:2,4 180:13,19
actual (3) 77:13 183:19 192:25
actually (77) 4:18 5:17 7:7 10:24 11:3,8 12:8,15 14:17 16:2 19:3 22:9,11,20,24 23:14,14 24:4 25:1,7 27:8 28:18 32:11,25 33:15 36:3,11,21 38:19 42:3,7 44:5,9 49:13 50:9,11 51:18 52:2,22 53:4,22 54:1,8 55:11,17 56:25 57:10,12,15,21 65:10 68:17 69:7 77:1 80:4 82:17 98:4 100:13 115:13 117:2 120:21 126:10 129:12 130:9 133:23 134:13 137:20 141:21 143:8 149:22 150:22 151:24 159:15 177:12 181:6 185:1 197:13
acuity (1) 134:25
acute (7) 24:10 25:11,20 26:9 134:2,17 164:1
adapt (2) 10:16 151:18
adapted (1) 114:19
add (9) 9:6 19:24 20:1 51:20 60:25 61:14 130:8 150:15 201:5
added (2) 24:8 49:20
adding (1) 201:1
addition (2) 12:4 62:14
additional (11) 133:25 134:9,16 135:10 136:18,18 144:8 150:2 152:22 154:13 155:14
additionally (1) 154:10
address (1) 153:6
addressed (3) 69:1 127:17 176:16
adds (1) 69:10
adequate (1) 131:6
adjourned (1) 203:6
adjournment (1) 105:3
adjustable (1) 14:16
adjustment (1) 102:13
adjustments (1) 186:15
admin (2) 112:23 148:15
administration (1) 170:4
admit (2) 186:22 190:20
admitted (1) 24:15
admittedly (1) 28:4
adolescence (1) 52:18
adopt (1) 126:4
adult (6) 8:15 15:16,18,22 39:21 188:14
adults (7) 24:23 39:20 88:10 97:1,1,3 188:20
advance (1) 42:25
advanced (1) 111:1
adventurous (1) 10:10
advertised (1) 168:13
advice (13) 14:24 39:1 54:2 55:24 87:4 113:19 119:17 146:13 154:23 165:1 166:2,23 187:12
advisable (1) 117:19
advise (1) 151:18
advised (1) 121:21
advisors (1) 86:25
advisory (1) 175:1
advocacy (6) 65:21 109:6,21,23 113:12 148:11
advocate (3) 65:14 66:3 75:25
advocating (2) 76:17 110:6
ae (4) 24:14,24 181:25 190:14
affect (6) 89:4 100:24 153:1 184:11 194:21 197:19
affected (10) 15:5 100:2 110:8 126:10 128:24 131:19 132:23,23 134:15 153:3
affects (3) 69:6 88:18 102:1
afflicted (1) 92:16
afforded (1) 168:22
after (28) 4:6 24:13 25:15 28:12 33:2 35:8 40:7,8 67:17 68:5,24 88:12 91:7,8 92:3 115:19 119:9 127:7 133:12 154:3 165:12 166:11 174:3 180:7,13,18 185:22 191:20
afternoon (11) 64:16 82:20 105:7,8,8,14,16 155:23,24 156:2,3
afterwards (3) 28:24 94:21 181:2
again (47) 6:2 8:1 18:3 20:16 28:4 29:6 32:7 36:11 46:17 49:1,8 54:24 55:14 58:7 62:25 67:24 68:20 70:7 71:18 88:16 92:5 97:12,18 98:9 99:22 100:12 101:22 103:4,7 104:25 112:13 116:20,24 119:12 128:16 131:11 132:20 134:23 140:22 141:18 151:20 154:15 155:23 179:4 183:15 190:13 192:11
against (2) 12:23 100:13
age (19) 24:12,19 32:12 71:10,11,18 106:5 156:8 178:9,22 195:18,24 196:3,6,14 197:7,13,20 198:3
agents (1) 132:5
ages (2) 2:7 187:10
ago (12) 8:20 14:20 22:11 58:8,8 82:18 108:9 157:10 162:10 172:25 178:3 195:22
agree (3) 28:21 138:17,17
agreeable (2) 64:3 66:17
agreed (1) 49:6
ahead (2) 84:24 111:15
aid (1) 63:20
aim (2) 7:23 8:19
aims (1) 75:14
air (1) 201:15
akin (1) 68:5
albeit (2) 27:14 121:24
alive (4) 39:6 48:2 118:3 132:17
allergic (3) 161:8,22,23
alliance (4) 76:5 79:12 103:24 107:16
allied (4) 5:21 31:24 35:25 36:2
allocated (3) 86:10 103:14,16
allow (1) 173:21
allowances (1) 101:17
allowed (2) 26:24 46:12
allows (1) 186:14
alluded (4) 47:24 51:16 82:13 97:19
almost (7) 38:1 54:12 59:1 92:8 96:18 157:10 182:8
alone (2) 37:2 73:12
along (6) 2:21 37:19 62:20 82:10 115:19 137:9
alongside (1) 132:16
already (25) 18:12,16 28:5 40:18,20 81:18 82:13 85:13 94:8 99:23 106:7 107:4 112:20 140:18 142:1,25 149:13 159:4 162:25 163:12 187:8 194:20 200:6 201:2,25
also (98) 2:19 4:24 8:14,22,23 9:8 10:22 11:6,17 12:12,17,20 13:1,3 14:2 16:8,14,18 19:11,13 20:1 30:1 31:2 36:14,15 45:16 48:18 50:22 51:9 52:18,20 53:18 54:11 55:18,22 56:23 57:3 62:6 63:21 66:11 70:9 74:4 76:4 83:6 84:5,13 88:15 89:1 91:4,16 92:15 100:21 102:20 103:24 104:4 106:18 108:4 110:10 114:20 115:8,10 117:7 119:24,25 121:4 122:4 123:5,10 124:12 125:1,15 130:22 131:17 132:8,12 135:10,15 136:25 139:13 140:16 143:17 146:6 147:6 153:19 160:21 161:21,25 162:3,5 163:15 167:11,13 168:15 184:3 195:5,9 196:6 200:9
alternative (1) 88:14
although (13) 65:6 71:11 73:18 103:19 108:13 112:25 121:24 142:7 154:8 172:16 182:18 184:12 201:21
always (21) 10:19 12:24 18:23 21:13 23:4 24:18 30:13 65:9,10 76:14 80:23 85:16 90:2,13 99:15,18 112:9 150:2 170:21,25 193:22
amazing (2) 53:21 54:6
ambulance (2) 24:14,23
america (2) 133:9 184:2
american (1) 74:10
amongst (3) 49:25 72:4 85:17
amount (5) 19:16 45:10 74:15 131:2 183:19
amplification (1) 63:24
analysis (2) 89:13 146:16
angry (2) 44:2,20
annes (2) 47:21 48:15
announced (1) 142:12
announcement (1) 122:17
annual (3) 126:21,21 152:13
another (11) 12:19 52:11 68:25 74:11 98:7 115:19 134:23 172:8 182:18 186:8 195:11
answer (7) 37:13 94:20 120:14 121:4 123:19 129:17 142:23
answered (1) 12:2
answers (1) 186:12
antagonism (1) 75:4
antibodies (1) 154:4
anticipated (4) 37:9 42:24 202:6,14
anticipation (1) 41:8
antihistamines (1) 185:16
antivirals (1) 200:9
anxiety (19) 22:16 62:13 68:15 69:10,11,12,18 70:4 92:12 93:3,4,8,9,22 139:17 190:15 194:3,4,4
anxious (4) 64:16 67:18 93:25 113:20
anxiously (1) 132:9
anybody (8) 25:5 48:10 69:15 93:22 114:24 122:1,1 180:22
anymore (5) 52:8 59:8 71:24 83:17 111:19
anyone (5) 62:16 75:21 175:21 178:9 187:20
anything (22) 9:6 12:2 26:1 28:15 48:7 53:3 61:14,22 82:16 85:22 94:18 103:9 106:19 123:23 133:18 146:2 149:13 150:15 165:12 177:4 181:11 201:3
anyway (6) 25:4 45:10 51:12 82:7 112:21 114:25
anywhere (2) 15:2 59:18
apart (4) 11:17 45:12 66:1 128:22
apocryphal (1) 165:5
apolitical (1) 175:12
apologies (3) 116:18 155:2 177:13
apologise (2) 37:7 150:23
apparent (3) 42:17 64:7 65:17
appear (2) 38:11 63:20
appeared (2) 121:12 158:25
appears (2) 183:12 194:21
applied (4) 122:12 124:9 158:20 160:20
applies (4) 26:6 90:8 125:17 201:13
apply (5) 119:1 122:8,24,24 124:12
appointment (4) 68:21 159:19,20 174:8
appointments (5) 69:9 127:8 141:16 184:25 190:1
appreciate (4) 29:13 31:11 116:8,16
appreciated (4) 28:17 33:24 147:12 149:19
apprehensive (1) 129:6
approach (2) 141:17 173:21
approaches (2) 125:7 135:19
approaching (1) 128:25
appropriate (7) 15:22 25:19 35:16 78:20 81:22 189:22,23
appropriately (4) 24:13 25:25 87:23 133:22
april (1) 129:23
aprons (1) 34:14
architects (1) 14:25
area (3) 12:6 26:5 167:25
areas (9) 14:2,4 36:10 72:24 94:5 95:24 96:8 144:7 184:6
arent (7) 12:24 20:23 58:19 108:23 135:22 172:23 190:2
argue (2) 29:19 41:7
arguing (1) 78:22
argument (1) 24:22
arguments (1) 202:15
arise (1) 74:24
arising (1) 37:17
arm (3) 53:23 128:8 135:14
arms (2) 127:20 151:6
around (32) 11:1 13:25 15:18,21 20:22 31:22 32:3 69:2 80:19 82:19 83:19,20,21 84:23 87:10 90:1 93:16 94:20 96:16,21 100:4 110:6 112:21 115:12 124:15 125:25 142:11 152:5 169:16 171:11 177:7 202:15
art (2) 57:14,14
article (1) 156:13
articulately (1) 31:14
arts (1) 10:6
aside (1) 201:24
ask (46) 2:8 11:25 18:8,16 22:1 26:9 27:12 32:4 42:3,4 43:1,16 47:15 53:12 60:16 74:13 75:13 76:8,11 77:21 96:7 99:20 100:14 104:1 106:6 108:14 115:22 117:1 121:7,13 124:4,5 126:11 130:22 139:18 146:20 147:21 148:9 157:18 163:18 164:25 169:20 189:7 191:7 193:8 200:19
asked (22) 1:7 37:14,18,19 38:9,11 39:7 77:19 87:7 91:14 94:19 105:18 124:3 142:3,6,10 152:25 158:6,8 164:23 174:24 202:2
asking (7) 1:23 28:23 37:24 42:22 82:9 101:9 116:24
aspects (1) 108:23
assessment (8) 38:25 48:22 49:5,19,19 99:12 124:10 146:21
assessments (3) 47:6 49:12 185:21
assistance (1) 80:1
assisted (2) 65:3 83:24
assisting (1) 110:2
assists (1) 158:18
associated (1) 199:11
association (2) 4:17 108:19
assume (2) 103:1 163:19
assuming (1) 40:19
assurance (2) 36:22 132:7
asthma (1) 192:21
attach (1) 162:19
attached (2) 178:12 179:12
attend (1) 64:17
attendance (1) 60:24
attended (2) 163:16 167:19
attending (2) 111:16 201:17
attitude (2) 22:19 77:16
attributed (1) 25:24
attrition (1) 115:1
authorities (1) 125:1
authority (3) 25:11 26:5 49:3
autoimmuneinflammatorytype (1) 195:7
automatic (1) 161:11
automatically (1) 162:16
autonomic (4) 161:8,9,11,15
availability (2) 81:1 132:13
available (18) 34:3 66:25 81:5,10,11 86:10,12 92:22 119:15 120:10 134:20 146:19 153:16 154:10,14,24 161:2 199:15
average (1) 103:17
awarded (1) 167:23
awards (1) 166:15
aware (12) 83:2 88:23 112:10 129:15 130:18 154:15 161:14 169:18 176:1 179:5 201:11,24
awareness (2) 40:25 113:25
away (19) 21:9,17 35:24 43:18 51:1,21,25 52:1,4 62:11 67:19 68:16 70:5,17 83:16 117:20 123:1 127:10 143:18
awe (1) 18:24
awful (2) 50:14 169:11

B

b (2) 88:1 133:17
baby (4) 61:3,3,6 136:22
back (58) 4:5,17 6:24 7:25 8:3 14:11 16:9 24:23 27:3 29:24 36:25 39:8 44:25 46:12 55:25 56:21 59:4,20 60:1 62:25 68:22,25 78:25 99:5 104:5 112:13 113:24 116:6 123:2 125:6,19 128:16 131:25 132:4 138:24 140:3,4 144:24 148:25 151:9,20 152:17 159:24 165:10 171:20,23,24 174:9,21 178:19,20 180:9,25 183:4,11 188:21 198:11 202:25
background (16) 3:23 5:19 8:5 28:14 64:20,21 65:3,11 70:18 73:24 107:21,22 157:2,7 158:17 162:4
backup (1) 196:21
bad (3) 69:8 70:15 177:5
badly (2) 131:1 152:13
bag (1) 188:17
bags (1) 188:16
bakes (1) 113:12
balance (1) 139:1
balanced (1) 136:23
banned (1) 151:10
bans (1) 151:2
barriers (1) 14:19
based (4) 14:4 24:3 31:20 87:7
basis (8) 11:16 17:13,14 38:2 41:4 87:21 129:14 167:16
beaches (1) 10:7
bear (3) 162:7 188:3,5
beating (1) 161:13
beats (1) 182:2
became (24) 3:21,23 25:14 36:16 49:22 50:19,20,25 51:5 53:20 56:19 57:18 65:21 68:22 93:14 111:19 117:7 118:16 121:15 123:24 132:14 134:24 146:14 153:16
become (5) 6:22 21:14,14 32:17 122:16
becomes (3) 54:17 70:5 98:14
becoming (3) 91:8 96:18 117:5
bed (14) 55:21 68:5 70:23 72:10 162:19 179:20 181:2 187:6 188:17,25 189:1 198:7,9,10
bedbound (3) 180:1 187:17 188:15
bedrooms (1) 34:16
before (41) 3:23 5:19 19:24 27:10 28:1 32:6 40:21,24 46:17 47:20 55:8 56:22 57:25 69:20 92:21 103:11 104:6 105:25 106:10,22 108:7 115:18,18 116:23 120:13 127:10 150:16 153:2 157:17 158:8 160:3,7 163:18 166:25 170:20 171:15 179:24 182:4 198:7 199:1 201:22
beforehand (1) 193:2
began (4) 50:12,13 54:9 157:9
begin (4) 50:10 67:1 144:21 145:25
beginning (9) 11:9 80:12 111:5,23 119:16,18 134:8 144:13 199:24
begins (1) 22:14
behind (4) 6:15 52:8 97:3 101:6
being (84) 7:8 11:4 19:6,8 20:17 22:5,15 23:10 24:16 25:17 28:1 30:7,9,20 33:6 34:21 36:7 40:8,12,14 43:17 44:11,15,18,21 48:21 49:25 51:10 55:6,7,17 56:15,22 59:25 65:23 68:16 69:14,22,23 73:7 74:3 81:21,25 85:6,15 86:14,24 90:3 93:19 96:16,23 97:4 100:3 104:8 116:11 120:22 128:25 134:20 136:3,24 139:6 141:19 144:25 145:24 148:6,12,13 149:2,4 151:16 153:13 164:22 165:22 169:15,23 172:19 176:24 182:12 183:13 187:1 188:15 190:22 193:15 195:16
believe (6) 12:14 93:20 125:20 168:23 183:2,16
believed (2) 90:3 96:23
bench (1) 14:16
beneficial (2) 165:13,19
benefit (2) 165:22 179:4
benefits (4) 74:2 110:2 186:15 199:14
bereavement (1) 16:5
best (8) 32:9 45:18 53:9 118:9 120:4 140:6 150:7 155:7
better (26) 11:23 21:16 36:21,23 70:1 75:12 85:7,24 93:18 95:5 97:13 104:1 107:13 121:7 140:8 141:24 161:1 167:23 176:12 180:24 188:8 192:6 194:2,16 197:14 201:1
between (10) 39:21 95:6 123:11 129:22 130:5 138:23 141:9 161:15 163:9 196:7
beyond (3) 9:22 16:3 92:10

big (4) 6:17 13:24 15:19 31:11
bigger (1) 74:5
biggest (2) 14:19 139:4
biobank (2) 184:9,9
birth (1) 16:2
bit (38) 4:1 6:17 8:17 9:3 18:16 20:18 21:7 33:13 41:25 50:1 57:16 64:21 65:12 70:19 72:5 73:3 75:13 76:8,12 84:24 85:7 91:14 96:7 115:7 120:6 126:9 128:19 140:5 141:12 142:2 149:22 151:17 153:12,23 175:4 191:7 192:21 195:25
bits (3) 80:21 185:24 186:16
black (2) 15:19 30:20
blink (2) 31:15 41:11
blood (13) 126:20 141:7,18,20,23 162:14,17 164:16 167:13 174:16,21 184:3 186:5
bloods (2) 159:2 186:6
blue (1) 199:24
board (14) 3:20 4:2,10 5:5,16 34:11 38:6 80:22 146:19 157:11 163:16 164:9,13 167:19
boards (14) 78:13,18 79:1,1 80:20 81:5,8,9 84:22 85:10 86:13,16 97:5 167:24
bodies (1) 198:19
body (7) 24:23 88:19 112:7 161:12 162:14 181:11,21
book (3) 24:1 57:12,21
booked (1) 168:7
boosters (1) 154:12
born (1) 39:2
both (25) 1:6,23 2:2,8 3:11 8:9 12:1 18:15 20:15 31:3 43:18 54:23 60:15,23 78:4 80:3 84:5 91:16 108:25 120:2 134:11 144:23 157:11 167:9 202:5
bottom (1) 34:4
bound (1) 187:6
boxes (3) 131:22 144:3,10
brain (15) 69:5 161:14 162:16,17 183:18,24 184:3,6 185:10,13 186:6,6,7,8,10
brains (2) 10:25 190:25
brainstem (1) 11:1
bravery (1) 62:4
break (5) 13:1 63:4 116:3 155:21 160:14
breaking (2) 109:19 166:11
breaks (1) 32:1
breakthrough (1) 11:12
breakthroughs (1) 11:10
breath (2) 169:11 173:24
breathlessness (2) 67:3 88:25
briefings (1) 148:24
briefly (7) 29:24 31:18 142:1 156:16 198:1 199:3 202:3
brilliant (1) 55:9
bring (9) 4:7 16:5 55:5 62:6 108:10 132:3 162:7 184:25 200:14
bringing (3) 16:13 41:6 55:10
brings (1) 188:10
british (1) 108:19
broad (1) 5:3
broaden (1) 42:8
broader (1) 5:8
broke (1) 44:14
broken (1) 189:5
brought (4) 54:1,2 79:8 94:25
build (4) 15:1 31:21 118:24 165:11
building (1) 132:21
buildings (1) 201:14
bulk (1) 34:16
burning (1) 164:11
business (5) 54:17 73:22 117:23,23 118:7
busy (4) 13:9 45:21 64:13 182:13
buy (2) 112:19,22

C

c (1) 133:17
cabinet (8) 27:5,14,16 28:4,11,17 29:14,15
cake (1) 113:12
call (7) 69:5 90:14 111:16 119:8 174:8 176:13 185:7
called (18) 1:16 2:2 34:18 63:10 105:12 112:8 141:2 145:1,2 146:16 150:22 156:1 161:17 162:9 204:3,5,7,9
calls (1) 23:10
came (23) 22:2 23:20 26:14 27:13 30:12 34:22 38:6 39:7 49:19 67:12 108:2 115:18 122:3 124:22 139:16 140:4 142:14 146:15,24 153:23 157:16 159:4 190:11
campaign (2) 14:20 107:13
campaigning (2) 7:5 146:15
campaigns (1) 183:8
canadian (1) 201:6
cannot (4) 81:15 88:13 181:10 187:10
cant (50) 22:25 25:1 30:4,18 33:20 34:10 35:18 52:8 59:25 62:10 72:11,13 79:3 80:3 81:13 93:25 95:15 101:16 108:9 114:10 115:3 118:21 125:20 127:16 131:25 132:10 142:8 144:6 145:1 151:7,7 177:12,23 178:20 179:20 184:13 185:1,3,9 186:16,18,19 187:15,21 190:1,5,16,24 197:1 201:10
capacity (5) 11:18 62:4 72:16 73:21 160:22
cardiac (1) 64:24
cardiologist (2) 173:9 174:19
cardiology (7) 98:22 99:3,4,5 159:20 162:5 173:24
cardiothoracics (1) 64:24
cardiovascular (1) 88:19
care (86) 9:10 12:7 15:22 16:19 17:8,15,16 28:23 29:3,17 31:7,10 33:5 34:5,21 35:3 39:17,18,22 40:3,12 43:23 44:6,17 45:4,5,7,14 46:11,21 47:2,7,25 50:23 51:1 54:15,17,19,21 56:16,23 57:1 58:7 64:24 76:4 80:11 81:15,22 85:11,21 96:24,25,25 97:1,2,4,17,21 98:6,10 99:16 100:12 103:24 105:9 106:4 107:5 108:4,16 109:10 114:5 115:6 119:22 124:5 127:4,6 129:1 131:5 132:24 133:11 134:11 137:4 152:20 159:16,17,22 173:5
cared (2) 25:25 35:15
career (3) 5:23 6:1 65:1
careful (1) 90:17
carer (4) 44:19 56:9 58:8 96:19
carers (27) 7:16 16:9 17:18 19:21 20:2,7 24:25 27:8 31:2 33:17,18,19,22 37:1 44:7 47:19 48:19 52:19 54:1,11,14 56:7,20,21 187:12 188:5,12
caring (6) 16:6 17:20,21 19:21 21:11 45:20
caroline (1) 106:3
carried (15) 34:21 44:18 57:15 65:4 66:10 67:6 73:25 89:7,14 95:20,25 101:21 102:10 112:1 199:9
carry (4) 36:3 48:22 70:24 139:7
carrying (2) 49:12,18
cases (8) 16:19 48:1 50:22 130:13 131:24 138:13 143:21 202:1
cast (2) 66:1 87:5
catapulting (1) 18:24
catching (1) 112:9
categories (1) 145:3
categorise (1) 179:13
categorising (1) 102:16
category (4) 146:5 179:25 187:14 196:8
caught (1) 53:19
cause (2) 174:15 193:15
caused (1) 132:4
causes (2) 177:17,18
causing (1) 174:14
cautioning (1) 164:10
cautious (1) 111:22
cease (1) 104:4
cellular (1) 181:12
cent (1) 200:8
centres (1) 36:6
ceo (2) 6:3,5
cerebral (4) 22:21 58:12,13,14
ceremony (3) 166:16,20,25
certain (7) 82:10 83:5,23 98:14 121:22 125:3 166:22
cetera (2) 125:8,8
chair (84) 1:3,9,11,14 3:16,21 4:20 5:5 27:12,19,23 28:10,16 29:1,13,23 37:4,11,13 38:11,15,17 40:16,24 41:4,6,15,17 42:20 43:4 60:23 62:25 63:6,11 64:8 65:4,19,23 73:23 87:17,20 90:11,17,23,25 104:22,24 105:1,7,14,17 115:11,15,23,25 116:5,7,11,14,19,21 120:13,24 130:15 140:12,15 150:22 155:16,19,23 156:2,4 160:16,18 169:11,14 189:7 190:9 191:5 197:23 202:21,23,25 203:3
challenge (11) 11:9 99:19 104:11 113:16 120:2 121:11 122:2 124:6,7 125:1 128:10
challenged (1) 135:2
challenges (1) 151:23
challenging (7) 17:5 19:14 51:13,20 90:2 122:5 155:6
champions (1) 166:17
chance (1) 166:25
change (10) 15:2 26:23,25 77:15 113:3 114:15 149:9 165:15 198:19,20
changed (6) 8:20 46:15 83:10 108:20 144:15 149:9
changes (1) 112:15
changing (8) 7:6 14:12,13,15 19:2 20:21 21:1 183:5
chapter (1) 94:14
characterise (2) 179:14 185:24
characteristics (1) 18:11
charge (1) 56:25
charitable (2) 113:5 114:4
charities (10) 107:17,20 108:1,2 113:9,16 114:9 125:12 126:5 147:2
charity (17) 7:10 30:25 65:21,22 75:17,19 106:4 108:17,18,25 114:1,8 120:12 121:3 124:5 145:13 159:16
chat (2) 167:6,8
chats (1) 55:19
check (7) 2:10 30:3 106:7 113:2 126:21,22,22
checked (2) 140:25 154:8
checking (1) 171:18
checkup (1) 141:5
checkups (2) 140:17 141:7
chest (10) 76:5 79:11 92:11 103:23 164:17 173:8,10,23 174:7,15
chief (1) 5:12
child (17) 8:15 15:2,15,21 19:17 21:20 22:11 24:11,11,12 39:2 52:17 53:8 61:2 96:19,22 198:4
children (25) 12:16 15:18 17:21 21:8 45:13 88:10 96:8,10,15,20 97:2,6,7,10 115:5 166:19 178:6,8,12,22 188:14 196:24 198:1,6 201:13
chiropractor (1) 47:11
choice (4) 127:13 128:24 129:8 140:11
choices (2) 127:17 128:9
choose (1) 113:10
chris (1) 142:9
chronic (12) 68:6,7 70:6 93:22 97:16 110:17 118:19 126:23 134:5,14 183:7,9
circumstances (3) 44:25 45:8 151:12
civil (3) 26:15 38:2 43:11
claims (1) 103:24
claire (4) 155:25 156:1,7 204:9
clarification (1) 130:17
cleaning (1) 45:21
clear (22) 3:9 41:17 43:7 48:22 50:23 80:14 81:3 84:8 103:20 104:12 107:2 109:10 120:8 125:2 128:21 132:20 140:6 147:1 150:24 154:7,16 191:8
clearly (3) 118:4 171:3 196:9
clinic (6) 167:17 168:5,15,16,17 192:18
clinical (10) 24:3 30:16 64:25,25 72:16 87:17 95:14 120:16 183:25 199:14
clinically (2) 64:24 142:3
clinicians (1) 87:24
clinics (1) 174:3
close (6) 59:21 112:25 125:13 137:22 200:14 202:23
closed (1) 137:6
closely (2) 26:15 61:8
clot (1) 174:21
clots (1) 174:16
club (1) 65:12
clubs (1) 16:12
coach (1) 152:5
cognitive (14) 32:16 52:20 89:1 99:13 180:15,16,17 184:16,18,23 185:18 186:4,21,25
cognitively (1) 46:8
cohort (3) 41:1 91:19 187:13
coined (1) 163:22
cold (1) 70:23
collaboration (1) 57:13
collapsed (2) 32:2,3
colleague (3) 74:11 115:11,20
colleagues (11) 42:22 73:13 115:13 117:15,16 118:8,9 143:20 148:11 149:1,2
collect (2) 152:6,7
collectively (1) 49:17
college (1) 103:5
combination (1) 96:15
combining (1) 119:22
come (43) 6:24 7:25 8:3 14:24 15:7,19 16:10 17:25 18:11 29:24 39:4 43:14 46:12 50:12 55:22 59:4 60:14 62:25 71:19 73:2 78:10 100:18 102:10 107:25 113:1 114:4 117:8 118:25 123:2,18 146:7 166:19 169:17 172:1 174:9 180:2 187:12 188:18 191:14 193:11,21 195:13 200:17
comes (8) 14:8 39:8 45:1 71:7 93:11 95:23 176:23 194:12
comfort (2) 73:11 151:21
coming (15) 11:6 19:23 26:10,17 37:6 55:1,12,25 56:21 57:23 69:22 122:11 147:12 191:15 193:19
comment (4) 90:23,25 165:4 176:22
comments (3) 30:14 100:17 192:12
commitment (2) 48:5 104:15
committed (1) 65:18
commode (1) 187:11
common (15) 18:10 43:18 88:24 91:10,19,21 92:6,10 113:8,15 161:21 162:1 165:7 181:13 194:24
communicate (2) 79:4 174:1
communicating (1) 174:19
communication (18) 25:3,21 56:8 59:5 78:25 120:7 123:17,20,22 125:11 139:25 140:8 141:4 142:20 146:18,22,24 152:21
communications (3) 78:24 126:6 155:8
communities (9) 6:21 8:23 10:17,18 13:22 14:25 20:22 21:5 41:25
community (11) 4:18 6:9 12:17 14:20,21 31:9 34:7 44:12 57:22 58:3 113:9
company (1) 132:5
compared (1) 199:13
completed (1) 92:20
completely (4) 53:3 113:3 124:11 189:5
completing (1) 84:1
complex (7) 9:11 15:15,16 16:19 17:7,9 61:6
complexity (1) 31:5
component (1) 17:17
comprehend (2) 62:10,12
comprehension (1) 9:15
comprehensive (2) 49:22 158:12
compromised (2) 35:3 101:15
compulsion (1) 29:18
conceivable (1) 25:23
concern (1) 24:9
concerned (9) 68:17 110:16 134:12 136:15 151:3 154:19 190:22 192:10 198:13
concerns (4) 26:11 148:25 167:14 182:6
conclude (1) 150:16
condition (25) 70:8 73:3,17 88:9 91:18,22 93:17,23 108:7 110:1,25 124:1 144:1 159:13 160:1 161:17 162:25 182:25 188:11,23 192:15,25 194:21 196:13 199:5
conditions (7) 74:22 99:21 167:21 172:20 192:10,23 195:1
conducted (2) 73:21 123:6
conduit (1) 121:6
conference (1) 142:8
confidential (1) 147:14
confidentiality (1) 191:12
confined (1) 76:11
confining (1) 77:19
confirm (5) 1:24 25:8 35:12 49:8 106:2
confirmation (1) 172:11
confirmed (2) 88:11 166:5
confused (1) 184:17
conjunction (1) 25:10
connected (2) 145:13 161:14
connections (2) 57:16 170:17
consciously (1) 161:13
consciousness (1) 11:2
consequence (1) 138:5
consequences (1) 129:9
consider (8) 45:5 117:22 143:11,14 149:15,17,18 156:22
considerable (3) 68:23 71:2 73:8
considerably (1) 67:8
consideration (2) 66:14 74:18
considered (5) 45:6 137:12 138:16 139:6 144:17
considering (1) 22:19
consistency (5) 125:15,25 126:4 146:2,6
consortium (2) 118:17 120:18
constitute (2) 63:25 106:9
constitution (1) 173:3
consult (2) 160:6 189:9
consultant (1) 55:3
consultants (1) 124:4
consultation (2) 170:24 171:13
consultations (1) 59:14
consulted (1) 158:3
consumption (1) 84:6
contact (10) 2:7 31:1 43:12 63:17 73:15 74:9 94:22 106:5 144:19 156:9
contacting (1) 146:1
contacts (1) 144:22
content (7) 2:2,11 63:22 66:11 106:8 156:20,22
context (10) 65:9 68:14 95:22 101:2 104:8 117:3 157:22 170:11 182:19 183:15
continue (4) 74:4 81:19 141:20 155:6
continued (4) 5:9 104:17 115:7 137:21
continues (5) 26:8 60:4 65:10,16 80:10
continuing (5) 25:15 60:7 80:2 100:9 114:17
continuous (1) 135:15
contract (1) 154:24
contracted (4) 66:19,20 92:17,21
contrast (1) 128:13
contribute (3) 37:14 93:22 155:4
contributions (1) 37:20
contributors (1) 119:21
control (4) 38:23 39:4,5 161:12
conversation (1) 119:5
convert (1) 54:22
cooker (4) 180:8 184:18,22 186:19
cope (7) 17:19 62:3 70:6 71:8 93:24 171:4,6
copies (1) 47:6
coping (2) 193:23 194:8
coproduction (1) 77:3
coproductive (3) 76:23 77:2,9
copy (2) 63:22 85:23
core (6) 12:1,3,12 14:1 23:3 80:24
correct (11) 1:12 41:2 64:10 77:24 106:11 107:6 111:9 120:16,17 140:21 148:22
correctly (1) 129:5
correlate (1) 197:5
cost (2) 53:5 200:17
couldnt (16) 28:21 33:6 34:22 35:11 45:16 46:1 47:4 51:5 62:12 111:15 159:16,17 164:22 168:21 177:5 198:25
counselling (6) 50:8,12 109:5 110:12 113:11 114:19
counsellors (1) 109:21
counting (1) 109:16
countries (2) 125:3 135:24
country (16) 7:16 14:23 45:9 55:12 107:20 109:4 122:13 125:17,18 133:23 135:9 140:6 141:6,10,11 146:11
couple (18) 43:6 44:24 70:16 78:9 82:13 85:20 94:22 103:22 114:24 131:24 133:12 147:15 150:18,19 153:4 172:25 178:16 196:20
course (22) 25:18 27:21 45:11 60:19 66:24 72:19 103:5 113:1,14 119:21 120:14 121:2 123:3 124:4 136:23 143:2 145:8 150:20 169:20 189:22 191:9 192:24
cover (3) 138:8 150:14 179:19
covered (2) 18:12 38:17
covid (295) 5:7 12:8 17:22 19:23,24,24 22:18 23:11 25:13 28:1,2 35:7,19 36:22 37:1 40:21,24 45:17 48:6,25 49:15 50:9 54:18 58:23,24 60:9,10,13 61:4,7 64:8 65:4,19,20,25 66:1,3,16,19,21,22,24 67:4,13,14,17,21,24,25 68:9,19,20,20 69:14,22 70:13 71:25 72:3,4,17,23 73:10,14,23 74:1,6,18,19 75:7,13 76:25 77:23 78:4,6,8,10 79:6,8,10,18,19,20 80:13,25 81:3,8,12 82:10,16,25 83:13,14,15,17,18,19,19 84:9,15,19,20 85:16,19,21 86:21,25 87:13 88:6,16 89:8,9,12,16,21,24 90:1,4,7,9,10 91:5,9,22 92:17 94:2,7,9,17,24 95:6 96:8,11,20 97:2,3,16,20,23 98:1,5,12,24 99:8,12,21 100:2 101:3,6,7,9,9 102:1,11,16,21 103:14,17,18 104:6,8,9,18 117:8,18 119:14 121:10 128:1 129:7,16,24 132:20,23 136:18,18,19,22,25 137:3 138:2,3 139:16 143:3,17 153:18 154:3,11,21,22 157:15,17,22 158:1,13,18 159:5 160:23 161:1,7 163:3,10,13,17,19,22 164:1,1,19 165:20 166:16,19 167:1,9,12,15,17 168:3,14 169:7,16,17,22,23 170:18,21 171:15,16 172:2,9 174:15 175:2,6,6,23,25 176:2,8,13,18,21 177:20,25 178:13 179:16,24 180:22,24 181:16 182:8 184:4,8,11 185:14 187:22 188:15,22 191:19 192:5,13,15,23,25 193:1,4,19 194:1,16,17 195:10

197:1,5,9,13,14,16,19 198:4 199:12,19,20,23,23 200:1,1,3,10,11,25 201:6,8,15,18,19,20 202:7,8
covid19 (12) 88:12 118:20 120:19 128:23 132:18 134:7,18 150:4 153:24 155:9 199:4,15
covidnegative (1) 131:9
covidpositive (2) 131:6,8
crafts (1) 10:6
create (1) 117:21
created (1) 84:11
creative (2) 113:17,22
credit (1) 9:16
criteria (3) 165:21 181:14,17
critical (1) 150:22
criticism (2) 87:3,7
crucially (1) 113:5
crudely (1) 70:14
crystal (1) 43:7
cuddles (1) 22:24
cultural (1) 12:23
culture (2) 10:6 77:16
curious (1) 152:12
current (3) 3:16 6:2 64:8
currently (5) 109:17 169:5 175:8 184:13 186:17
cycle (2) 94:16,23

D

daily (4) 17:13,14 38:1 183:20
damage (1) 47:12
damaging (2) 178:13 179:1
dampened (1) 198:21
dangerous (1) 201:20
dangers (1) 167:12
dare (1) 140:8
dark (4) 30:7,9 51:3 53:15
darkened (2) 179:19 187:24
data (7) 23:23,24 24:4 89:17 90:17 132:22 145:21
date (1) 130:12
dates (1) 130:15
daughter (15) 3:8,8 4:3,11,17 15:11 19:17 32:12,22 40:8 45:1 46:3,6 47:9 61:3
daughters (4) 16:15 45:6 47:2,7
dawn (3) 29:11,13,14
dawned (1) 29:10
day (37) 19:20,21 20:11 22:23,25 30:9,20 31:25 34:7,23 39:2 45:2 49:7 51:3 56:9 58:12 59:20 60:1 64:13 70:25 80:13 111:9,12,13,14,17 118:22 120:1 159:11 179:18 181:1,4 182:4,14 202:23 203:2,3
days (14) 38:1 45:23 70:15,15,16 80:4 90:3 130:6 142:11 176:19 180:13,18 181:2,25
daytoday (4) 17:17 69:16 71:2 93:24
dead (1) 115:25
deal (8) 5:3 72:25 92:24 97:11 99:8 122:2 194:7 196:9
dealing (3) 182:22 186:11 188:14
deals (1) 95:18
dealt (1) 126:15
death (1) 35:5
deaths (2) 22:13 130:14
debate (1) 64:15
debates (1) 15:23
decade (1) 104:10
deceased (3) 136:12 137:25 138:4
december (1) 115:15
decide (2) 52:7 167:18
decided (3) 46:11 111:18 172:5
decision (11) 4:9 24:3,5,7 56:24 114:9 133:13 136:1 138:7,11,22
decisionmaking (1) 158:4
decisions (1) 42:9
decline (7) 52:19,20 92:3 127:16 190:6 197:11,12
declined (3) 25:12 189:14 190:7
decreased (1) 78:7
dedicated (1) 104:16
deemed (1) 142:3
deep (1) 193:13
defecate (1) 188:17
deficiencies (2) 80:18,19
define (1) 191:19
defining (2) 17:25 117:24
definitely (9) 13:8 43:3 47:23 58:17 59:19 91:13 95:12 172:9 177:24
definition (3) 88:5 175:25 176:1
definitions (1) 176:4
degree (5) 7:21,22 157:3,4 176:20
delay (1) 25:16
delayed (2) 105:5 140:10
deliberately (1) 183:2
deliver (2) 78:16 133:4
delivered (2) 131:24 147:10
deliveries (1) 144:11
delivering (1) 73:6
delivery (3) 131:18 132:2,5
demand (3) 113:18 133:5,7
demographic (1) 71:18
demoralised (1) 96:2
department (2) 119:6,6
depend (2) 32:13 71:25
dependent (2) 33:5 132:17
depending (5) 118:22 163:9 172:14 173:3 177:20
depends (3) 31:23 72:1 100:8
deploy (2) 112:19 135:8
deployed (4) 114:16 117:9 137:3 138:1
depressed (2) 50:20,25
depression (3) 93:3,5,10
depth (2) 9:15 95:15
derive (2) 10:11 62:5
derives (1) 11:22
describe (12) 4:19 6:5 7:10 8:8 30:24 31:5 43:19 92:13 117:4 179:6 181:19 188:1
described (9) 20:15 37:8 43:22 92:7 98:20 122:15 155:3 179:6 182:15
describing (3) 179:14 182:7 189:16
description (3) 39:24 102:12 202:6
desert (1) 120:5
designated (1) 48:15
desperate (4) 38:8 133:16 168:8 170:4
desperation (1) 44:16
despite (5) 45:18 85:19 86:23 149:8 154:1
detail (12) 71:20 75:16 92:24 94:19,24 95:24 96:1 97:13 101:23 106:22 142:2 199:7
detailed (3) 27:5 63:19 185:21
detailing (1) 186:13
details (7) 2:7 63:17,17 106:5 156:8,9 166:6
deteriorating (2) 46:7 127:1
deterioration (4) 48:24,24 49:14,25
determined (1) 35:9
detrimental (2) 34:24 36:12
devaluation (1) 100:24
devastating (3) 32:21 53:10 130:7
develop (15) 10:5,16,25 12:14,17 14:7,8 54:10 58:11 59:4 86:4 95:7 104:9 180:12 193:11
developed (15) 8:19,25,25 9:20 53:25 54:15 56:7,7 66:24 67:8 76:23 84:21 85:10 103:15,20
developing (12) 6:12 13:22 14:2 77:13 79:10,17 84:25 94:17 95:11,12,14 126:14
development (14) 11:1 53:23 65:2,2 76:24 77:13 79:19 80:8 84:18,20 85:3 86:13 103:17 104:17
developmental (1) 24:19
diabetes (3) 82:23 126:20 199:11
diagnosed (8) 67:14,20 163:12,13 194:3 197:10,15,21
diagnosing (1) 81:3
diagnosis (18) 66:4,20,25 67:15 81:22 88:11,14 172:1,2,3,7,8,10,11,13,14 177:25 194:17
diagnostic (1) 181:14
dialising (1) 131:21
dialysis (70) 108:7 118:2 121:20 127:9,13,14,18,19,20,21 128:1,6,8,11,14,16,22,25 129:8,12,16,25 130:1,24 131:2,4,4,9,12,16,18 132:5,17,24 133:2,4 134:1,3,9,13 135:12,13 136:24 138:18 139:7 142:4,13,15,17,18,21,25 143:1,3,9,10 144:20 145:20 147:25 149:17 151:1,3,11,14,16,24 152:7,19 153:17,19
didnt (48) 10:3 20:10 29:5 32:23 37:24 40:9 42:3,9 44:20 46:17 47:4 51:6 52:5 58:15,15 67:11,20 69:19,19 80:3 85:4,22 86:4 111:21 112:13 117:19,23 119:1,18 120:7 123:9 129:9 136:16 138:25,25 139:13 140:19 143:8 144:13 145:12 147:20 148:3 150:14 165:12 169:4 192:6 193:3 202:12
die (9) 11:11 22:14 23:2 58:13,13,18,24 143:1 193:5
died (7) 22:12 35:4,6 58:12,23 115:17 129:15
dies (1) 16:1
difference (4) 116:1 123:10 142:16 148:14
differences (2) 145:14 176:3
different (45) 10:11,25 11:19,19 26:20 27:2 40:4 46:22 60:9 65:9,14 80:21 97:5 122:2,3,4,24 123:13 125:1,3,3,6,7,18,19,21,24 127:21 130:11 131:7,7 134:4 140:5 141:3 145:15,15 148:6,8 164:14 174:2,3,22 180:11 181:7 193:18
differently (5) 59:23 104:2,12 134:21,22
difficult (26) 21:11 23:15 24:20 26:2,19 36:17 49:16 51:6,13,20 59:12 61:4 62:17 68:18 98:3 114:9 125:4,22 126:3 151:12 164:23 170:23 177:25 182:11,17,23
difficulties (9) 25:3,21 42:24 51:11 70:12 81:20 102:3 159:21 173:17
difficulty (6) 24:10 81:24 86:16 92:11 177:15 188:11
digital (4) 23:25 53:18 56:6,10
dignity (1) 14:18
dimension (1) 77:3
diminish (1) 182:9
dire (2) 60:1,2
direct (1) 110:11
directed (1) 100:20
directly (7) 7:1 123:21 126:10 144:23 145:11,13 164:15
director (6) 106:3 107:5,15 108:3,11 116:9
directors (4) 15:7,9 49:4 55:16
disabilities (12) 5:25 7:15,20 8:2,12,22 11:16 12:12 15:12 25:20 27:7 42:11
disability (19) 4:4 6:22 8:15 16:23 17:6 21:8 22:13,21 23:7 24:18 36:14 43:12 52:21,24 54:4 61:6,6 102:12,16
disabled (1) 202:18
disabling (1) 201:22
disadvantages (1) 62:3
disappeared (3) 32:20 36:9 142:19
disco (1) 56:3
discomfort (1) 62:14
discuss (1) 175:7
discussed (2) 167:13 202:3
discussing (1) 30:10
discussion (1) 148:5
discussions (6) 5:1 35:25 77:12 79:25 80:2 200:16
disease (43) 107:12,14 108:5,22 110:8,9,17,21,23 111:1,20 113:21 115:21 117:11,12,18 118:1,20,20 119:2,8 120:9 121:10,18,19 124:1,15 126:15,23,25 130:7 134:5,14 148:2 150:3 155:13 159:1,1 174:18 177:7 183:13 194:11 195:8
diseases (4) 159:3 194:22 195:3,4
disinclination (1) 184:20
dismiss (1) 82:5
dismissal (1) 68:9
dismissed (4) 67:17 68:8,13 93:19
disproportionately (1) 102:1
distinction (1) 39:21
distinguishes (1) 39:11
distressing (1) 171:4
distribution (3) 133:13,21 135:19
diverse (4) 18:20 19:7,12,13
diversity (1) 18:6
doctor (20) 115:17,23 127:3 156:18 157:14,20 158:24 160:9,19 167:20,25 168:12 169:15 171:2,6,20 172:3 194:1 198:25 200:15
doctors (12) 119:6 124:3 136:15,15 141:16 143:22 144:15 165:9 170:17 175:5 196:25,25
document (6) 8:5,8 18:3 84:14,17 156:12
documentation (3) 2:21 31:5 60:18
documents (4) 66:7,12 89:5 196:10
does (19) 10:12 11:21 15:25 17:23 71:25 75:3 83:9 107:10 109:10 126:9 146:1 154:5,21 161:12 168:19 171:13 173:21 184:23 197:4
doesnt (16) 18:18 20:11 24:20 29:11 38:11 70:5 72:17 83:16,18,22 141:17 143:25 150:7 162:17 169:4 182:19
doing (34) 18:14 20:25 26:7 28:19 31:14 45:21 46:5 48:7 52:14 57:5,14 66:17 74:9 85:6 117:6 124:6 137:21 157:21,21 159:8 165:11 169:2,3 178:19,19,20 182:2,4 184:6 186:9 189:4,5 192:4 200:10
donated (1) 112:6
donation (2) 137:23,25
done (19) 6:10 28:15 39:6 74:15 82:19 139:3 140:7 145:12 158:23 159:15 160:1 174:9 175:10 177:4 181:2 183:23 184:1 186:3 201:24
donor (3) 136:8 137:24 138:3
dont (106) 3:1,5 5:4 10:12,13,18 13:5 15:2,14 20:8,22 21:4,5,13,14,22 23:4,5 27:16 28:23 29:17 34:8,9 35:16 41:25 47:2 50:9 52:4 58:11,13,13 59:20 60:15 62:9 66:16 72:6 74:13 75:22 79:2 81:14 82:1,2,8,16 83:4,18,20 90:9,18 93:20 97:5,12 99:8 101:7,7,11,22 106:16 114:23,23 115:25 131:13 132:10 134:25 141:21 148:13 150:7,10 159:20 160:10 161:12 166:13 170:3 171:23 173:4,6,7 174:1,25 178:8,8 181:3 182:1 186:11,12 188:3,4,4,7 189:2,22 191:8,12,14 193:13 194:4,11,16 195:19 197:6,16 198:2,18 199:25 201:8 202:12
doorstep (1) 46:2
doubled (1) 164:22
doubt (8) 28:10 40:22 74:2 78:22 80:12 87:6,23 90:6
down (25) 18:24 20:12 30:12,13 36:24 44:14 56:18 59:22 61:23 62:20 72:11,12 85:7 109:19 112:25 113:24 126:25 134:3 137:7 138:5 166:11 181:12 185:1 198:21 200:9
downgraded (1) 160:5
downhill (1) 69:21
dozen (1) 168:3
dozena (1) 168:3
dr (12) 82:20 93:4 155:25 156:1,2,7,12,17 201:3 202:19,21 204:9
dramatic (4) 11:12 54:6 58:6 198:20
draw (2) 172:21,22
drawing (1) 8:7
drink (2) 151:16,20
drinking (2) 151:2,10
drivers (2) 132:2,8
driving (2) 46:1,2
drop (1) 184:10
dropped (2) 50:12 185:9
dropping (1) 46:2
drowned (1) 38:6
drug (4) 82:10,23 199:10 200:2
drugs (3) 82:19 136:20 200:6
due (6) 23:5 103:5 111:7 123:3 129:7 169:20
dumfries (1) 162:10
dundee (1) 157:5
duration (1) 2:3
during (23) 5:7 12:8 17:22 25:13 26:12 61:4,7 68:20 92:17,21 101:8 114:24 127:24 128:1 136:1,4 139:20 140:24 141:21 151:2,10,16,25
duty (1) 27:24
dying (1) 166:11
dysfunction (4) 89:1 184:16,19,23
dysfunctioning (1) 181:22

E

ear (1) 149:21
earlier (17) 9:17 11:3 12:15 20:13 31:18 47:24 58:18 81:7 87:8,20 121:2 130:12 136:9,19 146:17 174:24 189:8
early (17) 5:23 11:1 30:4,5,8 37:20 38:1 45:23 80:4 90:3 130:6 150:23 161:20 170:6 176:19 181:25 202:8
ears (1) 32:3
easier (6) 48:17,19 56:17 82:4 122:16 126:8
easy (7) 10:14 26:3 65:9,10 103:21 116:16 149:24
eat (3) 151:13,16,19
eating (2) 151:2,10
ebook (1) 56:11
echo (1) 60:23
edge (1) 69:18
edinburgh (7) 20:25 24:1 57:12 73:5,6 137:20 157:4
educate (2) 20:7 40:22
educating (1) 12:10
education (11) 5:22 12:6,19 20:6 54:23,25 85:12,13 86:3 198:11 200:24
educational (1) 12:20
educator (1) 65:1
effect (10) 34:24 91:23 132:18 134:7 136:16 137:13 167:14 169:21 170:1 195:2
effective (4) 28:19 48:20 54:9 66:4
effectively (2) 112:25 166:2
effects (6) 58:4 87:22 91:9 178:24,25 196:11
efficacy (2) 82:22,25
effort (7) 19:16 53:6,8 68:23,24 77:10,11
efforts (3) 45:18 144:19 149:8
eg (1) 176:25
either (21) 21:14 26:21 30:15 39:25 78:19 80:1 81:16 82:3 127:11 149:9 161:3 168:1,24 171:14 177:3 189:9,12 190:11 197:21 202:16,16
elderly (2) 188:21 197:9
element (3) 12:20 18:8 195:11
elements (2) 81:4 200:17
eligible (2) 137:11 144:4
else (24) 11:20,21,22 12:3 17:23 49:9,10 59:18 61:14 78:12 101:19 113:13 122:1,1 142:9 145:2 149:13 150:15 151:2,5 154:5 160:4 165:12 187:20
elsewhere (1) 190:14
email (1) 123:22
emails (1) 118:14
emanated (1) 83:24
emanates (1) 101:4
embark (1) 119:5
embarrassed (1) 21:14
emergence (1) 86:21
emergency (1) 37:16
emotion (1) 124:21
emotional (12) 11:2 15:17,25 32:16 44:7 46:11 48:24 49:14 51:12 62:13 100:24 155:5
emotionally (4) 46:8 47:9 58:25 60:12
emotions (1) 22:10
emphasise (2) 62:2 127:22
employ (1) 167:25
employees (1) 196:17
employer (4) 72:2 100:9 102:5,7
employers (3) 196:12,15,16
employing (1) 196:16
employment (12) 16:9 71:13 72:1 89:8 100:8 101:20 102:4,5,14 110:7 144:9 197:8
enable (4) 10:17 14:10 100:9 128:2
enables (2) 11:22 72:11
enabling (4) 6:9,13,15 8:23
encountered (2) 26:13 187:4
encourage (1) 154:11
encouraged (1) 28:9
end (15) 5:25 23:22 25:8 52:2 76:11 77:4,6 93:14 106:19 151:17 153:16 157:18 168:25 170:22 185:8
ended (2) 23:11 146:2
ends (1) 86:12
energy (2) 181:11 183:19
engage (4) 12:12 20:4 56:24 59:13
engaged (1) 13:19
engaging (1) 86:16
england (7) 84:24 108:25 109:2 122:7,18 123:11 137:22
english (1) 74:5
enjoy (3) 18:14,17 62:6
enjoyable (1) 19:4
enormous (1) 50:19
enormously (2) 28:9 113:19
enough (13) 46:15 61:4 69:8 82:2 100:7 127:5,9 136:7 138:25 165:10 186:7,8 200:22
enshrined (1) 26:4
ensure (7) 8:11 9:24 25:25 27:6 29:20 34:21 47:7
ensuring (3) 9:4,8 53:8
ent (1) 98:22
entail (1) 107:10
entails (2) 17:2 107:11
entire (1) 181:21
entirely (3) 90:12 128:21 144:7
entirety (1) 80:17
entitled (1) 89:7
environment (4) 34:6,7 73:19 190:23
epilepsy (1) 17:12
epsteinbarr (2) 67:10 74:23
equality (2) 80:19 102:12
equally (1) 19:5
equals (3) 76:22,24 77:4
equates (1) 103:17
equation (1) 47:18
equipment (14) 34:14 52:15 55:6,9 131:18 132:3,9,13 133:10,22 134:16,16,20 135:17
especially (6) 110:9 137:5 153:1 170:22 188:3 201:13
essentially (5) 40:2 48:1 162:20 165:1 199:23
establish (1) 76:2
established (5) 4:6 77:24 78:1,24 198:2
establishment (2) 78:18 79:20
estimate (2) 110:20,22
estimated (1) 89:19
et (2) 125:8,8
even (29) 12:15 21:3,12 26:3,14,23 34:20 36:21 42:10 49:3 50:10 52:9 57:14 58:5 67:11,13 69:24 77:7 106:16 141:20 150:13 154:2,20 159:14 160:1 180:21 185:6,22 191:1

evening (3) 55:17 64:16 147:15
event (7) 19:17 37:16 38:17 41:8 79:24 111:6,13
events (4) 87:5 113:9,25 114:14
eventual (1) 30:1
eventually (9) 35:17 46:11 68:24 127:8 133:12 148:18 152:3 153:23 194:16
ever (8) 37:18 39:7 47:10 60:5 73:19 93:17 142:22 158:7
every (11) 14:21 22:22 34:23 39:1 48:3 100:2 146:8 164:13,21 165:24 175:7
everybody (31) 1:3 8:25 11:20,21,22 17:23 24:16 35:24 36:9 48:17 49:18 50:16 54:21 71:5,6 79:4 91:21 101:19 108:21 125:23 131:5 145:8,9 147:4,7,7 154:4 164:4 174:5 181:6 196:22
everybodys (2) 54:17 196:21
everyday (2) 17:20 89:4
everything (11) 2:20 31:16,17 41:12 51:21 60:17 79:15 106:15 150:13 185:1 191:21
everywhere (1) 109:8
evidence (41) 1:7 2:12,15 3:6 47:20 53:12 60:19 63:25,25 64:3,19 66:10 71:21 72:22 73:2 87:23 90:20 103:9 105:10,13 106:9,10,12,17,25 107:12 146:17 150:11,14,17 153:12 155:3 156:17,21,21,22 166:20 179:4 180:5 189:9 200:14
evident (1) 16:25
evolved (2) 5:6 9:20
exacerbated (3) 28:1 134:17 192:15
exact (2) 115:3 202:14
exactly (7) 17:24 18:7 27:18 28:8 41:9 151:8 157:10
examination (1) 164:18
examining (1) 171:17
example (36) 11:14 13:18,20 23:20 30:24 37:14 47:20 84:12 96:5 99:3 110:5,7,18 114:22 127:13 144:4,11 145:25 172:22 173:8,11 174:7 176:9 178:21 180:25 181:4 183:14 186:2,15 188:9,16 190:3 194:5 195:1 196:18 201:14
examples (1) 187:3
excel (1) 6:15
excellence (1) 120:16
excellent (1) 1:9
except (1) 138:12
excerpt (2) 143:15 156:13
excised (1) 116:11
exciting (3) 9:25 10:8,9
exclude (1) 10:19
exclusion (1) 67:1
exclusive (1) 7:23
exclusively (1) 71:11
excruciating (1) 190:25
excuse (1) 169:11
executive (1) 5:12
exercise (11) 65:16 82:14 158:4 165:6,13,16,17 166:3,11 192:4 201:1
exercising (1) 196:1
exhausted (1) 50:14
exhaustion (1) 59:11
exhibited (1) 21:3
exhibitions (1) 21:2
exist (6) 83:16,18,22 176:20 195:10 200:6
existed (1) 160:3
existence (3) 41:1 51:10 74:21
existing (2) 104:7 132:16
exists (1) 68:10
expanded (1) 92:6
expect (4) 11:10 87:2,14 152:24
expectancy (1) 11:7
expectation (2) 33:18 87:1
expected (7) 22:14 36:7 126:14 127:12 148:12 161:2 177:9
expecting (3) 11:8 23:1 105:9
experience (29) 4:8 10:1 20:8 27:8 28:8 73:9,16 77:25 78:2,3 84:10 87:2,14 89:3,12,16 91:10 104:14 108:10 131:15,19 152:1,14,16 157:15 162:4 167:16,22 181:7
experienced (4) 24:9 62:13 94:12,15
experiences (2) 96:11 162:7
expertise (2) 10:15 176:21
experts (5) 32:19,19 38:22 54:3 73:16
explain (17) 17:1 21:7,16 22:7 64:21 65:11 89:13 96:12,14 123:25 128:4 132:15 144:16 158:21 161:9 164:11 183:21
explained (6) 75:23 88:14 117:9,17 136:19 142:25
explaining (1) 53:19
explains (1) 11:6
explicit (1) 146:14
explore (3) 18:9 86:23 193:22
exposed (1) 153:22
exposure (1) 128:17
express (2) 69:4 183:15
expression (1) 182:9
extends (2) 4:1 12:21
extensive (1) 12:8
extent (7) 12:2 18:15 65:5 70:2 87:16 182:8 188:15
extra (1) 136:22
extraordinary (1) 198:22
extrapolate (1) 184:12
extreme (8) 179:9,12,14,18 187:4 189:17,20 190:10
extremely (4) 134:12 177:22 179:16 189:8
extremity (1) 188:10
eye (3) 31:15 41:11 53:19
eyes (1) 179:19

F

fabulous (3) 6:16 55:3,19
face (5) 102:21 110:14 185:8 189:9,10
facebook (1) 76:16
faced (1) 85:15
facetime (1) 46:18
facetoface (2) 31:1 73:21
facilitate (1) 10:15
facilitated (1) 1:10
facilitating (1) 6:8
facilities (2) 15:1 20:23
facing (1) 153:6
fail (2) 39:19,20
failed (3) 62:19 129:12 134:5
failing (1) 25:17
failure (10) 25:24 108:6 110:9 127:6 129:2,10,11 132:18 136:6,17
fair (6) 3:25 81:4 90:23 109:4,5 184:21
fairly (4) 15:12 41:4 156:16 162:21
fall (2) 179:25 187:14
falls (1) 21:9
families (83) 7:1,8,16 8:14,22 12:12 15:4,10,24 16:4,10,13,18 17:19 21:7,12,13 22:22 23:9,18,25 24:9 26:10 30:15 31:1 32:11,17 33:13,16 34:2,3,8,18,20 35:2,8,20,20 36:7,13 38:8,20,22,24 39:5 40:10 43:16,21,25 45:9 46:19,22 47:5,17,25 48:11,18 50:2,4,9 52:5,23 53:5,14,22 54:10,24 55:4,10,14,18 57:7,9 59:6,9,10,23 60:4,10 108:22 124:15,17 187:2
family (59) 4:14 8:16 9:20 14:1,3 15:6,7,9 16:2,8,20,23 17:3,18 19:20 20:1 21:17,20 25:10 26:7 31:19,20 32:3,7,9,22 33:1 34:12 35:10 37:1 43:20 44:19 46:13,24 47:25 48:3,5,12 49:4 51:10,24 54:1 55:1,16,19 56:7,9 58:8 61:19 69:24 70:2 71:16 83:8 94:1 96:5,21 101:12 124:13 177:19
familys (1) 17:17
fantastic (3) 6:7 15:13 20:7
far (6) 21:16 23:2 102:18 122:25 192:10 198:13
fast (1) 86:4
fatal (1) 129:10
fatality (1) 202:9
fatigue (18) 68:6,7 88:25 172:22 179:9,12,14,21 182:7,8,11,17,24 183:7,9,18 187:4 191:21
fatigued (3) 179:16,23 180:7
fault (3) 116:16 160:9 174:23
fear (4) 24:9 62:13,21 193:14
features (2) 2:25 162:2
feed (4) 55:25 56:1 79:24 147:17
feedback (3) 57:7 85:17 147:3
feeding (2) 34:15 187:11
feel (16) 44:20 46:4 59:1,6 70:21,22,23,23,23,24 78:19 101:3,5,5 120:7 181:20
feeling (8) 4:13 9:15 38:3 62:16 101:4 113:20 180:7 194:10
feelings (1) 100:23
feels (1) 181:8
felt (19) 28:25 37:20 38:6 42:6 50:15 57:2 62:17 67:2,13 68:12 70:1,1,4 92:20 124:24 139:21 145:4 167:20,22
female (2) 101:25 195:17
fence (1) 65:13
festival (3) 24:2 57:12,21
festivals (1) 10:7
fever (3) 67:11,11 192:21
few (14) 64:25 67:7 72:14,19 110:23 115:19 149:12 150:25 176:14 188:6,6 191:20 193:9 198:7
fife (1) 57:18
fight (2) 13:1 26:22
fighting (1) 25:11
figure (1) 101:24
figures (1) 90:21
film (2) 16:25 42:5
films (1) 24:1
filter (1) 40:6
filtered (1) 30:13
final (1) 155:25
finally (8) 101:20 103:6 106:22 135:25 140:16 150:15 153:10,25
finances (1) 17:23
financial (2) 109:7 200:18
find (9) 32:20 45:22 98:3 121:9 143:20 168:16 177:12 181:1 185:3
finding (3) 48:25 55:5 56:19
fine (4) 18:2 30:19 44:24 165:12
finish (1) 57:25
fiona (4) 105:9,12 106:3 204:7
firing (1) 185:10
first (26) 14:22 78:1 81:21 91:8 92:17,21 117:16 123:22 126:13,19 127:15 129:22 137:5 142:3 143:16 147:14 153:18 165:3 166:22 167:17 176:14 177:15 179:8,8 202:8,9
firstly (1) 105:24
fit (5) 72:17 80:22 100:3 102:11 159:6
fits (1) 80:21
five (8) 14:2 54:20 92:7 108:7 109:17,17 152:6 196:25
fixing (1) 201:25
flareups (1) 94:15
flavour (2) 18:12 157:19
flexible (2) 55:15 102:6
flickthrough (1) 56:11
floor (1) 15:2
flow (2) 37:5 78:25
flu (2) 70:22 181:10
fluctuating (5) 67:3,7 69:21 70:8 91:15
fluctuation (3) 67:22 68:1 69:3
fluctuations (2) 69:16 89:3
fluidgiving (1) 34:15
fluids (1) 131:22
focus (1) 99:16
fog (1) 69:5
folk (1) 21:3
follow (1) 197:3
following (9) 86:20 89:2,15 91:17 94:6 101:22 146:14 184:8 198:14
followover (1) 177:1
food (3) 144:3,10 149:4
footnoted (2) 66:8 156:12
fore (1) 11:6
foreseen (1) 202:17
forget (1) 180:8
forgetful (1) 197:11
forgetting (1) 180:17
forgotten (3) 59:7,17 82:23
form (4) 27:14 60:10 118:3 127:13
forms (1) 135:6
forth (6) 12:25 61:20 78:25 88:2 118:14 123:1
fortunate (3) 14:5 65:20 127:9
forward (8) 11:15 41:6 54:20 79:19 87:3 104:3 155:12 174:10
found (10) 54:8 69:20 98:3 118:6 145:24 146:7,11 158:4 165:18 184:4
founding (4) 8:9,10 9:24 20:14
fount (1) 73:15
four (15) 37:3 40:2 66:22 67:23 86:11 115:2 125:7 128:15 152:6 157:10 176:9,9 194:8 195:22 199:22
fragile (1) 31:22
frail (1) 132:1
frailty (5) 22:2,15 23:3 29:25 30:16
frame (1) 34:11
framework (5) 31:21,22,23 32:2 41:12
frank (2) 96:25 195:20
frankly (2) 189:21 190:12
free (3) 4:13 56:25 168:24
frequency (2) 130:23 136:3
frequently (1) 17:16
friday (2) 56:2,3
friends (8) 19:6 57:5,18 70:2 73:13 83:8 101:12 177:19
frightening (2) 32:9,25
front (1) 63:21
frontline (3) 44:6 98:13 114:17
frustrated (1) 185:10
frustration (1) 97:20
fulfil (1) 62:5
fulfilling (1) 11:5
full (15) 1:24 11:11 49:18 63:14 87:2,14 106:2 146:8 156:7 159:22 164:17 171:15 191:15 192:5 201:9
fulltime (3) 13:14 96:19 109:15
fully (4) 47:10 116:16 122:10 168:8
fun (2) 16:15 19:10
function (3) 185:3,25 186:2
functional (1) 99:13
functions (1) 184:6
fundamental (4) 9:14,24 12:13 39:15
fundamentally (1) 40:3
funding (6) 14:1,4 75:21,22 104:4,17
fundraising (6) 113:7,8,15 114:3,7,14
funds (1) 113:25
funny (1) 181:19
furlough (3) 114:22 115:1,8
further (21) 36:24 60:16 69:19 84:24 85:7 95:3,8 96:9 98:15 103:10 109:19 110:3,10 149:24 150:10 153:17,21,25 156:11 174:10 201:4
future (6) 12:6 38:19 62:23 93:25 103:7 155:10

G

gain (1) 73:11
gained (1) 73:24
gale (28) 63:6,7,13,14 88:4 90:19 91:3 104:24,25 155:23,24 156:4,5,6,7 160:17,18,19 169:17 191:5,6 197:24,25 202:19,24 203:2 204:6,10
galleries (1) 21:1
galloway (1) 162:10
garden (2) 46:25 113:24
gastrointestinal (1) 88:20
gather (1) 181:21
gave (4) 25:7 57:3 163:17 166:22
gazebo (1) 46:25
gender (2) 194:18 195:6
general (10) 32:14 33:5 75:4 88:23 98:1 157:7 164:15 168:19 189:12 197:12
generalised (1) 166:2
generally (9) 93:16 114:5,8 146:18 172:6 192:19 193:20,24 194:12
generation (2) 12:7,15
generic (1) 122:21
genetic (1) 108:6
genuine (1) 127:5
genuinely (1) 193:13
geographical (1) 109:11
geography (1) 80:23
geologist (1) 100:3
get (105) 5:18 6:20 7:5,5 9:2,2 14:21 15:22 19:17 20:4 21:18 22:18 32:7,23 36:19,21,23,24 40:9 44:11,24 45:16 46:1 50:18 55:21 59:9 60:6,11 68:22 69:9,9,10 72:5,10 76:1 81:6 82:14 90:20 93:17 98:4 101:13,16 109:10 113:17,22 119:14,22 120:24 121:13 122:6,21 124:7 127:10 128:5,9,20 129:21 132:6 141:5,7,8,19 148:7 149:4,10 153:14 159:23,24 165:10 166:2 171:1,20 174:2,8 176:3 177:6 178:19,20 179:20 180:24 181:7 182:13 185:9 188:7,25 189:25 190:1,4,4,22 191:23,24 192:6 194:15,16,17,25 195:4 197:10,11,16 198:19 200:1,10 201:1
gets (5) 10:23 174:5 180:23 194:6 199:23
getting (25) 14:4 25:16 43:25 44:10,10 50:17 59:15 67:15 73:5 76:14 98:24 110:2 117:11 126:21 138:2 140:12 143:17 149:10 152:16 161:1 162:17 165:8 180:24 186:7,8
gift (1) 136:13
give (42) 1:7 4:17 12:9 13:17 18:13 22:23 33:12 39:1 56:23 61:23 63:24 64:19 68:13 72:14 73:2 86:20 96:3,4,4 99:3,25 101:2,23 102:25 106:18 112:8 120:4 122:11 124:18 128:9 130:12 131:3 134:12 135:15 142:22 150:5 151:8 185:5 188:9,15 192:3 198:9
given (23) 9:16 63:19 73:3 74:21 81:23 95:22 105:13 114:2 125:8 127:12 135:11 146:13,22 149:12 151:14 158:13 163:5 165:5,19 166:6 175:8 181:19 193:23
gives (2) 7:18 10:1
giving (8) 3:5 58:1 71:20 105:10 106:9,24 137:8 158:11
glacially (3) 77:22 86:17,18
glandular (2) 67:10,11
glasgow (1) 137:20
global (2) 133:5,6
globally (1) 199:15
gloves (2) 34:14 45:25
goal (1) 7:23
goes (7) 4:5 16:2 34:1 71:1,7 190:8 194:6
going (75) 2:8 11:25 14:19 17:25 18:8,23 22:17,22,24 23:14,17 26:9,21 33:19,21,21,21 36:17 37:4 38:21 48:7 50:11 52:17 53:14 60:11,13 66:23 69:20,22,25 70:17 71:2,17 72:19 75:15 79:3 93:13,17,17,18 96:1 97:5 98:15,16 100:13,14 105:10,18 110:3 111:16,18 118:11 121:25 125:19 126:25 129:19 135:2 142:21 144:6 147:14 150:2 151:6 157:20 167:2 168:1 171:18 183:11 184:16 186:5,6 188:7 190:23 200:5 201:2 202:11
gold (1) 136:5
gone (2) 32:21 83:16
good (47) 1:3,4,14 23:23 32:10 55:8,18 57:18 62:25 63:6,7,11,11,14 70:15,16 71:23 72:4 78:24 82:18 97:7 104:22 105:1,7,8,14,16,17 118:18 120:22 140:11 146:25 147:3,8 155:16,19,23,24 156:2,3 159:6,6 160:18 196:9,16 202:13 203:4
goodness (1) 50:5
goss (2) 78:4 167:8
gotten (1) 135:23
government (47) 6:11 26:16 27:4 36:1 38:2 40:21,22,25 41:21 42:1,7,23 43:6,8,10 56:1 59:14 76:1,4,13 77:1,17 78:14,15 79:12,25 80:2,4,7 84:14 86:25 103:13 104:1,16 115:9 118:11 119:6 122:9 144:20,23 146:23,25 147:13 148:18 149:21 153:3 154:8
governmental (1) 119:1
governments (2) 130:19 138:10
governors (1) 3:20
gp (23) 67:16,20 68:18,22 81:16 85:17,23 97:18,21 98:2,4,13 99:4 146:1,8 148:2,3 157:11 160:22 171:20,24 173:12,17
gps (7) 68:13 69:9 85:14 86:1 97:23 146:7 189:20
graded (1) 165:17
gradual (1) 190:6
gradually (1) 118:24
graduated (1) 198:4
graham (59) 1:11,11,16,20,25,25 2:5,13,18 3:15,18,20,24 4:3,9,22 7:13 9:8 10:21 11:13 12:20 13:8 14:12 16:21 18:1,21 19:13 21:19 24:8 27:3,21 28:8,11,21 29:22 30:21 31:17 37:10,12 38:14 39:8 41:19 42:14 43:3 44:22 47:23 49:21 50:5 51:7,9 52:20 54:13 56:5 57:24 60:3,22 61:16 62:2 204:2
grandchildren (1) 124:18
grant (2) 109:7 110:11
grateful (8) 2:6,23 60:15,17,24 73:2 136:12 156:19
great (15) 4:16 5:3,25 7:4 23:16 53:5,5 72:25 75:16 94:19 95:15 96:1 107:4 131:15 139:17
greater (4) 9:14 78:20 112:9 119:3
grew (11) 52:18 118:16,16 119:10,10,20,20,20 122:15,15 168:21
grey (1) 184:10
grips (1) 98:24
ground (1) 7:9
groundwork (1) 84:18
group (63) 6:19 7:24 9:1,2 18:7 21:6 29:7,9,9 37:1 38:7 39:16 40:13,17 41:21,22 42:2,2,12,13,13,18,19 43:10 54:22 57:1,13,14 61:8,10,12 66:2 71:10,12 74:3,6,6,7,10 75:23 76:15,16,16,17 77:25 78:2,3,5,6 91:11,20 92:18 93:9 154:2 163:9 174:12 175:1,5 178:22 184:2 196:3,14 197:7
groups (6) 30:6 39:25 74:5,14,18 197:22
growing (1) 111:20
grown (2) 97:10 109:14
guarantee (1) 100:10
guardianship (1) 15:23
guess (17) 4:22 9:1 12:20,21 13:2 14:9 16:24 19:4,7,23 26:6 33:14 39:14,19 46:16 48:13 51:13
guidance (18) 26:14 27:1 46:13,14,21 47:1 48:23 50:23 117:2 119:17 121:5 123:6 144:14,24 146:19 147:11 165:16,17
guidances (1) 172:16
guideline (1) 85:21

guidelines (3) 85:20 120:19 172:24
guys (1) 13:3

H

hadnt (10) 28:14,15 29:6,10 61:13,21,22 123:21 164:17 170:20
half (7) 45:2 85:8 91:6 108:9 165:25 168:3 200:4
halftime (1) 100:7
hallways (1) 34:17
hampshire (1) 112:24
hand (1) 85:25
handing (1) 85:23
handled (2) 134:21,22
handling (3) 17:11 52:13 55:1
hang (1) 31:22
hanging (1) 196:23
hangover (1) 97:25
happen (18) 10:10 26:18,18 58:15 75:9 86:4,17 87:9,11 104:5,15 126:7 144:18 162:16 167:7 180:24 193:3,7
happened (21) 43:13 47:22 60:3 86:6,8,9,9,17 87:5 108:3 112:16 114:2 126:3 128:21 139:4 162:22 168:5 176:23 182:1 183:11 192:9
happening (12) 37:21 50:10 62:12 74:12 80:16 84:23 114:6 117:14 131:14 139:23 140:23 164:12
happens (6) 7:17 11:3 31:9 162:20 168:7 189:25
happy (3) 2:11,15 106:12
hard (12) 63:22 65:11 66:2 67:15,16 77:9,14,15 120:3 138:24 165:10 185:19
harder (3) 178:23 194:6 200:25
hardest (4) 67:25 68:9 69:2 124:25
harm (1) 35:10
harmful (3) 165:19,22 166:1
hasnt (4) 5:9 8:20 86:15 163:12
haste (1) 103:6
hasten (1) 35:5
havent (17) 20:7 36:25 37:3 58:18 61:1 78:6 137:15 152:22 166:6 173:13 177:4 182:14 185:22 186:3 188:23 192:19 193:24
having (42) 14:17 15:15,23 17:19 22:23 23:10,12 26:22 48:8 50:21,22 57:10,10 64:20 65:10 67:17 68:19 70:5 71:25 80:10 81:15 92:3 93:23 121:6 125:2 129:17 136:16,24 140:24 148:6 152:4 154:3,18 167:19,20,21 172:13 173:8 177:24 181:9,15 182:8
hay (1) 192:21
hazard (1) 169:13
hazarding (1) 39:14
head (6) 28:16 67:18 75:6 112:24 176:25 198:6
headaches (1) 191:22
headed (2) 89:12 157:2
heading (1) 187:6
headlines (1) 197:1
heads (1) 28:12
health (87) 5:21 9:11 12:7 17:7 29:3 31:10,24 34:25 35:25 36:2 46:6 49:5,9,10 50:1,3 64:22 65:7,11,12 68:17,19 69:20,23 70:3 72:15 76:4 77:5 78:13,18 80:20,22 81:5,8,9 82:6,7 83:19,20 84:22 85:10,14 86:3,13,16 88:6 93:2,7,23 95:7,8 96:23 97:5,14 98:13,23 99:21 100:15 103:23 119:5 123:18 140:25 144:24 148:24 152:22,23 153:2 154:18 155:11 157:11 163:16 164:9,13 166:21 167:19,24 170:11,13 175:2,5,24 192:20 193:8,10,14,21,25
healthcare (12) 23:5 31:6 58:16 72:21 79:12 129:6 167:11 168:20,22,24 177:18 179:2
healthy (3) 8:12 9:4 100:3
hear (17) 18:19 21:12 77:10 82:20 87:23 93:4 99:9 103:4 105:9,15,24 116:5,23 125:17 150:16 171:3 192:7
heard (32) 6:10 20:13 37:25 38:3,7 44:21 47:19 69:10 76:1,15,21 81:21,25 132:1 139:8 148:10 151:9,17,25 169:18,18 172:6 173:16 178:5 180:5 182:15 189:10 192:7,11 196:9 202:4,8
hearing (6) 8:20 72:20,23 148:25 149:2 203:6
heart (13) 76:5 79:11 84:10 103:23 104:14 137:9 161:13 162:18,21 164:21 174:17 182:1,2
heartbeat (1) 92:11
heartbreak (1) 48:18
heavy (2) 21:10 132:6
height (1) 50:9
heightchanging (1) 14:16
held (4) 3:19 5:14 64:11 107:8
helen (2) 78:4 167:8
hell (1) 188:1
help (27) 21:15 31:1 32:15,16 35:11 45:15 46:5 53:13 74:14 81:17 82:4 85:3 93:25 99:14 110:10,10 113:11 159:7 169:2 170:19 171:7,8 177:4 185:14 188:23 189:1 194:12
helped (4) 43:19 55:18 152:16 185:16
helpful (9) 18:19 56:10 88:15 89:18 95:20 126:2 149:16 150:16 166:3
helpfully (3) 2:8 66:6 92:5
helping (3) 55:8 110:4 114:14
helplines (1) 118:14
here (17) 18:3 36:24 39:20 47:22 59:18 64:8 73:2,7 85:3,7 93:1 122:11 133:6 135:8 157:14 186:11 200:2
heres (1) 122:17
heritage (1) 13:24
herself (1) 46:10
hes (1) 115:25
hesitate (1) 74:13
hide (1) 195:19
high (5) 31:6 86:24 126:20 137:12 169:12
higher (3) 25:23 48:11 161:17
highest (5) 117:24 121:16 137:9,15,16
highlevel (1) 4:20
highly (3) 22:5 115:16 177:8
history (10) 69:12 88:10 159:22 164:18 171:15 176:24 178:15 183:5,10 185:2
hit (1) 197:17
hits (3) 31:8 75:5 196:14
hmm (7) 70:11 83:1 90:16,22 94:10 102:24 103:3
hmmhmm (1) 192:16
hmrc (1) 3:24
hog (1) 77:17
hoist (2) 14:17 19:2
hold (6) 71:13,13 72:11,11 149:4 188:16
hole (1) 15:19
holidays (1) 16:12
holistic (2) 99:12 173:21
home (36) 4:11 17:22 22:23 32:4,12 33:1 34:3,8 36:16 39:22 43:20 45:1 46:13 48:10 49:19 67:5 71:13 72:10 100:7 112:1,11,12,19 115:6 117:9 127:18 128:1,6,11,16,21,23 131:18,21 133:2 159:24
homelessness (1) 196:20
homes (11) 33:14,16 34:2 35:10 39:17,18,24 40:3,5,13 152:8
honest (2) 72:3 73:18
honours (1) 157:3
hope (5) 37:4 50:25 59:12,18 155:3
hoped (2) 84:17 86:4
hopeful (2) 84:21 86:2
hoping (2) 78:17 139:9
hormones (2) 195:2,5
horrendous (2) 19:25 25:6
horrific (2) 97:9,10
horror (1) 171:3
hospital (33) 23:11 24:10,13,25 25:12,25 26:9 27:8 30:17 68:21,23,25 87:12 127:2,4,7,19 128:15 129:9 133:3,16 141:11,22 144:6 152:7,8 159:20 160:5 181:23 190:20,23 191:2 199:25
hospitalised (3) 67:2 86:24 193:5
hospitals (6) 128:13 129:17 130:25 131:1 133:4,17
hosted (1) 79:8
hour (2) 171:12,19
hours (8) 19:20 48:9 128:15 142:18 147:15 151:5,6 196:18
house (11) 19:16 45:1,6,7 46:4 48:8 72:14 121:25 132:3,7 188:20
housebound (5) 159:18,19 179:25 180:1,2
household (1) 168:21
houses (2) 33:7 201:10
housing (5) 4:12 32:1,22 34:19 110:5
however (7) 46:16 80:23 83:15 96:7 142:18 179:16 190:21
hscps (2) 27:6 28:12
hub (2) 67:4 99:16
hug (1) 124:18
huge (8) 21:21 26:8 36:12 45:10 104:11 132:15 148:25 197:8
hugely (1) 119:20
human (4) 11:17 18:8 33:19 183:20
humanity (1) 62:22
humour (1) 19:10
humza (1) 166:21
hundreds (1) 192:7
husband (3) 93:14 108:8 136:10
hyperimmune (1) 172:19

I

icu (1) 137:2
id (15) 46:9 67:11 68:19 86:22 89:11 91:21 99:20 110:14 142:1 157:16 176:15,17 179:7 191:7 193:8
idea (2) 79:18 85:1
ideal (1) 131:12
ideas (2) 12:24 56:23
identified (4) 126:24 135:15 163:6 200:17
identify (4) 94:5 101:25 173:19 198:17
identity (1) 168:9
ie (1) 80:15
ignorance (1) 83:5
ignorant (1) 169:12
ignored (1) 27:9
ill (27) 59:9 67:13 68:5 70:19,19,22,22,23 73:7 88:7,16 93:14,15 99:3 100:6 106:15 112:12 116:20 117:1 126:11 130:12 168:6 169:17 177:5 190:17 193:15 194:14
illness (18) 70:5,6 76:17,20 89:2 93:15 94:1 96:3 177:8 178:16 187:23 193:16,23,24 194:6,15 195:18 200:23
illnesses (2) 74:25 87:21
illustration (1) 13:18
im (61) 2:6,7 4:25 5:2 13:7 24:12 25:7 28:22,23 30:13 35:12 37:4,6 38:15,16,21 39:19 40:19 41:15 43:4 45:3 49:9 53:17 59:15 60:15,24 65:22 74:9 75:15 77:16,24 81:23 87:24 90:6,12 92:23 96:1 100:6,13 102:18 106:3 108:3,4 116:1,6,8 121:1 125:22 129:19 140:6 160:12 168:1 169:22 170:6,16 171:1,4,6 184:16 193:5 202:2
imaginary (1) 195:18
imagination (1) 11:2
imagine (5) 6:2 62:17 72:15 118:23 151:4
immediate (1) 43:12
immediately (1) 180:12
immune (6) 101:15 161:23 172:19 194:23 198:19,22
immuno (1) 136:20
immunosuppressants (1) 112:8
immunosuppressed (2) 111:25 112:5
impact (39) 15:8 19:11 30:23 31:8,11 34:23 36:12 43:16 49:24 50:2,14 58:2,6,18,22 60:25 61:2 62:11 71:2,10,21 89:7 93:1,23,25 94:7 96:4,5 97:7 100:14 111:3 113:6 114:3 126:12 129:4 130:22 153:4 154:17 197:8
impacted (1) 35:18
impacts (10) 8:16 35:17 71:14 72:6 95:18 96:22 149:6 153:9 155:11 170:11
implement (1) 169:2
implemented (1) 28:1
important (16) 12:6 25:14,18,19 29:16,17 36:8 49:6 58:9 62:2,8 79:17 100:16 117:6 200:24 201:18
importantly (1) 64:19
imposed (1) 29:18
impossible (1) 77:14
impression (1) 76:19
improve (4) 92:1 93:17 148:17 159:25
improved (5) 77:21 119:21 140:3 150:8 152:1
improvements (4) 147:9 148:19,19,20
improving (1) 98:10
inability (1) 183:19
inactivity (1) 47:13
inadequately (1) 17:2
inadvertently (1) 116:8
inappropriate (1) 189:13
inaudible (1) 176:6
incentre (1) 129:25
inception (1) 5:17
incidence (4) 88:1 177:9 199:5,12
include (13) 8:23,25 10:19 42:1 77:12 88:25 92:10 96:2 110:2,4,6 113:9 126:22
included (5) 75:11 98:19 117:12,24 142:5
includes (2) 101:12 143:8
including (4) 17:20 76:3 88:19 112:23
inclusion (1) 6:20
inclusive (10) 3:13 8:13 10:18 12:18 13:20,23 16:11 19:8 20:23 65:12
income (3) 100:7 196:20,22
incoming (1) 113:21
inconsistency (1) 146:10
incontinence (1) 34:15
increase (3) 50:13 197:2,5
increased (3) 52:16 78:6 113:18
incredibly (4) 16:17 50:20,25 136:12
independent (1) 188:19
index (1) 204:1
indicate (6) 72:18 91:4 94:12 158:19 196:6 198:13
indicated (2) 94:11 103:4
indicating (1) 101:25
indication (1) 163:5
individual (10) 16:3 18:22 56:12 57:4 100:21 152:3,14 157:11 166:14,15
individualised (1) 165:23
individuals (10) 3:5 6:19 18:7,14 35:3 49:15 56:13 88:9 106:24 124:14
indoor (2) 10:4,5
inequality (1) 94:5
infected (2) 69:14 169:23
infection (18) 38:23 39:3,5 75:7 88:11 91:23 92:4 112:9 135:2 137:1 141:22 150:4,4 152:2 153:1 160:23 163:3 202:15
infections (6) 44:17 136:18 143:3 145:21 167:15 201:7
infer (1) 27:24
inferential (1) 40:20
inflammation (7) 174:16 183:17,23 184:5,14 185:13,15
inflammatory (2) 159:1 194:23
influence (4) 6:18 41:22 42:7 83:15
influenced (1) 95:14
influencing (1) 85:6
inform (5) 76:24 79:18 80:7 84:11 86:3
information (61) 8:6 49:3 66:18 70:14 74:1,13,16 82:3 83:12 84:22 86:20 88:16 92:18,19 96:9 107:11 109:7 114:17 117:7,17 118:6,10,16,23,24,25 119:11,13 120:5,5,21,23 121:5,9,12,14 122:3,7,8,11,14,22,23 123:17 124:7,24 145:10 146:8,15 147:3,4,8,21 148:4 149:7,11,19,20,24 158:10 166:23
informative (1) 158:6
informed (11) 24:5,7 80:6 84:19 85:2,24 118:10,11,13 124:10 140:23
inhospital (1) 129:25
initial (5) 57:8 61:10 87:4 89:2 142:11
initially (4) 114:20 142:7,17 149:17
initiating (1) 80:1
injury (2) 134:2,17
innovated (1) 9:23
innovation (2) 12:25 135:21
input (7) 31:24 32:19 58:16 109:14 120:19 165:3 188:4
inquiry (38) 1:19 2:7,10,23 3:2 42:21 47:19 60:17 63:18 64:1,20 66:7,11 74:18 76:10 77:20 89:6 94:4 95:23 103:10 105:21 106:6,10,18 110:15 149:15,16 150:12,16 153:7 156:8,9,18,21 157:14 158:5,11 196:10
inquirys (1) 84:5
insight (1) 90:20
insisted (1) 81:10
insistent (1) 103:13
inspector (1) 3:24
inspiration (1) 62:6
instance (4) 87:25 96:5 147:16 180:9
instances (2) 35:2 98:25
instead (2) 148:3 194:15
instigated (1) 198:25
institute (1) 120:15
instruction (1) 27:13
instructor (1) 54:7
insurance (1) 173:7
intends (1) 90:19
intense (1) 16:17
intensive (3) 132:24 134:10 137:3
interact (2) 46:18 54:5
interaction (1) 59:3
interest (1) 79:9
interested (9) 53:17 92:23 110:14 158:24 170:18 171:4 175:6,9,21
interesting (10) 9:25 11:24 18:22 22:9,10 50:7 54:16 152:17 186:20 197:15
internal (1) 35:17
internationally (2) 74:7,8
interpret (2) 46:15 47:3
interpretation (3) 27:2 47:1 199:8
interpretations (1) 26:20
interpreted (1) 46:21
interrelationship (1) 95:6
interrupt (1) 37:5
intervention (1) 58:19
interventions (3) 31:1 58:14,15
interview (1) 158:7
intimately (1) 43:23
into (49) 2:24 3:1 4:12 10:23 14:8,19,21,23 15:18,22 16:9 19:24 34:11 46:10 51:21 53:8 61:5 66:17 70:18 72:25 78:10 79:20,24 90:21 95:1 104:7 106:17,22 117:6 119:3 120:24 127:6 131:7,7 132:3,6 137:3 147:17 150:12 151:6 158:20 160:6 161:5 173:2 179:25 183:11 187:14 188:17 196:8
intrinsically (1) 8:18
introduce (1) 141:14
introduced (3) 135:10 141:14 143:13
introducing (1) 133:20
introduction (1) 22:6
invariably (2) 17:14 192:1
invasive (1) 17:11
investigate (1) 173:9
investigated (1) 22:13
investigation (2) 98:16 190:21
investigations (4) 164:18 171:17 174:6,9
invisibility (4) 29:7 36:11 39:9 40:16
invisible (8) 6:9,23 13:3,4 20:17 29:9 40:14 59:11
invite (1) 126:5
involve (4) 49:17 76:25 128:17 171:13
involved (18) 4:20,25 5:2,4,16 6:6 7:5,5 13:15 43:23 45:4 79:13 107:25 108:2 114:13 137:24 157:16 167:4
involvement (5) 4:1,2,5 126:9 160:19
iq (1) 184:10
ireland (1) 122:20
irish (1) 74:7
ironic (1) 42:14
irony (2) 25:17 111:12
irregular (1) 92:11
isnt (20) 2:25 18:20 23:16 27:1 28:18 49:10 51:17 59:8 154:7 174:12 179:15 181:11,20 182:12,18 185:10,13 190:7 191:20 203:4
isolated (2) 43:17 122:22
isolation (1) 131:6
issued (1) 27:5
issues (26) 12:23 16:10 17:7,12,15 20:5 41:2 44:18 55:5,24 69:20 72:21 85:13 89:8 93:7 121:10 126:12 182:23 185:18 186:4,21,25 193:10,14,21,25
italy (1) 133:8
its (206) 1:11,21 3:6,25 4:22,24 5:5,17 6:12,14,18,24 7:8,13,13,17 8:11,20,22,23 9:3,8,19 11:17 13:2,15 14:4 15:19 18:2,8,19,20 19:4,9,13,13,18 22:9 23:14 24:20 26:1,2,4 28:16 29:7,13,15,19 31:3,21 35:15 38:18 40:3,19 50:6 51:18,19 56:8,10,11,12 58:9 59:12,19 60:1,1,3,6,6,10,12,13 62:2,7,16 64:13 65:9,11,16 66:22 68:3,5 70:17,18 71:14 73:14,17,19 75:14,14 76:19 77:6,8,14 78:2,15 79:2,14 80:17 81:4,5,9,11 82:4,24 84:16 86:11 88:9 91:22 92:15,25 93:16,21 95:22 96:18 97:8,25 98:7,11 101:21 102:5,11,17 103:20 104:11,25 109:12 118:3 119:13 120:6 121:2 122:19,19 125:23 127:19,22 132:21 134:23 137:17 138:24 140:3 152:24 153:5,11,11 154:9,22 156:14,15 162:21,24 163:13 164:3,4 166:14 168:13 169:5,15 170:8 171:11 173:10 174:3,4,5,5,17,20,23 175:12 176:11,15,25 177:1,1,1 178:4 181:9,10 182:9,11,14,18 183:10,18,18 184:9 187:19 188:5,6,6 191:21 193:23 194:3 195:16,22 197:7 198:6,18 199:21,23 200:22,23 201:21,23 203:1,3
itself (5) 29:18 86:25 108:14 128:8 184:23
ive (46) 3:20 28:5 63:19 65:20 67:22 70:22 73:13,18,20 74:3 78:22 82:11,12,13,23 91:14 96:25 101:5 103:4 122:15

128:18 129:5,20 133:1 142:25 150:8 155:4 157:21 158:7 163:11 166:8 168:12,13 170:8,16 178:15,18 182:15 184:17 189:1 190:14 192:7 195:14 197:11 198:9,20
ivf (1) 34:15

J

jane (4) 63:8,10,15 204:5
january (1) 115:17
jennifer (2) 1:16 204:2
jenny (20) 1:20 2:1,3 4:23 5:2,7,11 8:4 10:13 13:4 19:15 21:25 25:8 35:12 43:6 45:3 46:20 47:24 51:16 53:11
job (18) 5:18 72:11,12 112:21 158:21 159:4,6 160:3,4,20 171:7,8 172:8 186:1,2,24 188:22 192:5
jobs (5) 71:12 72:13 149:5 170:5 196:19
join (1) 4:10
joined (1) 109:13
joinedup (1) 141:19
joint (1) 92:12
journey (5) 35:19,20,21 67:22 128:16
journeys (1) 151:24
joy (1) 62:6
judgment (3) 22:17 23:17 24:3
judgments (1) 11:4
jump (1) 38:21
jumped (1) 33:10
june (1) 67:14

K

keen (1) 20:6
keep (10) 33:4,4,19,21 37:24 58:10 62:19 74:9 118:2 134:10
kept (7) 39:4 43:17 48:1 76:21 95:12 116:12 183:5
key (4) 44:3 48:16 49:25 123:16
kickback (3) 68:4 70:21 73:8
kidney (80) 105:9 106:4 107:5,12,14,16,17,25 108:2,4,4,6,16,16,19,21 109:10 110:8,9,9,17,21,23 111:1,9,12,13,20 112:6 114:4 115:16,20 117:11,18,25 118:19,20 119:2,8,22 120:8 121:10,10,18,18 123:25 124:4,5,15 126:12,15,22,23,24 127:3,5 129:2,11 130:7 132:17,23 133:11 134:2,5,14,17 136:2,5,6,15,17,21 137:1 140:18,19 142:4 144:20 148:1 150:3 155:12
kidneys (6) 129:12 132:19 134:2,4,8 135:3
kids (5) 39:6 71:9,15 166:16 167:9
killing (1) 201:21
kind (6) 18:4 60:7 117:21 125:24 145:3 155:4
kingdom (7) 109:8,24 110:19 132:1 133:14,21 135:22
kit (1) 34:8
knees (2) 45:15,17
knew (13) 32:20 36:17 42:2 82:18 94:2 123:23 124:2 142:21 147:25 162:23,25 164:19 167:20
know (205) 5:4 9:23 10:4,6,12 11:2 12:25 13:2 15:1 16:1,10,11,17,19,20 18:25 19:24 20:2 21:9,15 22:23 23:4,12,16 30:8,9 31:10,15,22 32:15 33:2 35:2,14 36:8,8,10,16,20,21,23 37:2,2 38:1 39:18 41:23,24 42:3,5,9 44:12,16,19 45:2 46:23,24 47:2,6 48:14,23 49:25 50:15,20,21 51:16 52:4,6 53:7 54:21 55:7,11,12,24 57:3,4,5,11,19 58:7,17,25 59:1,2,10,11,12,13,13,16,21,24,25 60:7,8 61:1,7,7,10,17 67:9,11 74:11 75:6 77:3 79:2 80:20 82:8,16,17 83:11,16 85:22 90:18 91:21,24 93:8,10 95:10,15 98:20 102:15,18 103:18 110:14,17 111:21 117:13,19 118:21 119:19,24 120:6 123:9,20 124:8,14,20 126:6,25 129:15,17 130:6 133:1,5 135:18 136:16 138:25,25 139:1,13 140:9 143:8,25 144:5 145:6 147:5 148:14 149:1 150:21 152:25 154:22 159:20 165:15,23 168:3,12 169:18 170:24 171:15 172:21 178:8 180:22 181:3,5,22,24 182:1,16,19 184:10,12,14 186:11,18 187:19 188:3,5,7 189:22 190:16 193:3 194:7,9,24 195:2,3,24 196:1,19,20 198:12,18 199:10 200:23 201:16,16
knowing (4) 62:7 73:11 93:16,18
knowledge (7) 7:17 34:22 72:3 73:15 82:2 85:19 178:12
known (17) 2:7 24:25 27:7 63:18 74:23 87:8,21 97:6 106:5 108:18 121:16 143:12 156:8 162:24 166:15 168:9,14
knows (1) 93:23

L

labour (1) 119:9
lack (12) 11:7,8 24:10 26:11 39:10,10 123:17,19 125:25 133:10 146:6 190:17
lanarkshire (1) 57:19
lancet (4) 82:22 156:13,14 199:4
language (2) 62:15 145:23
laptops (2) 112:19,22
large (1) 111:1
largely (1) 93:6
larger (3) 12:21 14:15 38:5
last (10) 36:18 67:22 78:23 85:8 88:13 103:22 112:3 178:16 180:18 199:8
lasted (1) 67:8
lasting (3) 58:22 91:5,12
lastly (1) 3:3
late (3) 110:9 116:9 148:1
later (14) 30:17 33:15 46:23 64:17 92:25 110:24 117:25 122:15 134:24 139:4 144:14 148:13 166:19 183:7
latest (3) 55:23,23 120:22
latter (2) 43:21 65:1
laugh (1) 19:10
lay (3) 84:18 90:25 119:3
lead (3) 8:12 10:22 96:11
leadership (2) 6:14 65:5
leading (4) 6:7,14 7:2 117:7
leap (1) 18:18
learn (15) 10:1 11:18,19 52:22 53:1 62:22 135:4 145:19 147:16 153:21 154:21 155:10 169:1 170:18 175:11
learned (6) 47:15,21 49:17 125:5 149:14 182:3
learning (31) 4:4 5:24 6:21 7:15,20 8:2,12,15,21 11:15,16 12:11 14:7 15:11 16:23 17:6 22:12 24:18 25:20 27:7 36:14 42:11 43:11 52:21,24 54:4 65:16 70:6 85:5 126:2 175:21
learnings (2) 135:8 142:24
learnt (1) 155:2
least (12) 4:5 12:2 27:20 31:2 47:16 88:13 89:23 91:6 165:25 177:11 186:14 189:24
leave (4) 103:11 113:1 114:25 184:22
leaves (1) 17:1
leaving (1) 52:8
led (1) 58:7
left (6) 25:4 101:5,15 127:3 133:18 197:24
legal (2) 27:15,24
legitimately (1) 43:1
leisure (3) 13:21,23 16:11
length (3) 91:9 174:3 176:4
lengthy (2) 95:17 100:11
less (7) 25:19 61:25 128:12,17 131:12 137:12 183:3
lesson (9) 47:15,21 62:23 125:5,9,11,12,15 153:21
lessons (6) 48:21 49:16 84:22 149:14 155:2,10
let (4) 59:9 62:20 114:10,24
lets (2) 11:10 90:14
letter (13) 27:5,14 28:4,6,14,18,22 29:2,5 123:21 145:11 148:3 171:20
letters (2) 146:7 148:23
letting (1) 200:10
level (30) 10:15 17:6 40:25 45:19 52:24 80:11 117:24 119:3 121:23 128:6,23 132:7 134:9,9 136:25 137:21 139:2 143:4 145:1,2,4,7,7 155:9 179:21 181:12,23 183:17 189:7 202:13
levels (5) 26:20 125:21 126:4 143:18 145:15
life (44) 7:19 8:16 9:5,9 11:5,11,23,24 17:17,20 22:4 23:7,8,16,22 31:18,19 32:9 35:4 47:12 51:12,19,22 52:2 53:9 62:9 69:16 71:3 72:7 89:4 93:13,24 96:5 97:8 100:2,5 101:18 108:23 136:13 138:20 171:16 194:14 197:18 198:12
lifeline (1) 57:10
lifelong (2) 11:15 14:6
lifemaintaining (2) 127:22 129:13
lifesaving (1) 17:16
lifetime (1) 16:3
lift (1) 152:10
light (7) 112:16 179:20 187:10,15,16,22 190:5
lights (1) 52:2
like (88) 3:10 7:9,19 16:23 19:18 31:18,19 33:9,13,20 34:1,14 38:19 45:25 46:25 49:17 56:14,14 57:5 60:23 61:14 63:1 65:12 75:9 86:23 87:9 89:11 99:20 101:7,8,11,18 103:10,12 106:10 109:11 112:5,11 113:9,10,13 114:16 119:2 120:2 122:18,19,19 124:5 125:12,13 131:8 136:22 141:4,21 142:1 145:13,18,21 147:2 149:13,15 155:9 157:16 161:13 167:21 171:16 172:18,19 173:23 175:5 176:15,17 177:3 179:7 181:8,9,21 183:13 185:16 191:7 193:8 195:23 196:3 197:13 200:6 201:4,5,9
liked (1) 119:24
likelihood (1) 85:5
likely (9) 17:3,7 21:19 100:24 110:23 161:22 184:22 195:3,7
likewise (1) 122:8
line (5) 20:12 34:4 36:24 62:21 85:8
link (1) 141:9
linked (1) 8:18
links (1) 122:10
list (28) 19:18 23:18 121:15,16,21 127:9 137:15,17 139:15 140:2 142:5,9,14,15,17,19,22 143:7,8 144:1,5,21 145:5,6,25 146:3 149:18 160:2
listed (3) 118:4 139:14 143:21
listened (7) 38:7 44:22 69:23 84:9 104:13 147:1 167:5
listening (4) 53:12 116:15 125:16 149:21
lists (8) 147:23 148:5,6,7,17,20 172:4 185:22
literally (1) 121:14
little (34) 18:15 20:18 21:7 44:19 50:1 51:1 52:1 59:2 64:21 71:20 75:13 76:8,12 77:22 79:7 84:15,24 85:7 89:10 91:14 94:2 96:7 101:2 103:6 126:8 142:2 144:14 149:22 152:5 153:12 157:19 169:17 175:4 191:7
live (12) 11:5,8,10,23 34:18 39:23,24 46:3 67:5 97:8 119:12 154:21
lived (11) 4:7,11 73:16 77:25 78:2,3 84:9 104:13 108:4,10 151:11
livelihood (2) 187:1 196:24
livelihoods (1) 186:24
lives (13) 8:13 9:10,25 10:10 19:12 23:2 35:13 48:19 62:3 83:14 96:4 97:8 101:13
living (12) 23:1,2 34:19 40:12 52:3 89:23 97:14 110:17,20 136:8 137:23 188:1
local (9) 6:20 25:11 26:5,20 49:3 141:10,19 157:11 163:16
locally (4) 109:25 141:7,8,9
locations (1) 157:8
lockdown (2) 50:13 142:11
lockdowns (1) 142:12
london (1) 113:13
long (208) 3:19 4:6 5:14 36:17 40:6,19,21,24 46:16 48:2 52:21 53:1 60:5,9,10,13,14 64:8 65:4,19,20,25 66:1,3,16,21 67:14,21,25 68:9 69:22 70:13 71:25 72:3,4,17,23 73:10,14,23 74:1,6,18,19 75:13 76:25 77:23 78:4,6,8,10 79:6,8,10,18,19,20 80:13,25 81:3,8,12 82:10,16,25 83:13,14,17,19 84:9,15,19,20 85:16,19,21 86:21 87:15 88:6,16 89:8,9,12,16,21,24 90:1,4,7,10 91:5,9,22 92:17 94:2,7,9,17,24 95:6 96:8,11,20 97:2,3,16,20,23 98:5,12,24 99:8,12,21 100:8 101:3,7,9,9 102:1,11,16,21 103:14,17,18 104:6,8,9,18 107:8 112:4 120:14 124:12 155:1 157:15,17,22 158:1,13,18 160:2,25 163:17,19,22 164:1,19 165:20 166:16,19 167:1,9,17 168:3,14 169:22 170:18,21 172:2,9 174:15 175:2,6,23,25 176:2,8,13,18,21 177:20,25 178:13 179:16 180:22 181:16 182:8 184:4 185:14,21 187:22 188:15,22 191:19 192:13 193:1,19 194:16,17 195:10 197:1,5,9,16,19 198:4 199:12,19,20 200:3,9,11,25 201:5,8,18,19
longcovidinformed (1) 80:15
longer (5) 4:1 23:2 45:11,13 134:6
longerterm (2) 58:2 153:8
longterm (1) 87:22
look (27) 33:2 48:23 66:8 76:22 89:9,11 95:23 98:6 104:12 118:19 123:9,20 124:2 138:24 153:4 156:16 169:20 174:25 177:19 179:3,7 183:4,4 184:7 189:24 197:3 199:6
looked (12) 23:24,25 24:13 25:15 35:7 40:8 50:24 99:15 127:7 161:2 184:2,3
looking (20) 6:17 16:8 40:7 49:13,18 76:24 78:23 91:12 94:22 95:24 110:23 125:6 130:19 159:13 163:10 172:11 174:13,17 185:4 199:20
looks (1) 197:13
lose (8) 16:6 53:9 62:21 114:21 133:23 144:2,2 170:5
losing (1) 201:10
loss (4) 16:5,6 59:11 184:10
lost (13) 35:13 50:25 53:6 59:1,5 72:12 114:23 115:11,13,19 185:25 188:22 196:19
lot (62) 6:10 11:3 13:4,9,25 14:24 15:17 19:22 23:10,21,23 27:1 30:11 37:19 42:14 45:24 48:17,18 53:4 54:2,10 55:17 58:23 61:5 67:3 73:25,25 82:17 84:2 85:4,15,16 96:25 112:21 124:16,21 126:8 139:16 142:19 146:15 148:5 151:25 159:14,15,18 160:1 161:25 168:23 169:11,16 170:8 171:11 177:2,7 187:22 188:2 195:21 196:2,3 198:6 201:24 202:17
lots (30) 4:25,25 5:1,1 10:5 11:3 15:14,20 22:24 32:17,19 34:4 35:6 40:7 57:9 60:4 131:23,23 141:3,3 161:4 170:7,7,19 173:6 177:9 183:8 192:4 194:13 197:1
lottery (2) 97:22 98:8
loud (15) 51:18 105:9,12,14,21,24 106:3 116:5,23 120:15 121:2 140:16 150:10 155:16 204:7
love (3) 62:6 94:1 119:9
loved (8) 34:23 36:13 43:23 44:5 50:19 55:21 59:2,6
lovely (5) 16:12 54:7 57:13,15,20
low (1) 137:10
lowcost (1) 199:16
lower (1) 128:23
lucky (3) 20:24 58:22 170:16
lumped (1) 39:16
lungs (2) 132:19 135:3
lupus (1) 195:1

M

machine (3) 112:24 151:4,5
machines (1) 33:20
main (1) 125:16
mainly (1) 168:11
maintain (3) 21:10 81:10 129:13
maintained (2) 80:24 134:10
major (4) 95:2 141:22 159:21,21
majority (2) 87:13 187:19
majorly (1) 89:4
makes (6) 91:24,25 92:2 116:1 189:15 192:25
making (11) 8:24 24:2,5,6,11 30:14 41:15 42:9 57:16 99:4 172:9
malaise (15) 68:2 71:6 161:25 179:11 180:3,10,12,23 181:7,15,18,19 184:19,21 191:22
malnutrition (1) 151:15
mammoth (1) 19:18
manage (4) 17:8 21:18 181:1,4
managed (6) 54:22 55:21 62:21 134:24 170:17 198:9
manager (2) 107:24,24
managers (1) 78:14
managing (2) 17:22 37:2
mandatory (3) 28:5 29:18,21
manifest (1) 184:23
manifestation (1) 179:13
manufacturers (1) 132:5
many (80) 9:3,9,10 11:7 16:4 17:9,12 19:20,20 25:13 28:12 34:8,18 35:1,14,20,20 40:10,10,10 45:9 46:19,21 47:13 48:1 58:23 62:12,15 68:7,8 70:14 71:9 73:10,13,18 74:21,23 81:8 83:15 85:21 91:24 98:18,23 100:18 101:14 108:12 109:10 110:16 113:8,15,20 115:1 117:13,13 118:13 120:8 125:24 129:15 137:1 139:8,8,8,21 144:15 154:3 165:19 169:9 171:10 173:12 177:2,3 183:24,24 184:25 187:14,16 189:9 190:22 197:16,21 179:17 182:4 192:20 195:22
map (1) 79:15
marathon (1) 113:13
march (11) 1:1 32:2 111:10 112:3 115:12,14 129:22 142:4,12 143:6 203:7
marchapril (2) 30:8 132:21
marginalised (2) 20:17 42:12
marked (2) 111:5 152:13
marshal (1) 69:6
mask (2) 151:19,20
masking (1) 83:21
masks (1) 101:10
massive (2) 149:8 163:4
massively (1) 9:21
materials (4) 54:23 133:1,2,3
matter (3) 95:3 184:10 202:3
matters (5) 3:3,10 77:20 84:2 184:17
maybe (15) 17:21 23:15 44:22 127:4 148:3 160:25 169:1,1,2 177:19 178:16 179:17 182:4 192:20 195:22
mean (54) 6:13,18 10:18 12:8,23 16:16 19:7 20:11,20 21:15 23:9 26:15,19 35:23,24 36:1 38:4,23 42:10 44:25 45:12 48:2 49:20 51:2 54:7 55:10,14 57:15 58:3,7 61:3 74:2,9 76:22 78:22 80:12 84:19 89:22 94:14 95:12 98:25 110:19 113:21 114:24 115:2,25 124:23 126:10 148:21 150:7 175:17 182:12,19 186:23
meaning (1) 60:9
meaningful (3) 16:14 32:8 40:11
means (9) 7:7 8:1 11:3 77:10 83:14 98:21,24 101:16 161:10
meant (11) 37:25 46:22 47:3 112:2 119:7 132:25 137:13 138:4 145:6 152:4 166:10
meantime (1) 40:7
measured (1) 55:7
measures (1) 152:14
mecfs (5) 74:22 176:24 179:15 183:5,9
media (3) 118:14 170:16 177:20
medical (18) 23:21 31:10 32:15 33:3 83:6 117:15 118:9 125:24 142:20 143:20 150:6 156:25 163:20 165:3 167:4 176:20 185:2 195:15
medication (2) 193:10 200:12
medications (3) 159:23 185:14 192:19
medicine (5) 17:10 157:4 162:24 163:25 190:18
medicines (3) 17:9 118:17 120:18
meet (8) 73:20 74:8 80:3 81:14 165:20 175:7 181:17 183:19
meeting (7) 30:6 48:9 74:3 81:12 103:21 167:10,11
meetings (8) 5:1 77:12 80:5,6 141:15 163:16 164:9 167:19
member (11) 3:6,7 13:21 32:4 33:1 46:24 48:1,5 55:15 61:7 106:25
members (30) 4:23 5:2 12:13 32:7 42:17 48:12 51:11,24 71:9,24 72:12,14 73:10 81:20 83:6,8 84:7,8 85:17,22,25 93:9 94:19 98:2 103:25 109:17,18 112:19 124:12 195:15
membership (1) 75:24
menopausal (2) 94:16,23
menstrual (2) 94:16,23
mental (22) 32:15 50:1,3 68:3 69:19 93:2,7 100:15 123:18 152:22,23 153:2 154:17 155:11 170:11,12 193:8,10,14,21,25 194:15
mentally (4) 46:8 60:12 193:15 194:14
mention (13) 6:23 14:12 42:15 79:5 84:13 92:15 160:10 175:1,12 177:11,13 182:5 191:8
mentioned (27) 2:25 6:25 9:17 12:4 13:17 15:6 33:25 39:9 46:20 53:11 61:13 69:12 75:18,25 83:7 93:8 115:23 116:8 120:14 121:4 123:2 136:9 142:1,13 146:17 160:9 187:8
mentioning (1) 16:21
message (1) 154:7

messages (1) 50:3
messaging (5) 83:19,20 97:14 153:5 154:15
met (7) 14:18 34:5 57:20 73:19 103:16 165:4 170:20
metformin (4) 82:22 199:10,14,18
mid (1) 123:14
mid2020 (1) 163:23
middle (2) 77:8 139:20
might (63) 11:18 16:21,23 18:23 19:3 25:5,21 33:11 34:17 37:8,15 42:22 51:17 59:4 60:13 61:11 76:25 77:1 80:22 85:1 87:9,10 97:25 104:1,2 106:19 113:10,12 117:24 119:4,17 123:1 125:17 148:1 151:13 153:2 164:16,16 168:3 170:5,23 174:7,14,19,20 178:14,21 179:22 180:25 181:1,23,25 182:14 183:13 185:7,25 190:2,6,15 191:1 192:20 200:4 202:6
mild (2) 192:21 193:4
milder (2) 87:2,14
mildly (1) 179:22
miller (66) 1:12,16,20 2:1,1,4,14,17 3:14 5:13,15,21 6:4,7 7:4 8:11 10:14,22 12:5 13:6,13,20 14:13,15 15:10 18:20,22 20:1,20 21:24 22:9 26:14 27:18 28:7,22 29:2 30:4,20 31:13 35:22 37:18 38:13,18 40:23 41:3,5,14,16,20 43:2,10 44:2 48:21 49:22 50:6 51:8 52:11 53:16,20 54:14 56:6 57:9 58:6 60:21,25 204:3
million (3) 89:19 104:9 110:20
mind (2) 53:19 79:15
mindful (1) 94:4
minimisation (1) 69:3
minimise (3) 39:3 155:11,11
minimised (3) 68:13 69:23 70:1
minister (12) 27:14,16 28:4,17 29:15,15 36:22 81:7 144:24 147:14 148:24 166:22
ministers (1) 28:11
minute (6) 59:10 61:25 111:21 115:22 123:25 182:2
minutes (3) 150:19 155:17 197:23
misogyny (2) 195:11,16
miss (1) 146:5
missed (6) 24:4 45:13 106:20 138:5 141:13 145:17
mistake (2) 116:17 120:1
misunderstanding (1) 39:15
misunderstood (1) 8:17
mix (4) 19:25 51:21 160:24 166:25
mixed (1) 196:15
mixing (1) 96:17
mobile (2) 7:6 17:5
model (4) 165:2 167:1,3,11
moderate (1) 111:1
moment (14) 14:3,6 16:17 39:2 59:13,24 65:23 66:1 78:7 130:13 139:13 160:12 199:21 200:5
money (12) 86:9,12,14,15 103:13,16,19 113:11 167:23,24 173:4,6
monitoring (4) 140:17 141:15,20 176:8
months (25) 20:4,4,11 32:6,23 40:10,11 46:14,17 61:17 67:7,9 88:12,13 112:13,14 115:19 168:7 176:7,10,11,14 188:6 191:20 199:5
moods (1) 194:10
more (77) 3:13 4:13 11:23 12:18 20:18 21:7,19 22:15 25:14,18 28:21 30:21 32:24,25 40:2 48:20 52:5,5,9 54:8 56:19,20 66:3 67:13 70:19,20 71:20 77:10,11 80:5 82:17 83:12,12 85:8 90:6,8 91:7,12 92:12,24 94:24,25 95:24 125:22 126:8,8,9 135:9 139:19 141:15 142:2 146:18 149:22,23 152:15,20,21 155:12 158:7 161:22 164:19 165:3 168:12 175:11,21 184:18,22 187:20 191:24 194:24 195:3,7 197:11 199:20 200:3 201:12 202:1
morning (15) 1:3,4 63:6,7,11,12,14 68:12 169:19 173:16 175:23 178:5 179:5 194:20 202:4
mortality (2) 25:23 130:4
mortgage (1) 72:13
most (39) 13:14 19:21 28:19 39:23 42:16,18 51:13 56:4,4 72:8 87:1 92:16 117:5 138:12 142:3 148:4 157:25 158:11 163:11 166:8 172:3,10 173:3 179:16,18,24 181:14 183:8,16 185:22 186:2 193:6,13,22 196:7,22 198:20 200:17,21
mostly (2) 132:24 192:7
motivation (1) 194:10
motivational (1) 120:3
mouth (1) 189:11
move (17) 15:18 27:10 30:22 33:6,6 35:15 38:24 53:4 101:13 104:2 106:22 117:1 126:11 141:25 151:7 184:16 188:21
moved (7) 9:21 30:2 50:16 101:6 112:21 131:3,7
moving (9) 4:12 17:11 33:4 47:12 52:13 55:1 79:19 111:3 117:3
mri (1) 183:25
ms (132) 1:11,11,16,16,25 2:1,4,5,13,14,17,18 3:14,15,18,20,24 4:3,9,22 5:13,15,21 6:4,7 7:4,13 8:11 9:8 10:14,21,22 11:13 12:5,20 13:6,8,13,20 14:12,13,15 15:10 16:21 18:1,20,21,22 19:13 20:1,20 21:19,24 22:9 24:8 26:14 27:3,18,21 28:7,8,11,21,22 29:2,22 30:4,20,21 31:13,17 35:22 37:10,12,18 38:13,14,18 39:8 40:23 41:3,5,14,16,19,20 42:14 43:2,3,10 44:2,22 47:23 48:21 49:21,22 50:5,6 51:7,8,9 52:11,20 53:16,20 54:13,14 56:5,6 57:9,24 58:6 60:3,21,22,25 61:16 62:2 105:12,14,21,24 116:5,23 120:15 121:2 140:16 150:10 172:22 204:2,2,7
msc (2) 118:17 120:17
msps (3) 144:23 148:8 153:15
much (62) 4:3,9,13,15 5:8 9:14 10:11 11:23 21:19 22:15 25:14,18 27:9 32:24,25,25 35:9,18 40:10 48:11,14,19,20 52:5,9 53:2,8 56:17 60:20,24 63:2 68:5,24 76:21 86:13 87:12 90:8,24 92:2 95:15 104:20 111:21 113:8 117:19 119:19 141:14,24,24 147:12 148:13 149:19 151:7 152:15,23 155:14 170:4 173:4 188:4 199:25 201:3 202:19 203:4
multidisciplinary (3) 81:1,2 99:16
multiple (12) 5:24 7:15 8:2,12,21 15:12 16:22 17:13 42:23 88:18 184:6,6
multisensory (3) 13:23 19:6 53:24
multisystem (4) 178:24,25 193:1,23
multisystemic (2) 98:12,20
mum (3) 22:25 44:8 50:24
muscle (1) 166:10
muscles (2) 166:10,12
musculoskeletal (1) 88:20
music (3) 10:6 54:7 57:13
must (7) 30:7 33:14 62:17 87:10 118:21 157:25 192:14
mustnt (1) 116:15
myocarditis (2) 173:11 174:20
myriad (2) 97:15 173:18
myself (14) 2:22 37:24 45:5 69:20 70:20 78:4,9 97:9 98:19 112:2,5 118:8 141:4 175:6

N

nail (1) 75:5
name (12) 1:25 2:1 3:5 63:14 106:2,24 107:1 108:9,20 115:23 116:8 156:7
named (4) 120:21 143:7 145:5 146:4
names (4) 1:24 116:20 160:10 191:8
naming (1) 166:13
nasty (1) 132:18
national (4) 20:25 120:15 133:20 172:24
nationally (2) 6:10 74:5
nations (4) 122:2,4,21 125:7
natural (3) 114:25 194:9 202:10
nature (8) 48:10 69:21 90:18 91:18 97:16 98:12,20 172:14
nearly (3) 91:6 179:25 200:4
necessarily (6) 18:18 52:14 108:13 119:1 141:18 148:6
necessary (3) 78:19 80:11 134:1
necessity (1) 196:12
necrosis (1) 166:10
need (53) 17:8,8 20:9 31:23 32:19 36:3 61:9,11 62:22 74:13 84:9,11 95:5 97:13 99:11 101:17 110:3,10 115:22 128:6,12 129:13 131:22 133:16 134:3,9 135:3 143:4 153:22 165:6,12 170:6,12 171:6,9,11,11 174:25 178:19,23 186:1,15 187:11,11,23 190:23 195:25 200:15,21,24,25 201:12,15
needed (21) 9:13 33:3 45:15 54:21 115:5 119:2 129:1 132:23 134:16 135:5,5,7 149:7,7,11 152:20,21 153:15,20 165:3,10
needing (4) 23:12 44:11 54:18 129:7
needles (2) 135:14 151:6
needs (16) 9:11 14:18 15:15,16 31:6 41:2 61:5 81:12,14 84:10 102:4,5 103:16,21 154:16 200:2
negative (2) 51:15 100:17
negatively (2) 90:5 100:25
network (18) 74:4,7 77:23 78:1,8,11,12,16,17,21 79:1,1,21 84:20 85:11 86:2 175:2,5
networked (1) 74:4
networks (1) 21:9
neurological (2) 88:20 173:25
neurology (2) 173:25 190:3
neurons (1) 184:11
neuropsychologist (1) 186:14
neuropsychologists (1) 185:20
neuroscience (1) 157:3
never (7) 59:4 140:11 158:3 168:13 172:25 197:10,14
nevertheless (2) 137:23 144:15
newly (2) 136:20 138:2
news (2) 124:22 125:16
next (16) 12:15 49:7 63:7 67:7 72:19 74:9 95:17 104:10 110:23 119:13 136:25 151:5,23 155:24 166:14 180:12
nhs (20) 5:22 22:2 27:6 29:25 31:24 54:25 108:24 118:12,25 133:11 139:22 141:14 159:16,17 168:23 169:1 172:4 173:2,3,15
nice (5) 118:16 120:15,17 165:15,16
niche (1) 162:21
night (5) 19:22 55:20 56:2,3 112:12
nightmares (1) 25:7
nine (1) 137:17
nobody (12) 22:13 24:16 32:20 35:11 36:17 39:7 49:12,13 123:22 133:23 164:25 178:24
nobodys (1) 50:23
nods (3) 92:14 100:19 101:1
noise (6) 187:10,15,16,22 190:24,24
nomenclature (1) 182:6
none (1) 172:16
nonmobile (2) 17:4,16
nonpandemic (1) 31:20
nonverbal (1) 17:4
normal (9) 17:20 31:2,19 44:25 69:8,15 70:20 159:2 198:12
normally (4) 56:12 112:23 185:8 199:10
northern (1) 122:20
note (4) 43:4 111:4 131:13 133:6
notes (1) 184:25
nothing (6) 28:5 36:6 99:6 133:18 168:24 169:3
notice (6) 114:5,12,15 126:9 136:2 185:7
noticeable (1) 20:15
noticed (5) 27:23 52:15,18 114:8 161:6
notifications (1) 129:23
nuanced (1) 92:13
number (27) 20:9 58:8 66:7 72:20 82:12 85:25 86:24 93:12,21 105:21 107:19 108:5 110:24 111:1 114:12 123:6 132:19 137:6,16 143:21 144:22 148:9 176:16 188:19 191:3 202:4,14
numbered (1) 96:2
numbers (17) 1:19 50:11,13 78:5 90:7,9 115:3 121:5 128:25 129:19,21 130:10 137:7,14 143:17 197:4 201:22
nurse (2) 64:23 102:25
nurses (3) 102:20 103:5 119:6
nursing (1) 64:20
nurturing (1) 62:19
nutrients (1) 186:8

O

objectives (3) 8:9,10 20:14
obligation (1) 94:5
obliged (2) 38:16 121:1
observe (1) 127:24
obtain (1) 187:12
obtained (1) 66:9
obtaining (3) 81:21,22 128:2
obvious (6) 29:8 96:13 111:19 123:24 151:8 161:20
obviously (27) 15:5 36:10 45:13 71:19,21 72:25 77:19 80:9 83:2,7 89:18 93:8 94:4 95:23 101:23 110:16 114:12 130:18 150:5,12 159:17 160:3 166:7,22 197:5 198:3 201:16
occasion (3) 147:1,11 177:11
occasional (1) 51:25
occasions (1) 43:7
occupational (4) 5:22 164:10 167:4 169:13
occurred (2) 74:17 79:6
occurs (1) 88:9
oclock (1) 55:20
october (8) 89:19 143:5,6 144:14 146:14 156:14 158:20 199:8
odd (1) 51:24
offer (6) 109:5,6,6 153:5 168:12 172:15
offered (3) 154:12,13 191:2
offering (1) 168:25
offers (1) 109:3
office (2) 112:24,25
officer (1) 5:12
officers (2) 109:21,23
officially (1) 144:14
often (36) 8:17 9:1,15 12:23 14:8 15:20 16:12 17:4,18 19:2,22 21:7,11,21 33:4 34:16 42:12 55:20 56:21 69:4 82:1 97:20 99:9 101:16 110:25 135:24 152:12 163:12 174:10 189:2,4,25 190:13 193:25 194:14 195:19
oh (15) 14:13 18:1 29:4,10 50:5 70:16,17 74:2 78:22 80:12 90:24 91:13 105:17 170:3 192:13
okay (19) 36:18 61:24 85:9 105:25 106:15 116:13,23 129:20,22 134:24 150:19,21,24,25 160:11 164:8 174:23 175:22 187:7
old (2) 24:23 197:13
older (3) 36:5 197:20 198:19
once (6) 20:9 122:10 149:9 153:15 170:7 200:11
ones (4) 43:23 92:10 187:17 196:18
onethird (2) 136:10 166:9
ongoing (6) 50:6 60:7 93:3 104:14,16 176:9
online (14) 45:24 53:25,25 54:10,24 57:14 73:19 117:3 118:5 159:11,14 160:2,6 189:10
ons (2) 89:19 176:8
onset (1) 88:12
open (3) 12:24 21:5 95:1
opened (1) 21:2
opening (1) 192:8
openly (1) 149:23
operational (1) 4:24
opportunities (2) 11:21 12:10
opportunity (10) 4:16 10:1,9 57:4 58:1 59:21,22 106:18 140:9 151:13
opposed (1) 122:13
opposite (1) 48:6
option (1) 118:2
options (1) 127:11
oral (6) 2:12 60:19 63:24 106:8,17 150:14
ordeal (1) 73:3
order (7) 3:4 10:17 106:23 128:5,7 132:7 186:18
ordered (1) 133:16
organ (1) 135:1
organisation (37) 3:11,17 6:8 7:2,14 9:19 10:12 13:11 30:23 37:14 40:4 49:2,20 65:21,24 84:3 88:7 89:7 108:14,15 109:3,9,14 111:4 112:15 113:5 114:21 115:12 116:9 117:4,6 121:3,9 140:22 144:19 175:13,25
organisational (1) 2:9
organisations (13) 6:11 7:21 12:21 15:13 30:6,12 38:4,6 72:20 76:3 114:16 117:5 118:12
organised (1) 79:24
organs (2) 35:17 88:18
originally (3) 66:22 107:23 160:4
ormerod (17) 63:8,10,11,14,15 72:18 103:6 104:20,22 169:19 173:16 175:23 178:5 194:19 196:9 202:4 204:5
ormerods (2) 179:4 180:6
orthostatic (1) 161:18
ostracised (2) 101:3,4
ostracism (1) 100:23
others (9) 39:12 47:4,14 117:20 148:9,13 153:22 181:4,10
otherwise (1) 133:15
ours (4) 125:12 126:5 145:14 147:2
ourselves (2) 79:11 84:25
outcome (3) 30:1 79:14 174:4
outcomes (2) 52:6 174:18
outdoor (1) 10:4
outlined (1) 37:15
outlines (1) 18:4
outlook (2) 51:14,15
outpatient (3) 199:4,9,14
outright (1) 75:4
outset (4) 2:19 60:17 74:17 106:15
outwardfacing (1) 30:25
over (32) 4:15 5:6 9:19 16:11 20:9 46:9 47:13 50:7 60:6,11 67:7,22 83:10 86:10 100:6 101:6 110:23 127:3 133:8 134:5 137:5,5 152:9 157:9 160:5 176:24 182:3 183:8 190:13,13 192:8 199:5
overactive (1) 172:20
overall (8) 118:20 123:15 131:15 137:13,23 139:16 149:25 159:13
overanxious (1) 68:16
overlay (1) 175:18
overly (1) 68:17
overnight (3) 31:13 41:12 54:12
overreacting (2) 161:24 194:23
overridden (1) 30:10
overspeaking (1) 176:6
own (28) 3:25 4:7 24:17 39:25,25 40:5 48:11 63:22 93:13,15 149:2 151:21 152:16 161:3 163:17 164:8 167:16 168:2,5 170:3,12,23 178:11,11 183:10 185:2 188:20 197:12
owners (1) 136:12
oxford (1) 146:16
oxygen (1) 186:7

P

pace (1) 11:19
package (3) 51:2 191:15 193:1
packages (3) 15:23 31:7 50:24
packed (1) 34:17
pact (1) 51:4
pacts (1) 51:16
pads (1) 34:15
paid (7) 20:7 47:19 48:19 54:11,14 56:20,21
pain (6) 62:14 173:8,10,23 174:7,15
painful (1) 191:4
pains (2) 92:11,12
palsy (4) 22:21 58:12,13,14
pamis (35) 1:7 3:12,20 4:1,5,6,15,17,25 5:3,12,17 7:10,23 8:6,9,10 9:17,18 12:1 13:19 14:10,20 20:14 25:10 26:7,12 27:3,4 30:25 34:18 40:18 43:25 46:19 53:13
pan (4) 87:11 180:7 184:18,22
pandemic (48) 15:8 25:17,18 26:12 30:23 31:7 33:23 37:17 41:9 43:13 45:23 51:10,21 58:2 59:17 75:9 98:1 101:8 111:3,6,23 112:17 113:6 120:11 126:3,12,13,18,19 127:24 129:4 130:20,22 131:20 133:8 134:24 136:1,4,14 139:5 140:24 142:24 143:17 150:4 157:9 158:20 176:19 197:3
pandemics (1) 155:10
panel (4) 1:8 78:23,24 84:12
panic (1) 62:21
paper (5) 56:8 82:21 156:14 175:8 199:3
papers (5) 44:3 82:21 129:20 163:8 183:24
paragraph (54) 7:11 8:4 68:11 76:6 79:5,22 84:3,4,7,13 86:22 91:16 92:9,13,15,24 94:6 95:4 97:19 98:11 99:10,25 100:17 101:21 102:9,20 123:8 127:25 132:14 138:15 157:19 158:19 159:9 161:6 163:15 166:14 170:10 174:25 179:7 182:21 183:16 185:18 186:20 188:1,12 189:16 191:14,25 193:9,12 194:19 196:6 198:5,14
paragraphs (9) 86:19 89:14,15 91:16 99:22 126:16 138:8 148:16 200:19
pardon (1) 86:7
parent (6) 17:19 21:17,20 34:12 96:19 97:9
parents (9) 96:16,18,22 97:7 188:13,16,21,25 189:4
park (1) 48:9
parks (1) 10:7
parlance (1) 163:20
parliament (1) 64:15
parliamentary (1) 111:6
part (33) 6:22 12:19 13:24 20:20 38:19,20 44:5,12 45:5,6 65:1 70:3 83:5 85:11 90:23 97:24,25 100:2 115:4 131:11 134:5 139:4 141:10,10 146:10

154:20 161:8 169:15 172:8 182:3 183:18 187:23 189:18
particular (11) 13:18 26:5 40:17 83:8 134:7 135:1,23 162:1 173:10 178:6 195:24
particularly (30) 5:6 13:22 17:15,21 25:13 34:19 37:19 53:17 67:2,15,16 76:9 82:6 85:14 92:23 98:9,25 99:24 100:16,20 118:7 131:10 133:9 134:8 158:24 166:3 176:18 178:13 179:1 190:10
partly (6) 4:24 118:10,11,12 121:24 195:5
partner (2) 48:8 71:15
partners (1) 115:6
partnership (1) 29:3
partnerships (1) 76:2
parts (1) 140:5
parttime (1) 109:15
pass (2) 117:8 127:10
passing (1) 143:18
passport (3) 53:18 56:6,8
passports (1) 24:1
past (3) 63:1 67:12 199:21
pat (16) 1:20,24,25 2:2 3:7,16 7:10 9:7 14:5 21:6 29:4 30:24 43:14 59:3,9 61:15
pathway (2) 81:2 97:4
pathways (5) 24:10 25:12,19 26:10 98:10
patient (20) 65:13,14 78:23 98:6 106:4 107:19 108:16,19 109:6,20,23 113:18 152:13 165:25 172:1,15 173:18 185:6 188:17 195:20
patients (115) 76:25 77:4,6,11 79:2,2,13,15 85:10 93:4 99:8,11 111:16 129:25 132:2,8 139:8 141:16 143:23 144:16 146:9 148:25 151:15,25 157:15,25 158:12 159:2,7,13,15 160:22,24,24,25 161:4,7,21 162:8 163:6,9,11,14,22 164:13,14 165:9,14,17,20 166:9 167:1 168:4,8,11,11,15,15,16 169:21 170:1,5 171:10,24 172:18 173:4 174:2 177:3,9,15,22,24 178:17 179:17,24 181:5,8,9,14,16 183:17 184:4,8,9,24,25 185:15 186:13 187:6,9,13,22 188:2 189:3,9 190:21 191:7,13,14 193:9,19,21 194:7,18 195:14,21 196:7,17,17 197:12 198:2,3 199:19 201:25 202:12
patricia (2) 1:16 204:2
pause (3) 138:11 160:12 162:12
pay (2) 29:17 72:13
payback (1) 182:4
pays (1) 28:23
peers (1) 96:17
pejoratively (1) 83:5
pem (2) 180:3,21
people (426) 5:24 6:21 7:14,20,22 8:11,21 9:3,9,12,25 10:2,20 11:4,7,10,15 12:10,11,17,24 13:2 14:10,19 15:14 18:24,25 19:10 20:17,22 21:5,14,16 22:19 23:1,2,4,8,10 24:6,19 25:8,14,20,24 26:17,19,21 27:6 29:11 30:14 32:17 33:1 35:6,13 36:4,5,5,18,25 39:11,23 40:7 41:9,23 42:8,11 43:17,19 44:10,13,16,20 45:20 46:3 50:14,15,20 51:10 52:15,23 54:2,11 55:6,8,11,20 56:20,23 57:3 58:18,19,23,25 59:5,15,20 60:5,8 61:18 62:2,8,18 66:3 68:6,7,10 69:4,5,24 72:5,8 73:16,17,18,20 74:4,25 76:17,20 78:5,15 79:9,10,17 80:13 81:2,12,13,14 82:1,3,4,8 83:11,13,15,15,21,24 84:9 85:15 86:24 87:1,11,13 89:2,9,20,23 90:3,5,6 91:4,6,11,19,24 92:2,3,20 93:6,19 94:1,2,24 97:20 98:19 99:2 101:2,6,7,7,9,10,11,17,25 104:9 107:12,13,24 109:12,15,25 110:8,20,22 111:20 112:4,11,20 113:4,10,19,19,23 114:10,11,13,25 115:2,2,5 116:14 117:11,12,18,20,22 118:2,6,15,18 119:2,2,8,18 120:8,22 121:17,19,19,21 122:12,21 123:9,20,25 124:7,14,15,17 125:14 126:14 127:10,12,15 128:3,17,23,25 129:5,15,24 130:7,23 131:2,3,9,11,14,15 132:16,19,22 134:1,10,13,17 135:4,11,16 136:12,25 137:3,8,10,11,14,16,24 138:5,17 139:6,8,16,19,19,21 140:4,9 141:4,6,8,13 142:6,10,13,14,17,18,24,25 143:2,2,6,8,10,17,18,20 144:1,2,8,12,25 145:4,12,12,18,20,20 146:2,5,11,25 147:20,22 148:5,8,10,11 149:3,6,10,17 150:1,3 151:3,9,11,18 152:6,9,12,19 153:5,13,17,18,19,21 154:1,2,10,11,17,18,24 155:8,12 158:25 159:4,23 160:6 163:2 164:20 165:2,6,24 167:3 170:7,19,19 171:8,22 172:7,10 173:5 174:12,18 175:10 176:13 177:6 179:21,22 180:7,20 181:20 182:13 183:9 185:22 186:2,17,21 187:1,14,21,24 188:11,13 189:2,16,19 190:18,25 192:13,19,22 193:2,2,6,22 194:11,13,24 195:19 196:19,22 197:2,4,6,9,17,17 200:10,21,25 201:9,16,21,23 202:11,17
peoples (6) 10:24 19:12 34:5 103:15,21 186:23
per (4) 103:18 171:11 182:2 200:8
percentage (1) 82:24
perception (5) 9:12 83:7,9,9,9
perhaps (44) 12:1 22:6 58:4 70:17,18,19 76:20 77:7 83:4 84:2 90:19 92:6,12,25 93:19 96:13,18 99:9,25 115:2,5 120:7 122:22 123:10 127:3 129:2 136:24 137:10,11 139:11 140:11 146:12 148:2 149:22 151:11 152:6,15 154:7,20 187:4 188:9,10 189:11 200:20
period (15) 5:7 47:13 67:16 70:19 72:9 77:20 83:10 101:11 123:23 130:11 134:6 139:20,24 140:10 141:21
periods (1) 131:10
peritoneal (1) 135:12
permission (1) 130:8
persistent (2) 134:14 191:19
persisting (1) 85:1
person (22) 16:22 17:3 22:12 23:15,17 34:11 57:21 79:3 103:18 115:20 147:24,25 152:10 167:4 170:9 171:12,14 174:12,13 177:6 182:14 184:13
personal (7) 4:7 14:18 44:6,17,25 63:17 156:8
personally (4) 81:20 93:12 111:18 169:7
persons (4) 41:1 71:22 90:25 126:24
perspective (7) 41:20 93:7 158:10 163:17 164:8 169:21 178:11
perspectives (1) 193:18
pet (1) 184:2
philosophy (1) 168:19
phone (3) 170:22 174:8 190:12
phoned (1) 49:8
photographs (2) 46:9 56:17
phrase (2) 123:8 132:14
physical (12) 32:15 48:24 49:14,24 52:11,14,19 58:21 62:14 68:3 99:12 164:18
physically (5) 34:9,10 46:7 47:10 60:12
physiological (1) 200:23
physiology (1) 198:18
physiotherapists (3) 164:10,20,24
physiotherapy (1) 167:3
pick (3) 52:12 106:20 121:12
picked (4) 30:15 127:15 129:1,3
picking (2) 16:4 19:5
picture (5) 33:13 71:5,5 87:10 109:10
piece (3) 47:16 49:22 166:2
pieces (2) 55:6 56:4
place (22) 3:4 7:6 14:12,13,15 19:2 20:21 21:1 22:16 25:12 76:21 106:23 111:7 112:21 118:18 120:22 124:3 126:1 127:14 133:24 147:18 182:19
placebo (1) 199:13
placed (1) 104:1
placement (1) 23:22
placements (1) 12:9
places (1) 129:6
plan (4) 104:16 159:25 171:19,21
planned (1) 111:13
planning (3) 14:23 38:12,20
plans (3) 34:21 95:7 165:23
plate (1) 13:10
please (21) 1:23 3:1,5,6,11 22:8 64:21 68:14 79:7 84:16 96:12 100:1 106:2,23 160:10 173:9 179:3,8 191:8,12 200:20
pleasure (1) 62:5
plus (1) 137:1
pm (10) 105:2,4,6 116:2,4 155:20,22 160:13,15 203:5
pmld (27) 7:23 8:1 9:10,13,25 17:3,25 19:15 20:16 21:20 22:8 25:14,24 31:6,9,19,20 32:9 34:13 39:11,21 51:11 54:2,11 58:3 62:3,8
pointed (1) 119:25
points (7) 18:4 81:18 89:10,11 96:10 102:9 155:15
poisoned (1) 181:9
policies (1) 8:24
policy (7) 106:3 107:5 108:3,11 118:8 149:9,9
policymakers (2) 139:5 150:1
politely (1) 13:7
pools (1) 90:14
poor (1) 53:13
popular (1) 56:4
population (13) 72:4 85:18 89:20,22 110:15 111:2 125:13 130:1 132:16 167:14 184:7 200:8 201:8
portfolio (1) 43:12
position (14) 3:16,19 5:14 25:9 47:14 54:18 56:16 64:11 65:22 73:23 140:24 172:13 191:1 194:9
positioned (1) 56:15
positioning (1) 58:10
positive (4) 51:14 57:7,11 129:24
possibilities (1) 37:16
possible (12) 35:10 51:22,23 93:10 102:14 125:2 135:5 149:25 152:15 154:16 155:7 192:24
possibly (12) 17:22 32:11 34:25 62:10 83:8 111:15 117:20 118:4 120:4 171:1 177:5 190:17
post (10) 6:1 36:22 60:6 113:1,2 160:23 163:3,10,25 176:9
postcovid19 (1) 199:5
postexertional (15) 68:2 71:6 161:25 179:11 180:3,10,11,18,23 181:7,15,18 184:19,21 191:22
postural (14) 17:15 33:5 34:5,21 35:2,3 49:25 54:15,16,19,21 56:16 58:7 161:18
posture (2) 34:24 58:10
postviral (5) 74:22 177:2,2,8 202:5
pot (1) 186:19
potatoes (1) 45:25
potential (1) 62:5
potentially (3) 166:1 197:11 200:12
pots (15) 161:19,20,21 162:14,23 163:3,11 164:21 168:15 171:18 172:18 186:5 194:4 198:10,21
power (2) 27:15 83:24
powerpoint (1) 56:11
ppe (2) 45:22 135:5
practice (12) 6:12 10:23 12:9 14:7,9 53:23 65:2 95:14 168:2 183:25 192:22 197:12
practices (3) 97:21 157:12 161:3
practised (1) 157:8
practitioner (3) 156:25 157:7 176:20
practitioners (6) 12:7 23:5 54:24 58:16 164:15 189:12
pre (1) 37:1
precautions (1) 101:18
precious (2) 62:18 112:6
precise (1) 82:24
precisely (1) 7:25
precovid (1) 192:2
predict (1) 75:8
predictable (1) 98:7
predicted (3) 74:19 75:7 104:9
predominantly (2) 71:10 194:21
preexisting (5) 27:25 93:6 192:10,23,24
prefaced (1) 77:19
pregnant (1) 194:25
preliminary (2) 3:3,10
prepandemic (2) 34:4 127:14
preparations (1) 75:10
prepared (3) 73:6 75:12 132:3
preparing (1) 73:1
preponderance (1) 94:8
prescribe (1) 199:18
present (5) 80:13 90:7 175:16,19,19
presentation (4) 29:4 31:14 74:9 191:18
presented (2) 175:20 190:13
presenting (2) 163:2 165:14
press (3) 70:20 83:12 142:8
pressure (1) 126:20
presumably (3) 41:4 80:10 93:10
presume (1) 86:24
pretty (5) 27:9 29:7 30:18 60:1,2
prevalence (3) 161:17 163:8,20
prevalent (1) 197:7
prevent (1) 201:25
preventable (1) 200:12
prevention (2) 199:20 201:18
previous (7) 3:22 5:19 107:21,22 193:10,21,24
previously (5) 5:9,16 9:12 10:2 193:7
primarily (2) 9:21 201:22
primary (2) 8:19 127:4
principally (1) 110:16
principles (1) 9:24
prior (7) 68:19,20 69:12 107:15 126:13,17,19
prioritisation (3) 153:20,23 155:8
prioritised (1) 153:19
prioritising (1) 155:12
priority (3) 36:10,12 144:11
private (8) 81:15 168:17,22 173:2,5,7,14 184:2
privilege (1) 62:7
privileged (1) 65:22
probable (1) 88:10
probably (43) 6:17 7:16,17 9:12 10:3 17:1 21:6,16 37:3 45:9 47:11 51:15 54:20 66:23 71:1 73:22 83:23 85:8 87:7 88:23 94:21 99:23 108:8 112:3 123:14 146:10 148:15 152:24 153:11 156:16 158:11 165:5 168:21 184:17,20 187:18,20,25 193:18 196:23 197:14 200:2,16
problem (16) 27:25 28:18,20 29:6 69:1 95:2 98:17,18,18 128:2,3 132:4,15 164:25 180:17 190:16
problems (11) 23:13 41:10 68:19 94:11,23 102:21 161:8 172:18 177:17,18 192:20
procedures (1) 17:11
proceedings (1) 105:5
process (2) 37:15 38:20
processes (2) 84:12 151:18
procurement (4) 132:12 133:13,20 134:19
produce (3) 120:18 124:25 154:4
produced (5) 79:15 84:17 89:5 199:3,7
producing (1) 84:14
products (3) 133:6,7 135:21
profession (2) 83:6 195:15
professional (12) 3:22 5:21 35:25 64:23 65:2 98:13 100:3 107:20,21,22 157:1 171:8
professionals (12) 31:25 69:24 70:3 77:5 78:10,13 82:6,7 85:14 86:3 96:24 174:1
professions (1) 36:2
profound (26) 4:4 5:24 6:21 7:15,20 8:2,11,15,21 11:16 12:11 15:11 16:22 21:8 22:12,21 23:6 24:18 25:20 27:7 36:14 42:23 52:21,24 54:4 61:6
profoundly (1) 19:11
programme (3) 13:25 14:3 54:1
programmer (1) 107:23
programmes (1) 13:15
progress (1) 66:14
progressed (1) 74:1
project (3) 14:6 78:14 107:23
projects (6) 5:1 6:13 13:15,17,18 14:5
promise (2) 6:24 36:20
promote (1) 155:7
promoted (1) 87:13
promoting (2) 3:13 6:19
proper (1) 167:10
properly (6) 25:15 35:15 165:23 167:6 181:12 185:11
proportion (2) 71:23 176:13
proportionately (1) 89:21
proposals (1) 102:15
proposition (3) 28:16 41:15,18
proprioception (1) 19:5
protect (1) 170:12
protecting (2) 42:16,16
protection (7) 121:23,24 135:6 143:4 144:8,9 196:22
protocols (1) 133:24
proved (1) 35:1
provide (21) 4:23 7:21 12:22 13:22 15:17 16:11,14 30:24 45:11,14,18,19 47:5 57:1 114:18 121:23 131:5 132:7 134:1 157:14 169:5
provided (23) 2:9,22 12:8 34:16 47:7 60:18 63:18 66:6 88:5,6,15 89:17 92:5 96:9 100:11 106:7 121:24 144:8 156:9,18 175:24 196:10 200:15
provider (6) 45:14 46:11 47:2,7 172:2 173:14
providers (1) 46:21
providing (13) 15:25 30:25 32:18 44:7,8 66:18 114:17 121:3,9 141:19 158:5 164:8 168:10
provision (6) 45:4 80:25 97:4 125:23,24 168:20
provokes (1) 22:9
prudent (1) 154:22
pry (1) 66:17
psychological (2) 99:13 200:22
psychosomatic (1) 176:25
ptsd (1) 60:6
public (15) 49:5,9,10 83:7,19,20 84:6 88:23 97:14 125:23 144:1 158:15 175:9,9,10
publicly (1) 147:9
published (7) 2:16 64:3 106:13 118:5 119:23 130:2 156:23
pulled (1) 117:16
purchasing (1) 135:18
purposeful (1) 16:14
purposes (2) 42:20 103:8
push (3) 69:18 153:17,24
pushed (2) 87:15,16
pushing (1) 54:19
puts (1) 196:8
putting (6) 24:22 52:15 87:3 145:14 180:7 184:18
puzzle (1) 47:17

Q

q (236) 63:17 64:3,6,11,13,15,19 65:3,15,17 66:6,14,16 68:11 69:11,14,17 70:7,12 71:1,18 72:18 73:9,23 74:15 75:3,13,21,23 76:18 77:19 78:12,19 79:5,14,22 80:9,16,18 81:18 82:14,20 83:2,4,23 84:1,13 86:6,8,19 91:14,23 92:5,15,23 94:4,11 95:3,10,17,22 97:12 98:9 99:7,9,20 100:11,20 101:2,20 102:9,20,25 103:4 104:20 106:2,5,12,15,22 107:4,8,10,15,21,25 108:10,14,25 109:3,9,19 110:13 111:3,9,24 112:15 113:5 114:2,21 115:10,22 117:1 120:12 123:2,5 125:5 126:11 127:12,24 129:5,15 130:22 131:17 132:12 134:19 135:25 138:7,15 140:22 141:25 143:10 144:19 145:23 146:17 147:20 148:16 149:12 150:10 156:25 157:7,14,24 158:3,10,15,17 159:8,11,13 160:9,12 161:6,16,19 162:3,7,12 163:2,5,15,24 164:3,6,8 165:4,8,13 166:2,5,13,19 167:7,16 168:9,17,19 169:7,9,25 170:2,10,15 171:1,10,13,23 172:1,13 173:1,16 174:23 175:4,12,15,18,22 176:5,7,15 177:11,15 178:2,5,8,11 179:3,11 180:2,5,14,16,20 182:5,21 183:2,15 184:16,23 185:12,18 186:20 187:3,8 188:1,9 191:10,12,18,25 192:10,17 193:8,18 194:18 195:9,13 196:4,6 198:13,17 199:3,18 200:14 201:3 202:2
qrisk (1) 146:16
qualifications (2) 102:23 157:1
qualified (1) 87:23
qualify (2) 145:7,16
qualitative (2) 23:24 24:4
quality (10) 11:23 22:4 23:16,22 35:4 62:9 118:9 119:20 120:4 146:21
quantitative (1) 23:23
quarter (3) 184:5 187:18,25
quashed (1) 30:18
queries (1) 110:1
question (14) 8:9 31:11 69:11 87:8,17 94:20 98:14 121:8 123:19 134:19 141:2 174:21 189:7,19
questions (25) 1:22 42:4 60:16 63:13 105:18,23 109:25 116:24 117:10,13 118:13,19 121:13 124:16,19 148:9 150:10 156:6 158:7 163:18 186:13 204:4,6,8,10
queue (1) 23:13
quickest (1) 198:15
quickly (13) 19:19 30:11,18 38:5 53:20,25 84:21

114:19 134:3 163:1 168:7 189:25 190:7
quite (59) 4:1 11:12 13:14,15,16 14:8 16:6 17:18 19:1,21 21:7 26:3 30:4,4,5,11 34:17 47:4 53:21 54:5,6,16 61:8 64:13,24 65:18 72:14 77:9,14,15 91:9 95:17 99:9 100:11 112:21 114:9 122:1,4 124:1,6 125:4 130:6 132:25 134:25 135:24 136:15 139:3 140:4,6 142:19 151:15,17,25 152:13,24 158:5 160:1 161:7 202:17
quo (1) 126:17
quotations (1) 95:19
quote (4) 96:3 99:24 102:25 192:3
quoted (1) 30:16

R

raise (2) 113:10,25
raised (3) 43:14 72:22 133:11
ran (2) 55:4 123:13
randomly (1) 161:23
range (10) 5:3 34:13 75:3 78:15 79:9,12 96:21 110:7 119:17 154:5
rapid (1) 120:18
rapidly (6) 56:22 112:18 113:14 117:9,15 122:16
rate (6) 25:23 136:3 162:18,21 182:1 202:9
rates (1) 164:21
rather (9) 11:11 23:1 27:24 107:1 120:14 131:4 150:22 152:4 155:1
reach (1) 53:22
reaction (1) 43:24
reactions (1) 43:21
reactive (1) 199:22
read (25) 23:21 33:8,12,25 34:25 61:24 62:23 75:14,24 84:6 86:21 88:8,16 99:25 100:14 101:23 103:7 122:17 130:5 143:15 145:9,9 157:2 167:17 200:20
readers (2) 119:21,24
readily (1) 28:2
reading (4) 50:7 55:14 61:18 199:6
ready (3) 1:14 105:19 156:4
real (8) 11:9 27:2 39:10 55:2 57:22 59:15 113:16 138:19
realise (1) 25:17
realised (9) 23:23 24:2 28:14 61:13 111:14 117:10 118:6 168:1 193:6
really (92) 4:16 5:6,9 6:15 7:9 8:20 9:13 12:5,5 13:24 15:14 16:3,19 18:22 19:4,19 20:24 21:11,11 22:9 24:7,8,20,20 26:1,19 29:14 30:11 31:21 36:16 41:25 42:4 44:2,13,13 48:22 49:6 50:6,12 51:5,6 52:23 53:7,7,7 54:3 55:7,15 56:9 57:2,2,18,19 58:17 59:12,12,19,22,23 65:18 67:1,17 69:2,25 71:25 73:15 92:3 94:2 111:22,22 114:13 120:2 133:8 134:8 136:14 137:6,20 138:24 141:5 145:18,19 149:5,5,16 153:1 168:23 177:5 182:18 185:9 189:17 193:3 201:18
reason (6) 25:15 52:7 120:20 141:13 146:10 198:17
reasonable (5) 41:15,17 44:23 102:13 152:24
reasons (4) 11:13 89:25 151:8 197:6
reassurance (1) 134:13
recall (2) 29:25 30:4
receded (1) 70:18
receive (15) 75:21,22 99:11 107:12 127:21 131:12,22 136:7,8 144:3 147:20 152:10 153:18,24 154:6
received (14) 28:13 123:15,21,22 129:23 137:13 140:18 144:24 145:10 146:25 147:7,7 154:2,3
receiving (7) 108:8 118:13 121:6 129:16 130:23 149:6,6
recent (4) 10:24 103:22 166:8 201:6
recently (2) 22:11 197:2
recipient (3) 4:15 28:6 137:25
recognise (2) 164:24 173:22
recognised (5) 33:23 76:15,17 97:4 163:1
recognition (2) 48:13 97:15
recommendations (1) 103:7
recommended (1) 118:18
record (5) 1:17 18:5 105:20 116:11 120:25
recorded (4) 2:15 64:4 106:12 156:23
recover (7) 47:10 67:5,19 93:18 176:14 177:10 202:12
recovered (3) 47:9 137:15 159:5
recoveries (2) 198:20,23
recovery (6) 87:3,15 89:2 198:13,15 202:13
redacted (2) 115:15 160:7
reduce (5) 51:2 95:8 185:15 200:3,9
reduced (4) 35:5 100:8 196:17 199:11
reduction (3) 48:5 151:1 199:13
reemergence (1) 67:10
reexamined (1) 165:18
refer (14) 3:8 8:4 18:3 68:22 82:21 94:6 99:22 106:25 120:22 129:20 171:23 173:2,8 189:14
reference (12) 1:19 8:6 63:19 70:9 105:21 111:6 156:10,11,15 180:6 185:19 187:5
referenced (2) 8:1 89:6
referral (7) 98:21 99:4,4 171:22 173:1,20 185:20
referrals (2) 173:6,14
referred (13) 68:25 71:19 98:15,16 99:14 110:25 120:20 127:1 164:13,15 176:7 178:5 189:21
referring (3) 106:25 128:11 173:17
refers (1) 109:20
reflect (2) 37:23 135:20
reflected (2) 45:8 143:19
reflection (2) 134:23 152:12
regard (1) 66:11
regarding (1) 102:21
regards (5) 114:2 130:17 136:1 146:22 149:14
regenerate (1) 166:12
regimes (1) 17:10
registered (3) 75:19 108:25 109:2
registration (3) 64:23 102:22 103:2
registry (4) 129:23 130:3,10 143:15
regret (1) 147:6
regular (5) 41:4 80:5 100:5 129:14 131:22
regularly (4) 47:11 74:8 119:23 140:23
regulation (1) 27:20
regulations (1) 14:23
rehab (1) 164:22
rehabilitate (1) 165:2
rehabilitation (2) 66:5 165:2
rehearsal (1) 75:11
rehearsed (1) 75:10
reinforces (1) 40:13
reiterate (1) 150:11
rejecting (2) 112:6 136:21
rejection (1) 100:23
relapse (1) 91:14
relapses (1) 89:3
relapsing (3) 70:9 91:18,22
related (1) 21:25
relates (1) 202:3
relating (1) 72:22
relation (15) 30:2 90:25 96:10 102:3,15 146:20 158:17 162:8 163:2 174:7 178:6 185:18 191:12,13 195:10
relationship (7) 21:21 59:8 71:8,15 76:9,9,12
relationships (3) 21:10,22 96:6
relative (6) 15:25 20:2 23:11 26:21 52:16 59:25
relatives (1) 17:21
relevant (3) 22:3 119:5 127:11
reliable (1) 90:21
relief (1) 194:25
reluctance (1) 85:5
reluctant (2) 24:19 186:21
rely (1) 32:16
remain (4) 16:20 154:5,10,21
remained (1) 154:2
remaining (1) 136:11
remains (1) 154:20
remember (21) 18:23 30:7,9,18,20 31:14 36:18 42:20 44:8 45:23 50:24 115:3 118:22 133:9 142:8 145:1 149:1 185:1,9 186:19 201:20
remind (4) 3:4 106:22 140:12 197:23
reminded (1) 101:8
reminder (1) 119:14
reminds (1) 101:11
remiss (1) 53:12
remit (2) 77:20 130:18
remitting (4) 70:10 91:15,18,22
remotely (2) 100:9 105:11
removed (1) 35:9
renal (6) 129:10,23 130:2,10 135:16 143:15
renew (1) 103:1
renewables (1) 132:10
reorganised (1) 122:16
repeat (2) 100:16 116:15
repeated (2) 68:12 167:14
repeatedly (1) 169:23
repetition (1) 20:3
replace (1) 141:18
replaced (1) 183:6
replacement (1) 135:16
report (5) 97:20 130:2,3 143:16 171:24
reported (4) 94:12 130:13 131:25 152:13
reporting (4) 90:9 143:16 201:19,19
reports (2) 103:22 151:9
represent (2) 3:12 69:7
representation (1) 74:17
representations (2) 27:4 28:3
representative (1) 65:14
representatives (1) 202:5
represented (1) 130:1
representing (6) 1:6 46:20 72:20 107:17 108:15 125:15
represents (1) 42:22
reproductive (2) 95:7 98:22
request (1) 74:10
require (4) 31:7,9 34:13 98:7
required (4) 10:17 98:21 127:14 183:20
requirement (1) 99:17
requirements (1) 34:5
requires (1) 77:15
requiring (1) 99:3
research (19) 5:1 6:13 10:16,22,22,24 14:8 23:21 74:15 82:16 95:10,25 163:8 175:7 183:24 184:14,15 200:7,22
researchers (4) 76:6 77:5 94:22 95:13
resembles (1) 198:12
residential (1) 32:6
residual (2) 87:22 91:9
resilient (1) 16:20
resolve (2) 26:2,3
resolved (1) 26:4
resonates (1) 73:9
resource (1) 36:6
resources (4) 31:8 34:14 54:10,15
respect (5) 1:19 14:18 23:5 29:1 102:18
respected (1) 115:16
respecting (1) 9:4
respective (3) 1:18 2:6 109:22
respiratory (4) 23:13 88:19 98:22 173:24
respite (2) 31:25 50:22
respond (1) 192:17
responding (1) 199:22
response (5) 130:19 138:10 165:8 196:15 198:22
responses (1) 123:15
responsibility (1) 48:2
responsible (1) 186:1
rest (4) 5:8 47:12 84:23 122:13
restriction (3) 3:4 106:23 131:2
restrictions (1) 131:20
result (3) 71:24 87:9 114:6
resulted (1) 188:24
results (5) 66:9 70:4 99:2 129:24 159:24
resurfaced (1) 68:20
retire (1) 170:6
retired (1) 160:8
retiring (1) 4:11
return (1) 5:25
returning (1) 102:14
reusable (1) 131:23
rewarding (1) 9:9
rgn (1) 103:2
rheumatological (1) 159:1
rheumatology (1) 162:5
rhyme (1) 20:3
rhythm (1) 20:3
rich (1) 149:24
rise (1) 110:23
risk (37) 38:25 39:3 47:6 48:12,22,23,25 49:4,12,13,15,18,19 111:19 112:9,10,11 117:25 118:15 121:16 136:19 137:9,10,12 138:2,19 139:16,25 151:15 152:2,9 154:21 200:3,9 201:5,7,11
riskassess (1) 55:8
riskbased (2) 124:10 155:7
risks (6) 95:8 117:18 120:9 136:23 139:1 155:11
robust (1) 82:18
role (20) 4:20,21,22 5:5,11,20 6:3,5 12:19 14:9 15:9,14 16:7 21:11 65:18 107:5,8,10,11 108:10
roles (5) 4:8 33:22 65:6 109:22,24
roll (3) 7:4 14:3,9
room (6) 19:4 34:9 113:1 116:14 187:24 190:24
rooms (1) 179:19
root (1) 98:11
rotations (1) 162:22
round (3) 85:14 143:20 145:24
route (2) 81:17 145:8
routes (1) 141:3
royal (1) 103:4
rudely (1) 116:1
run (2) 132:11 175:2
running (2) 52:13 113:24

S

sad (2) 53:7 130:3
sadly (4) 8:19 16:1 33:19 143:18
sadness (1) 62:13
safe (3) 58:10 62:19 199:16
safely (3) 34:10,12 139:3
safer (2) 127:25 128:12
safety (1) 47:8
same (28) 17:18,23 39:17,18 40:3 44:18 45:19 47:14 48:14 49:13 68:7 75:1,3 101:16 104:6 108:20 122:8 150:5 154:4 156:15 167:9 178:2,4,17 182:12 192:8 199:21 201:21
sandwich (1) 151:14
sanitising (1) 45:21
sars (1) 202:12
sars1 (1) 177:9
sarscov2 (2) 75:8 88:11
satisfactory (1) 79:2
saved (2) 48:17 199:1
saving (1) 137:3
saw (6) 14:14 24:1 46:17 67:20 135:2 161:3
saying (16) 27:24 28:17 29:16 31:15 39:4 71:1 81:13 90:11 99:5 118:12 147:2 175:15 181:25 183:21 187:9 193:20
scale (8) 22:2,15 23:3 29:25 30:2,16 62:10 179:15
scanner (1) 184:13
scanning (2) 183:25 184:2
scans (1) 190:4
scary (1) 24:7
scenario (1) 25:6
sceptical (1) 59:24
scepticism (3) 75:4 176:18 195:10
scheme (1) 115:9
school (5) 34:6 36:15 96:17 178:21 201:17
schools (4) 12:16 31:25 36:5 201:13
science (3) 175:16,16,20
sciwt0417000001 (1) 1:21
sciwt0417000002 (1) 8:7
sciwt0417000004 (1) 18:6
sciwt0426000001 (1) 105:22
sciwt0456000001 (1) 63:9
sciwt0460000001 (1) 1:20
sciwt0562000001 (1) 156:11
scoliosis (3) 35:14,15 58:11
scope (1) 153:11
scotland (46) 5:23 7:20 14:22,22 26:6 30:11 54:25 57:17 64:9 65:4,19,20 73:10,14,24 74:12 75:14 76:5 80:20,21 89:22,23 97:3 109:1,2,16 110:15,16,21 121:16 122:6,8,12,12,19,24 123:11 130:18 131:1,13,14 137:19 142:16,20 157:9,25
scotlands (2) 84:14,19
scottish (36) 27:4 30:16 43:8,10 76:1,4,13 77:1,17 78:14,15 79:12,25 80:2,4,7 84:14 103:13 104:1,16 118:17 120:18 122:9 130:10,19 138:10 144:20,23 146:23,25 147:13 148:10,18 149:21 153:3 154:8
screen (1) 63:21
second (1) 202:10
seconds (1) 179:17
secretary (2) 27:5 166:21
section (11) 84:1 89:11 95:17 98:10 100:11,16 101:20 157:1 180:2 187:5 200:15
sector (5) 32:1 65:7,8 114:4,8
secure (1) 15:20
see (60) 4:19 7:8 20:22 21:6 32:7,23 40:9 43:24 47:3 49:6 51:5 70:13 85:4,10 86:3 88:7 91:15 105:14,24 109:13 111:22 116:23 124:17,17,21 130:5 135:1 140:19 144:1 149:10 159:6 161:2 162:3 167:22 168:5,6,15 171:10,12 172:5 177:21 178:15 180:14 183:5 187:18,20 190:2,3 191:20 192:18,18,22 193:2 195:21 196:1,2 197:20 198:2,3,8
seeing (10) 36:3 44:4 46:23 58:4,5 122:1 159:4 160:21 184:24 198:5
seek (3) 41:23 75:25 161:4
seeking (2) 82:3 103:1
seem (3) 148:9 183:2,12
seemed (3) 22:3,20 53:14
seems (5) 25:23 169:12 191:23 197:19 198:24
seen (19) 36:11 46:9 69:10 126:25 127:2 145:10 157:25 163:11 166:7,8 168:8,12 185:22 189:1,12,20 190:6 197:11 198:20
segment (1) 135:25
segregated (1) 131:8
seizures (2) 17:13,14
selfreported (4) 89:20,25 90:14 91:5
selfreporting (2) 90:4,12
sending (3) 99:5 148:24 167:3
senior (1) 13:16
sense (10) 7:13 19:9 22:15 40:17 57:22 59:15 77:2,10,22 189:15
sensitive (1) 191:1
sensitivity (2) 187:16,23
sent (5) 36:9 55:6 67:5 159:19 189:12
separate (1) 42:13
september (2) 75:18 130:11
serious (6) 24:9 29:19 76:15 174:15,17 183:3
seriously (3) 48:4 93:15 177:22
servant (1) 6:14
servants (3) 26:15 38:2 43:11
service (20) 4:12 9:21 15:20 34:7 50:8 64:22 65:7 72:15 76:25 77:13,13 79:17 80:25 81:8,17 84:15,19 160:6 168:10 190:8
services (50) 15:19,21,22 27:6 30:24 31:25 32:14 34:7 36:24 37:22 59:21 60:1 76:23 78:18 79:10,19 80:8,11,15 81:10,14 84:18,21,25 85:3,9 86:4,13 96:24 98:23 103:14,15,17,20 104:5,6,7,18 109:3,6,8 110:11,12 114:18 121:3 123:7 125:23 168:13 169:6 172:4
session (2) 2:3 151:14
sessions (3) 55:4 57:14 151:1
set (8) 39:4 117:21 146:8 157:1 160:7 167:16 168:5 183:19
sets (1) 34:15
setting (4) 8:5 16:23 24:13 32:6
settings (2) 26:1 43:18
seven (2) 65:24 130:4
several (9) 65:5 151:4,6 157:21 169:7 180:18 198:24,25 199:2
severe (3) 17:12 23:13 181:5
severity (1) 179:15
shall (1) 64:3
share (3) 55:23 74:12 147:18
shared (4) 51:3 133:22 149:20 161:21
sharing (6) 49:2 55:13 115:6 135:9 149:18,23
shes (1) 196:10
shield (11) 121:22 124:11 142:4,7,10 143:23,24 144:6 145:3 152:25 154:18
shielding (28) 121:15 122:18,23 123:2 141:25 142:14,17 143:5,7,13,21 144:5,10,17,21 145:5,5,16,25 146:3,12,13,20,22 148:17 149:14,18 154:19
shift (2) 26:23,25
shifts (1) 72:16
shocked (1) 23:3
shocking (1) 51:17
short (9) 32:1 63:4 94:21 105:3 116:3 155:21 160:14 173:24 199:6
shorter (1) 53:2
should (63) 2:19 10:9 11:20 26:4 29:13,14,20 37:20 40:4,15,24 41:7,13 42:15 62:18 72:18 75:6,8 76:21 80:24 87:8 89:13 102:13 113:18 117:14,14,22 121:15 124:6,12,12,17,17,18,25 126:6,21,22 127:15,15,17 134:21 135:4 140:2 143:11,23 144:18 145:4 146:12 148:2 154:14 160:9 162:15,15,16,24 167:5 173:20 174:6,24 190:3 201:20 202:2
shouting (1) 13:4
show (4) 16:25 56:15 57:4 184:1
showed (2) 29:6 142:17
shows (2) 132:22 145:21
siblings (1) 36:15
sick (1) 70:23
side (6) 46:9 65:13 76:18 190:24 197:21 202:16
sidelined (1) 42:19
sidelying (1) 34:11
sign (1) 82:7
signals (1) 161:15
signed (1) 85:20
significance (3) 84:16 175:15 182:9
significant (2) 12:5,19
significantly (2) 35:4 46:7
signs (1) 58:4
similar (5) 108:12 134:16 161:7,11 177:1
similarities (1) 161:16
simple (6) 10:14 159:24 164:3,4 181:6 185:15
simplicity (1) 24:21
simplistic (2) 189:8,18
since (16) 3:20 5:15,17 43:14 66:22 75:18 77:21 83:10

94:17 95:1 100:15 107:9 163:13 166:5 171:17 184:8
single (7) 17:19 21:17,19 34:12 40:1 146:8 165:24
sit (4) 168:19 169:4,4 175:1
sitting (4) 151:4,5 180:21 181:6
situ (1) 81:9
situation (8) 25:2 35:23 43:22 102:5 108:13 133:15 139:13 192:1
situations (3) 188:12,19,24
six (7) 67:9 128:15 145:1,3 151:24 168:7 169:10
size (4) 13:10 52:16 109:9 110:13
skilled (1) 32:18
skills (5) 16:4 53:4 59:3,5 102:22
skype (2) 46:18,24
sleep (1) 182:15
sleeping (1) 92:11
sleeves (1) 7:4
slept (2) 37:3 182:16
slightly (6) 33:15 95:3 100:12 109:19 130:10 180:11
slow (1) 77:22
slowed (2) 137:6 138:4
slowly (3) 86:17,18 140:4
small (9) 13:14,16,16 38:4 39:25 42:6 65:24 66:2 200:8
smaller (1) 152:3
smart (1) 135:18
snowslope (1) 18:24
soap (1) 45:25
social (17) 12:7 21:8 29:3 31:10,24 32:20 34:19 59:2 76:4 96:11 100:5,23 103:24 118:14 151:12 170:16 194:14
socially (2) 101:3,4
society (5) 3:13 12:21 42:17,19 62:19
solely (1) 7:14
solutions (2) 84:10 104:14
somebody (52) 11:8 16:1 17:3 19:15 20:4,10 22:17 23:6,14 24:17 26:25 30:15 34:13 36:1 39:21 49:1,5,7,8,10 51:1 52:9,20 54:4 56:15 57:18,19 58:12 68:7 71:8 126:10,19,20,23 136:6,17 138:2 148:1 151:5 160:4 162:19 164:19 168:9 170:21,25 171:15 179:18 182:7,7 190:20 196:13 199:23
somebodys (5) 50:7 58:10 132:6 176:12,25
someone (7) 27:19 42:22 56:24 113:1 125:16 142:9 190:9
something (74) 2:24 4:17 10:9 13:1 22:1 25:2 26:2,12 27:12,16 28:19 29:23 33:10 37:5 46:5,25 51:17 53:18 56:6 57:11 59:22 60:5,9,11 61:9 63:1 71:7 75:9 82:2 88:22 91:19 97:18 98:9 99:23 113:13 120:1 122:18 124:23,24 134:11,21 135:20 138:8 140:22 142:1,12 143:11 144:25 145:2,18 146:16 147:5 151:1,16,19 152:12,17 153:7 155:9 161:12 168:25 169:3 173:22 176:16 182:4 188:18 192:14 195:6,13,21 198:11 199:7,18 200:4
sometimes (26) 13:3 16:1 17:13 20:2,6 26:23 40:10 41:24 44:6 52:25 69:18 118:22,25 122:6,9 138:16 147:22,23 151:12 171:21 172:11 173:12 176:3 186:4 189:5 194:3
somewhere (3) 62:20 77:7 138:23
son (4) 15:11 19:17 32:12 40:8
sons (1) 16:15
soon (1) 129:3
sooner (2) 129:1,2
sore (1) 67:8
sort (26) 12:22 16:11 25:6 28:24 32:7 41:9 52:1,3 60:6 71:4 77:2 87:10 119:9 124:9,19 128:15 132:21 136:22 154:20 168:6,14 177:7 186:13 187:14 192:8 197:18
sorted (2) 25:16 160:16
sorts (5) 10:8 59:14 75:1,3 188:24
sound (3) 13:9 51:17 190:5
source (4) 45:24 117:7 119:12 122:14
sources (3) 100:18 119:1 121:5
space (1) 84:11
spacious (1) 34:20
sparsely (1) 119:19
speak (9) 28:12 37:21 64:8 85:15 132:4 170:20,25 189:2,3
speaking (6) 61:18 79:16 83:13 94:14 99:2 101:9
specialised (1) 9:23
specialist (11) 34:13 99:14,17 127:2,6 140:20 145:11 147:24 173:19 189:13,14
specialists (5) 125:14 143:22 144:16 173:1,13
specialties (2) 158:23 190:6
specialty (5) 174:22 189:13,22,23,23
specific (7) 6:18 29:8 72:23 122:23 130:9 144:19 188:9
specifically (8) 26:10 107:1 114:5 143:7 146:4,20 149:14 175:12
specifics (1) 175:22
spectrum (2) 179:22 197:19
speculate (1) 93:11
sped (2) 19:19 54:20
speeds (1) 162:18
spend (5) 18:14 19:21 22:22 51:23 68:5
spending (1) 45:23
spent (9) 7:1 23:24 61:17 64:22 86:14,15 103:15,19 108:7
spinal (1) 58:20
splendid (1) 105:17
spoke (4) 31:17 81:7 94:19 166:20
spoken (4) 61:1 62:15 85:13 94:25
spread (2) 109:11 111:23
staff (36) 3:6,7 4:24 5:2 6:13,15 13:13,14,21 15:8 33:9 45:7,10 48:10,11 61:7 86:16 106:25 108:12 109:10,17,18 112:19,22,23 114:21 133:25 135:10 137:1,2,2 138:1 139:10,22 142:20 150:6
staffing (2) 114:3,6
staffs (2) 55:15 61:19
stage (5) 42:21 103:11 117:25 148:1 166:19
stages (6) 110:21,22,25 117:12 121:18 122:3
stairs (1) 113:24
stakeholder (1) 84:12
stand (4) 36:2 162:15 190:5,24
standard (3) 136:5 191:18 201:14
standing (1) 34:11
stands (1) 3:12
start (15) 1:23,24 3:11 35:19,19 44:23 50:15 105:25 116:20,23 126:7 156:15 163:19 174:10 185:7
started (19) 5:23 9:20 14:20 38:23 56:20,20 67:21 73:20 111:22 117:21 118:24 119:19 121:14,17 124:2 136:14,14 170:20 183:6
starting (2) 94:25 119:16
starts (2) 16:2 192:1
stated (1) 143:10
statement (78) 2:25 7:3,11 8:5 14:14 15:6 18:4 22:2 50:8 55:15 61:2,23 63:8,19,20,23 64:7 65:17 66:8 68:11 70:9 73:1,7 75:15 76:7 79:5,23 81:19 84:4 86:20 87:4 92:25 93:5 94:6 95:17 100:12 105:21 106:7,8,16 107:16 109:20 111:5,24 115:10 117:5 123:5,8 126:16 127:25 131:18 132:13 138:9 140:17 148:17 150:13 156:10,10,12,18,20 157:2,18 158:5,19 170:10 175:24 177:12 179:7 180:6,20 182:5,22 183:16 187:6 190:15 192:8 193:12
statements (14) 1:18 2:9,10,20 20:15 31:3,4 33:8,11 60:18 61:18,19,19 83:23
statistical (1) 89:17
statistician (2) 90:12,20
statisticians (1) 90:13
statistics (1) 91:1
status (2) 126:17 146:9
statute (2) 27:19,21
stay (5) 115:5 117:20 122:22 127:4 132:17
staying (2) 48:8 121:25
steadily (1) 69:21
step (1) 14:11
stephens (84) 1:4,6,10,13,15,17,22,23 2:2,6,15,19 3:16,19,22,25 4:7,19 5:10,14,19 6:2,5,23 7:10,25 9:6 11:25 13:7,9,17 14:14 15:4 17:24 18:2 20:13 21:25 26:9 27:10 29:24 30:19,22 37:4 38:16 42:21 43:4,5,14 47:15 49:24 53:11,17 57:7,25 60:15 61:14 62:1,24 104:25 105:1,7,8,18,19,20,23,24 106:1 112:18 116:21,22 120:13,25 121:1 125:2 130:17 140:13,14,16 150:20 155:14,18 204:4,8
stick (2) 3:6 168:2
stigma (7) 96:12 177:7,11,15 178:2,6,12
still (59) 7:4 11:18 14:21,24 15:24 16:5 29:11 30:13,14 32:4,18 35:20 36:25 37:1 46:5,23,23 50:6 51:8,9 56:4,5 59:20 60:2 62:4,8 68:1 81:13 86:17 87:15 98:3,25 108:20 119:12 129:6 137:15 139:14 140:6 154:9,15,18,19,22 155:2 159:14 169:5 172:5 176:19 178:2,4 186:10,13 195:23 196:16 199:25 201:6,11,20,23
stock (1) 34:18
stoicism (1) 62:4
stood (1) 164:21
stop (9) 37:7 108:5 111:25 112:7 113:14 115:22 183:13 200:21,24
stopped (2) 31:13 112:2
stops (1) 112:6
stories (2) 13:25 171:3
story (2) 24:21 192:1
storytelling (3) 13:23 19:6 20:10
straight (1) 142:23
straightaway (1) 22:10
straightforward (1) 121:8
strain (1) 47:18
strange (1) 111:11
strategic (1) 4:22
strategies (2) 8:24 125:25
strategy (12) 6:17 54:19 59:14 77:23 78:8,11,12,16 79:21 84:20 85:12 86:2
stress (6) 21:21 52:3 60:7 90:25 132:25 201:2
stressful (2) 22:5,7
stroke (3) 76:5 79:11 103:23
strong (3) 7:19 83:18,20
strongly (1) 12:14
struck (1) 145:23
structure (1) 75:23
structures (2) 75:14 84:11
struggle (6) 69:4 71:16 76:14,14,19 194:9
struggled (1) 67:7
struggling (1) 69:9
stuck (3) 33:7 164:2 195:23
student (1) 23:20
studied (1) 166:9
studies (6) 165:18 166:6,7 184:7,12 200:7
study (5) 176:8 184:1,15 196:25 201:6
stuff (3) 131:23 132:6 133:16
style (1) 199:22
subgroup (4) 42:10,10,11 44:19
subject (1) 123:6
subjected (1) 75:1
subsequent (3) 66:20 91:23 92:4
subsequently (2) 87:5 167:7
suddenly (10) 15:21 21:13 36:6 52:13 54:16 57:17 61:12 134:3 181:3 190:11
suffer (3) 41:1 68:1 70:12
suffered (1) 108:6
sufferers (2) 78:20 94:8
suffering (3) 16:18 199:1 201:10
sufficiency (1) 134:20
sufficiently (1) 29:16
suggest (3) 29:20 37:6 146:1
suggested (3) 22:16 150:9 201:7
suggesting (1) 87:25
suggestions (2) 12:25 149:12
suicide (3) 51:4,4,16
suitable (1) 136:6
sum (2) 58:2 61:20
summarise (1) 8:8
summer (1) 107:9
summit (2) 79:6,8
supermarket (1) 144:11
supervised (2) 162:9 165:23
supervising (2) 162:21,23
supplement (1) 95:18
supplemented (1) 2:11
supplies (2) 132:10 134:15
support (71) 4:12,15,23 5:7 7:22,24 9:21 14:1,3,24 15:6,7,9,17,17,25 16:2,8,13,19 21:9 24:24,24,25 25:6 32:1,5,22 33:3 34:10,18 35:12 36:4 44:7 45:10,12,14,19 47:5 49:4 50:21 55:2,16,22 61:11 66:4 74:6 81:17 102:14 108:16,21 109:6,7,20,23,25 110:4 115:9 123:18 135:1 146:13 149:11 151:21 152:22,23 153:15 154:24 170:4,6 187:1 188:4
supported (10) 24:16 27:7 39:23 40:9 43:15,20 47:22 50:19 59:7 108:23
supporting (9) 6:8 8:14 15:24 26:7 34:12 61:10 147:19 170:7 187:2
supportive (1) 139:22
supports (1) 7:14
suppose (29) 4:8,24 6:7,14 12:5 13:24 31:17 37:23,23 41:22 43:17 57:22,25 58:2 100:21 102:3 103:25 109:19 110:13 115:3 121:7 139:18,18 149:25 153:10 172:14 179:11 187:13 196:8
supposed (1) 59:17
suppress (1) 136:21
sure (26) 8:24 10:19,23 13:7 24:11 25:7 30:13 35:9,12 42:4,5 43:4 62:1,22 69:25 77:16 81:23 87:11 90:6 102:18 116:1,8 125:22 172:9 173:10 193:6
surely (1) 75:10
surgeons (1) 128:9
surgery (5) 58:20 128:2,5,6,20
surprise (1) 35:22
surprising (2) 51:19 71:14
surrounded (1) 176:18
survey (7) 92:19,19,20 99:1,24 101:21 102:10
surveys (11) 66:9 89:6,14 95:19,25 123:7,13,16 141:1 152:20 153:4
survive (4) 21:22 22:25 35:18 51:16
suspect (4) 12:1 39:13 90:18 197:20
suspended (2) 139:15 140:2
suspicious (1) 90:14
switching (1) 180:9
sympathetic (2) 72:2 196:12
symptom (2) 191:15,21
symptoms (57) 67:6 68:1,6,16,21 69:3,22 70:1 87:2,14 88:12,22,24 89:1,3,12,21 90:1 91:5,7,12,25 92:6,7,10,13 93:3,21 94:16,17,23 97:15 98:14 102:11 158:25 160:22 163:2 165:14 169:17,19 171:16 173:19,25 174:14 176:9 179:3,6 180:18 185:17 189:17,19 190:9,14 191:16,20 194:2 195:1
syndrome (5) 161:18 164:1 183:7,10 202:6
synonymously (1) 70:10
system (8) 81:3 133:21 138:4 141:9,19 167:13 172:19 194:23
systems (8) 88:18,21 101:16 135:1 150:6 161:24 181:11 198:19

T

tablets (1) 112:7
tachycardia (2) 67:3 161:18
taken (24) 2:24 3:1 47:17 51:21 52:1,4 62:11 81:5 99:24 101:18 106:17 116:7 125:7 127:6 133:13 136:1 138:8,22 139:11 142:22 165:16 170:8 182:12 201:15
takes (5) 52:21 53:1 89:21 171:19 190:8
taking (6) 5:20 46:2 85:23 107:11 136:20 177:22
talk (27) 15:7 19:23 22:4,5 23:1 34:1 39:4 40:16 55:24 60:8 79:22 89:15 92:9 93:1,2,20 97:13,17 100:21 131:17 138:9 140:16 167:11 170:12 187:3 188:12 201:4
talked (20) 18:10,15 29:8 40:21,21 43:17,21 47:18 51:4 59:3 83:4 113:4 133:1 135:11 145:24 150:21,25 152:22 153:12 171:21
talking (27) 13:11 19:15 21:12 22:3 23:21 24:12 38:2,23 39:19 42:5 43:8,9 44:9 56:2 70:8 101:10 121:25 128:18 146:18 148:19 160:19 169:22 179:18 180:21 184:17 185:8 186:5
talks (3) 18:6 39:9 175:9
task (3) 19:18 110:13 121:9
tax (1) 3:24
taxi (1) 152:11
taylor (12) 82:20 93:4 155:25 156:1,2,7,7,17 201:3 202:19,21 204:9
taylors (1) 156:12
teach (1) 52:23
teacher (1) 64:25
teachers (1) 102:21
team (10) 5:8 12:13 13:10,16,16 45:5,7 113:15 115:20 118:8
teams (4) 114:20 119:22 152:21 190:2
techiesavvy (1) 53:20
technique (2) 135:13,15
techniques (1) 135:11
teenage (1) 197:18
teenagers (3) 198:1,14,21
telephone (1) 114:18
telling (8) 13:24 28:23 87:25 168:11 175:20 178:22 200:21,24
tells (2) 56:11 84:7
temperature (1) 67:4
temporarily (1) 139:15
ten (2) 109:13 162:10
tenancies (1) 40:1
tenancy (1) 39:25
tend (6) 21:16 51:11 174:1 191:23 193:2 197:16
tends (4) 71:10 180:23 182:9 197:17
tenets (1) 80:24
term (11) 100:8 125:17,18 163:19,22 164:2,3,4 182:17 183:5,9
termed (1) 97:22
terminology (3) 123:11 125:9 126:5
terms (33) 3:3 4:20 47:25 50:2 66:3 69:5,8 70:10 75:6 76:10 79:16 80:22 84:25 85:18 91:8 97:3 109:9 110:13 113:6,22 114:15 119:4,7 125:3 135:21 136:2,17 137:24 141:12 163:25 194:18 196:6 200:18
terrible (5) 32:8,8,24,24 182:24
terrified (1) 23:19
terrifying (1) 32:13
test (4) 90:9 141:18,23 162:19
testament (1) 35:7
tested (2) 90:4 183:22
testify (1) 21:22
testing (8) 66:24 90:1,2 92:21 162:9,13,14,18
tests (9) 141:7,20 159:24 162:22 164:16 173:7 183:23,24 191:3
thank (82) 1:14,17 2:6 3:9 4:19 5:10 7:25 9:6 11:25 17:24 20:13 21:25 27:10 30:22 43:5 60:19,21,22,23 62:24,25 63:1 64:6 66:6 73:9 81:18 84:13 86:19 88:4 91:3 95:21 103:12 104:19,20,22,23 105:20 106:1,5,11,14,21 107:3,4,15 110:13 111:3 114:2 116:6,21,22,25 117:1 120:12 126:11 130:17 131:17 134:19 135:25 141:25 145:23 149:12 150:10,24 155:13,14,15,16,19 156:5 158:17 160:18 179:3 191:6 197:25 200:14 201:3 202:19,20,21,22 203:4
thankfully (1) 154:5
thanks (2) 150:5,11
thats (113) 3:18 5:4,9 7:2 8:6,9,16,17 9:19 10:17 11:13 13:1 16:12 17:24 18:2,5 26:5,6 27:13,15 28:5 29:1 30:19 31:11 35:7 39:19,20 40:12 41:24 44:23 45:8 48:2,16 51:17 52:22 53:6 63:16 64:10,11,12,18 65:6 72:5 76:6 77:8 78:17 82:9,15 86:25 89:24 94:20 95:20 96:8,16 97:6 99:6 101:13 102:2 105:17 107:19 108:16,18,25 110:21 111:11 112:2,12 120:15 121:16 123:13 128:10 129:11,20,25 130:16,21 136:10 139:3 140:11,21 143:6 145:21 150:13 157:22 160:9 161:19 164:23 168:4 169:11 171:1,7,7,8 172:8 173:2 174:4,8 175:20,21 176:17 179:21 180:16 181:13,16 184:18 185:24 186:8 190:16 192:7,18 195:22 200:6 202:10
theatre (1) 66:23
theme (2) 21:25 120:6
themselves (10) 50:11 69:4 96:19 98:23 138:3 149:3 152:19 177:4,16 190:11
therapist (1) 5:22
therapists (1) 164:11
therapy (2) 135:16 167:4
thereafter (2) 81:22 160:21
therefore (10) 28:15 40:24 41:6 83:17 87:22 101:6 109:3 131:10 138:7,18
theres (58) 2:24 3:4 10:24 13:9 15:20 16:12 43:10 47:15 59:19 64:15 69:3 71:21 74:6 77:3 78:7,9 82:15 86:22 90:6 96:15,21 99:17 106:19 110:20 125:9,11,12 127:21 135:13,17,17,18 148:5 150:18 152:25 155:1,2 159:14 170:21,25 172:21 175:18 177:7 180:5 184:10 187:16 190:17 194:12 195:20 197:1,6,21 198:5 200:2,5 201:24 202:2,15
theyd (3) 28:13 145:10 161:1
theyll (5) 17:12 185:4,5 190:22 196:2
theyre (49) 8:17 10:14,14 17:7,19 22:24 25:25 34:12,19 50:21 59:25 60:11 61:12 71:11 74:24 98:5 103:20,21 112:8 127:5 151:4 154:12,13,15,19 159:18 173:4,24 175:9 177:4,6 178:14,20,21 180:8,24 181:2 185:4,7,19 186:18

188:7 189:3 190:23 191:15 195:17,20 197:14 201:2
theyve (44) 1:7 21:1,2,3 39:6 57:15 59:1 74:23 78:7 163:12,13 171:17,18 172:4,5,6,6,9,25 173:23 178:17,18,23 181:1,3,8,24 182:3,13 185:25 186:25 188:22 189:10,12 190:7,15 194:1,1,2 195:18 197:13 198:22 199:1 200:11
thing (28) 11:14 20:1 25:7 38:22 44:23 51:24 60:25 61:16 67:25 69:2 74:16 77:7 90:1,2,4 96:17,23 97:11,24 98:7,7 123:24 140:6 151:22,23 176:15 178:17 191:24
thinking (9) 24:15 36:18 39:1,3 58:9 59:15 61:9 69:6 113:22
thinks (1) 29:15
third (3) 32:1 65:7,8
though (9) 3:25 28:22 60:25 67:2 70:22 108:21 154:20 159:14 160:1
thought (27) 9:17 10:25 29:7 37:8,10,15 41:7,13 42:2 44:23 55:23 61:5 79:16 81:23 85:9 86:11 125:20 148:2 152:1 159:5 168:6,25 189:18,19 190:10 202:9,10
thoughts (4) 6:25 69:7 176:15,17
thousands (1) 66:2
thread (1) 196:23
threatening (1) 51:1
three (18) 32:23 40:1 45:1 46:14,16 86:11 88:12 115:2 123:13 128:14 131:4 143:16 144:6 176:10,11 179:8 181:2 201:7
threemonth (1) 47:13
thrill (1) 19:1
thrilled (1) 5:18
throat (1) 67:8
through (44) 8:13 13:2 19:19 23:25 40:6 46:24 52:17 53:14 55:1 56:16 66:10 75:16 81:16,16 96:1 97:12,18,21 101:22 114:25 118:13 120:11 121:12 123:14,16 124:22,24 125:19 127:20,20 129:16 135:14 141:1,1,2 145:7 148:10 149:10 152:20 159:16,22 171:18 184:13 201:2
throughout (7) 16:20 33:23 81:19 109:24 141:6 146:11 158:23
thursday (1) 203:7
thus (1) 84:25
tie (1) 27:10
tier (1) 123:1
tiers (4) 122:18 125:7,19,21
ties (1) 186:25
tightly (1) 34:17
till (1) 202:24
tilt (5) 162:9,12,14,19,20
tilting (1) 46:9
time (98) 4:10,13,13 7:1 17:18 22:6 23:25 24:7,16 30:8 32:8 33:14 36:17 40:6,19 42:15 45:2,11,24 46:6,10,15 48:2 49:1,1,7,16 50:16 51:6,23 52:22 53:1,2,6,15 55:20 60:5,14 63:6 65:8 68:5 70:19 87:15 93:13 94:21,21 100:12 112:3,4 113:2,2 114:24 115:4,8 119:25 122:25 123:23 126:13 127:3 128:15 130:4,11 131:10 133:10,17 134:6 136:24 138:25 139:5,24 140:10 141:2 143:12 144:9 147:8 149:7 150:5,21,22 151:25 152:9 155:5,6 156:16 160:25 164:21 165:13 167:6 171:9 172:3 174:3 176:4,12 182:3 192:5 193:22 194:6 200:1
timecritical (1) 140:12
timely (4) 126:8 127:16 152:15 153:14
times (15) 16:16 20:9 31:2,20,20 32:10 45:1 125:3 128:14 131:4 144:6 152:15 153:2 169:7 192:8
timescale (1) 76:10
timing (1) 29:25
tired (3) 70:24 72:5 182:12
tiredness (4) 181:20 182:13,20 183:18
today (28) 2:12,25 3:12 18:16 20:16 31:3 43:22 60:19 61:22 63:25 64:13,17 73:2,7,8 90:8,8,10 106:9,17 108:15 125:20 150:14 153:12 155:4,25 156:21 181:22
together (20) 1:7 16:13 36:20 50:16 54:1 55:10 57:20,23 59:18 63:23 69:7 71:13,14 79:9 117:16 118:9 119:16 156:20 174:13,19
toilet (6) 7:6 15:3 21:1 179:21 187:11 189:1
toilets (6) 14:12,13,15,16 19:2 20:21
tokenistic (1) 77:6
told (24) 40:18 58:11 59:25 67:18 68:14,15,15 104:4 116:14 119:25 147:11 152:19 166:23 178:18 190:15 193:4,15 194:2,15 195:16,23 196:2 198:6 199:24
tolerate (5) 179:17 187:10,15,17,21
tomorrow (3) 111:12 202:24,25
too (12) 51:14 62:22 70:24 100:5 108:22 120:19 150:22 172:12 178:21 188:24 189:3 191:4
took (11) 40:5 44:5 49:4 54:2 59:4 68:23,25 133:8,8 138:11 153:23
tool (1) 57:3
topic (1) 117:2
total (2) 77:4 130:1
totally (3) 8:18 42:12,19
touch (7) 22:1 95:13 106:16 126:15 132:12 142:2 170:10
touched (4) 49:24 84:2 97:16 99:23
towards (3) 110:11 168:19 196:13
tracking (1) 14:17
tract (1) 44:16
traditional (1) 5:5
tragic (1) 52:6
tragically (2) 62:20 115:11
training (5) 57:1 133:25 135:9,17 158:23
transformative (1) 15:4
transitions (1) 15:18
transplant (22) 108:8 118:1 127:9,10 136:5,7,8,9,15,16 137:2,6,13,16 138:4,19 139:9,12,23 140:1,10 141:11
transplantation (1) 137:21
transplantations (1) 138:12
transplanted (2) 138:2 139:20
transplanting (1) 137:19
transplants (13) 121:19 136:2,11 137:7,9,14 139:3 140:18 141:5 142:6 143:2 145:20 153:19
transport (6) 151:23 152:1,3,9,11,14
trauma (2) 60:3 62:14
travel (1) 122:25
travelling (2) 73:5,6
treat (7) 178:8,8,14 182:23 185:19 186:4,12
treated (12) 39:17,18 40:2,5,12,14 74:25 76:22 139:6 177:3 178:25 198:21
treating (8) 81:3 82:25 157:15 158:12 169:21 176:21 186:4 200:11
treatment (40) 22:18 66:4 81:23 82:9,19 85:11 95:7 97:18,21 98:10 99:17 107:13 110:7 118:3 127:23 128:8 129:14 134:4,10 135:7 136:5 154:23 157:17 158:18 165:1 171:19 172:15,17,21 175:8 185:12,13 198:10,23,25 199:4,9,11,15 200:1
treatments (10) 119:15 120:10 132:11 154:6,9,14,24 172:17,20,23
treats (1) 46:4
trial (1) 199:8
trials (2) 82:18,19
tribunal (1) 110:3
trick (1) 19:8
tried (5) 40:22 68:22 115:7 148:17 167:19
triggered (1) 180:21
tripled (1) 133:7
true (4) 48:6 77:9 87:24 88:1
trust (6) 158:21 159:8 160:20 161:3 167:22 179:1
trustees (1) 65:24
try (20) 3:6 14:7 20:8,9 26:16 45:22 46:4 51:13 72:8 121:13,17 124:25 126:4 153:5 159:25 173:12 178:23 180:25 195:19 200:25
trying (28) 11:14 15:22 17:1 21:9 33:2 36:15,16 42:8 45:24 47:5 53:13 59:13 61:20 69:7 72:8,16 85:15 96:24 97:8 121:11 124:21 128:8 132:6 148:22 164:20 165:1,10 185:3
tubes (3) 34:15 131:22 187:11
tummy (3) 127:20 128:7 135:12
tunnel (1) 52:2
turn (4) 5:11 28:16 32:5 175:22
turns (1) 172:7
tv (1) 83:13
twice (2) 118:22 131:3
twothirds (1) 136:11
twoyear (1) 24:22
type (8) 16:6 40:4 71:25 134:1 135:7 137:2 177:6 181:23
types (3) 114:14 195:3,4

U

uk (22) 84:23 89:20 105:9 106:4 107:5,17 108:4,16,18,25 109:10 119:22 120:12 121:2,4 124:5 129:23 130:2,9 133:11 143:15 184:9
ultimately (1) 128:22
ultrarunner (1) 100:4
unable (4) 43:24 57:20 62:16 180:8
uncommon (1) 51:19
undergoing (1) 131:9
underlying (1) 99:21
understand (42) 3:12 13:11 15:14 20:2 21:13 23:6 28:3 29:5 39:11,19,20 40:16 41:24,25 42:9 47:4 49:15 62:8,9 63:23 71:16 72:6 75:17 82:2 91:17 95:5 97:23 119:7 121:17 122:7 124:8 135:6 138:21 139:10,24 149:25 150:1 157:16 189:15 190:9 193:20 194:11
understandable (1) 101:14
understanding (17) 7:19,22 9:14 10:16 12:10 20:8 27:9 28:11 39:10 42:18 50:18 85:19 90:13 95:10 102:17 119:3 190:18
understands (3) 72:2 98:5 164:5
understood (8) 15:5 29:6 35:23 41:21 129:5 139:11,21 143:12
undertaken (1) 136:3
underway (2) 102:17,19
unfamiliar (1) 65:6
unfortunate (2) 127:5 187:21
unfortunately (8) 67:6,20 68:1 78:5 92:2 138:6 143:18 150:2
unique (9) 7:10,13,18 9:18,18 15:14 16:6 35:23 102:21
united (7) 109:8,24 110:19 132:1 133:14,21 135:22
units (13) 131:8 132:24 134:11 137:4,6,19,22 139:23 151:3,7,8,9,18
universal (1) 92:8
universities (1) 76:6
university (2) 157:4,5
unknown (2) 112:10 138:1
unlearn (1) 53:2
unless (5) 23:24 66:17 145:10,12 146:4
unlikely (2) 165:21 193:5
unpaid (7) 33:16,18,19,22 54:13,14,14
unpredictable (1) 97:15
unreliable (1) 90:21
unstimulated (1) 53:3
unsupportive (1) 100:17
until (10) 22:11 29:4 73:22 80:13 94:18 143:5 146:14 178:14 199:24 203:6
untruths (1) 87:25
unwell (15) 67:2 70:22 91:8 159:3 177:23 178:22 181:20 188:25 189:3,25 190:18 194:7 201:9,17,25
updated (3) 118:21 119:11 172:25
updating (1) 102:22
upfront (1) 153:7
upon (9) 8:7 31:8 58:3 111:4 114:3 126:12 130:23 169:25 172:14
upset (2) 149:2,4
upsetting (1) 170:24
uptodate (2) 120:23 148:4
urgent (2) 95:5 138:12
urgently (2) 133:12 135:14
urinary (1) 44:16
used (15) 19:3 55:19 56:3,8 108:18 112:23 123:8 125:20 152:4 163:25 173:20 177:23 179:24 183:2 199:14
useful (9) 6:2,4 38:18 56:20 57:2 73:14,17 92:25 187:3
users (1) 123:7
using (9) 40:17 54:9 55:9 56:10 70:10 107:13 114:19 133:3,4
usual (1) 173:5
usually (8) 36:4 40:1 88:11 161:25 171:19 174:4 176:11 184:1

V

vaccination (1) 153:2
vaccinations (6) 115:18 153:13,14,16,24 154:1
vaccines (4) 119:13 153:18 154:3,12
validated (1) 103:24
valuable (2) 30:25 118:7
value (5) 11:22 23:4,6,7,7
valued (3) 8:13 33:24 59:11
valuing (2) 9:4 62:18
van (1) 152:5
vanished (1) 41:12
variable (1) 141:6
variation (2) 128:19 140:5
varied (4) 15:12 16:10,16 85:18
variety (1) 175:10
various (10) 45:24 76:3,5 89:25 95:18 118:12 152:20 157:8 158:23 173:18
vascular (1) 128:5
vehicles (1) 152:4
ventilate (1) 23:15
ventilating (1) 201:14
ventilation (3) 23:12 83:21 101:10
ventilators (1) 135:3
versus (2) 48:25 49:15
vessel (1) 167:13
vessels (1) 184:3
via (3) 54:5 105:13 144:23
viable (1) 51:22
video (3) 2:22 60:18 185:7
videolink (2) 105:13 171:14
videos (1) 56:17
viewed (1) 90:5
views (1) 80:10
viral (2) 87:21 160:23
virtual (5) 56:3 73:19 76:16 141:15,15
virtually (3) 57:12 73:22 137:22
virus (7) 67:10 75:7 87:9 178:24 186:10 201:21 202:18
visible (1) 6:22
visit (3) 45:2 46:13 129:17
visiting (2) 44:4 129:6
vital (2) 33:22 149:11
vocally (1) 37:21
voice (3) 56:13 76:1 78:20
voices (3) 6:9 8:21 37:25
volume (1) 117:10
volunteer (2) 100:5 122:9
volunteering (1) 7:7
volunteerled (1) 75:16
volunteers (1) 65:25
vulnerability (3) 145:19 150:3 155:9
vulnerable (10) 42:16,18 52:9 124:1 136:22 142:3 143:1,3,11 154:10

W

wait (4) 138:18 141:23 152:5 199:24
waiting (12) 11:11 68:21 132:9 137:14,17 138:19 139:8,15 160:2 172:4,5 185:21
wake (1) 182:14
wales (1) 122:20
walk (2) 21:17 48:9
walked (1) 35:24
wandering (1) 20:22
wanting (3) 14:25 113:19 171:1
wants (1) 101:19
ward (2) 24:15,25
wasnt (28) 27:21,25 33:21 35:5 36:13 38:7,7 44:9,15 46:20 56:21 61:11 66:24 67:9 94:18,18 114:11 115:14 116:16 128:21 141:8 142:13 143:5 165:19 167:2,2,24 183:13
waste (1) 198:24
watch (2) 42:4 162:20
watched (1) 2:22
watching (2) 18:24 185:6
wave (2) 92:17,21
way (46) 5:8 10:25 11:19 16:13 28:19 32:8 39:18 40:3,11,14 44:18 46:16 47:3 48:14 49:13 51:5 55:9,12 56:14,22 58:9 72:9 76:23 77:2 79:14 82:11 101:17 113:3 114:15 121:12 124:7 127:16 137:25 139:7 141:17 147:9,16 153:14 162:18 163:21 168:4 169:5 177:19 186:3,9 202:16
ways (15) 30:21 46:22 54:8 112:16 113:17,23 114:18 126:23 127:21 139:2 143:20 145:15,24 150:8 153:5
weakness (1) 82:8
wear (1) 101:10
webinars (5) 52:12 53:11,17 55:11 141:2
website (3) 117:5 147:18 154:9
wed (7) 54:19 55:3,24 113:10 114:13 122:10 145:18
wednesday (1) 1:1
week (15) 45:2 70:17 74:10 81:7 120:1 128:14 131:3,4 144:6 151:24 159:11 171:10,11 182:16 191:3
weekend (1) 51:25
weeks (12) 44:24 72:19 91:6 103:23 133:12 143:16 166:12 175:7 176:9,10 188:6 196:20
weight (2) 52:16 195:25
welcome (2) 1:3 141:17
wellbeing (10) 16:18 32:14 33:5 51:12 52:11,19 58:21 93:2 100:15,24
wellknown (1) 115:16
welsh (1) 74:6
went (12) 31:17 36:19 37:19 38:24 41:12 112:4 117:22 118:17 122:25 137:9 181:25 193:25
werent (32) 24:6 26:3 33:23,24,24,25 36:11 37:14,18,25 38:9,11 40:14 44:2,4,18 45:17,19 48:7,9 69:24 90:3 129:2 141:8 142:6 145:5,24 146:13 147:22 161:1 165:9 194:14
westminster (1) 111:14
weve (33) 1:10 11:14 14:5,21 15:23 16:8 19:1 20:24,25 33:8 39:9 61:17,17 73:21 74:4 84:2 85:13,16 90:17 116:14 137:17 155:3 169:18 171:21 175:8,10 176:10,16 180:5 192:11 198:2 200:16 202:4
whatever (8) 24:12 25:21 32:12 39:24 46:25 51:25 60:12 77:5
whats (19) 4:20 5:5,19 6:6 15:8 25:1 59:16 71:16 74:12 76:18 109:11 138:23 162:9 175:20 176:23 182:1 192:8 197:15 202:9
wheelchair (1) 18:25
wheelchairs (1) 35:16
whenever (1) 29:2
whereas (4) 128:16 137:21 138:16 180:15
whereby (2) 135:11 201:15
whilst (1) 77:1
whitty (1) 142:9
whizzing (1) 19:3
whoever (2) 119:7 190:12
whole (20) 8:16 22:19 24:21 50:17 53:21 57:17 59:10 70:4 72:6 77:3,17 90:1 96:21 109:24 110:19 114:4 130:8 133:14 179:18 197:19
wholly (2) 65:18 179:24
whom (2) 98:16 173:19
whose (1) 40:8
whove (1) 189:17
wide (2) 16:9 110:7
wider (3) 42:1 71:16 72:4
willing (2) 77:17 98:5
willingly (1) 189:24
willingness (1) 102:6
window (2) 46:24 117:6
wish (3) 66:16 150:5,15
withdrawal (2) 37:22 41:10
withdrew (1) 46:10
witness (20) 1:18 2:9,9 7:3,11 8:4 31:3,4 63:7,8 105:10,21 106:7 117:4 123:5 126:16 127:25 150:13 155:24,25
witnesses (5) 1:4,18 72:24 176:17 202:5
woken (1) 182:16
women (13) 71:11 94:7,9,11,15 95:2 102:1 194:21,24 195:3,6 196:2,3
womens (1) 95:8
wonder (9) 16:21 20:18 22:4 33:8,9,11 39:14 84:1 202:10
wondering (1) 18:13
wont (4) 20:11 23:17 47:10 106:6
woodwork (1) 67:12
wordsearch (1) 185:4
work (73) 6:10,16 12:1,3,11,16 14:1 15:10,10 20:25 21:3,4 31:24 36:16 43:11 49:22 51:23 55:17 65:3 66:2 71:22,24 72:7,8,8,10,15,16,25 73:25 76:24 77:2,9 80:6,13 98:6 100:6,7,9 102:17 104:17 108:5 112:12 113:11,12 115:7 117:15 120:3 124:11,22 126:6 143:19 149:22 159:8 164:20 167:2 168:1 170:23 177:17 180:25 181:4 183:14 186:15,18 196:11 197:1,3,3,6 200:3 201:10,12,24
worked (20) 5:22 26:15 49:5 54:7,25 55:2,3,16 61:8 64:23 65:1,5 76:2 112:20 113:3 114:16 120:17 148:8 167:21,23
worker (1) 32:20
workers (3) 48:16 72:21 102:14
workforce (1) 12:17
working (36) 5:24 6:10,12 7:1,8 17:22 50:16 65:7,8,12,13 73:13 77:4 78:16 85:2 96:4 100:4 111:25 112:1,1,16 125:12,14 157:10 158:21 159:11 167:2 170:21 174:13 181:12 188:20 192:5 194:13 196:8,14 197:4
works (2) 13:21 141:12
world (9) 7:18 88:6 100:4 111:9,12,13 175:2,5,24
worldwide (1) 7:17

worried (5) 23:10 26:17 54:3 124:2 149:5
worry (5) 3:1 24:6 26:8 61:12 166:13
worse (12) 67:25 68:22 91:25,25 92:1,3 100:2 169:3 188:23 190:22 192:23,25
worsening (1) 94:16
worth (4) 16:21 52:3 85:1 201:23
wouldnt (16) 22:18 24:5 51:15,15 74:8,24 87:18 111:18 133:18 134:15 139:12 161:24 177:10 191:3,10,11
wrapped (1) 15:21
wrestled (1) 168:22
write (6) 29:16 144:16 147:13,24 148:7 185:1
writing (7) 28:18 56:17 61:17 148:3,23 175:8 177:21
written (8) 2:20 56:12 63:22 85:21 148:12,12,13 177:20
wrong (11) 11:5 25:1,3 39:13,14 120:1 138:23 161:9 181:24 185:5 192:14
wrote (5) 28:4 44:4 61:23 99:1 143:22

X

x (1) 194:2
xray (1) 164:17

Y

y (1) 194:2
yeah (71) 6:12 7:4 9:8 11:13 13:15 19:7,9 21:23,24 24:8 27:3 37:23 38:9 40:23 44:22 49:16,21,23,23 50:6 51:7,9 57:21 64:22 73:5 79:8 82:15 88:3 109:12 156:24 157:6,23 158:2,9,14,16 159:10,12,14 162:9 163:8 164:4,7 168:18 169:8 170:8,14 171:25 175:3,14 177:14 178:4,7,10 179:10 180:4,22 183:1,4 185:24 186:23 188:3 191:17 193:17 194:22 195:12 196:5,14 198:9,16 199:17
year (13) 30:17 46:23 69:1 73:20,22 85:8 91:7,12 100:6 123:14 137:5 159:9 199:8
years (56) 4:5,15 5:6 8:20 9:19 14:20 22:11 25:13 37:3 54:20,20 55:3 58:8,8 59:4 64:11,25 66:22 67:23 68:8 74:21,24 78:23 81:6 82:18 86:11 108:5,7,9 110:24 137:18 139:4 140:20 157:9,10,21 160:5,7 162:10 172:25 176:24 177:3 178:3,16 183:8 185:23 188:6,7 194:8 195:22 197:18 198:7,24 199:1,2,22
yearsplus (1) 64:22
yearsthree (1) 81:6
yesterday (1) 119:11
yet (4) 20:14 117:19 172:24 186:11
york (1) 133:9
youd (3) 38:3 128:20 149:13
youll (3) 9:2 21:6 63:24
young (8) 12:16 18:25 22:12 34:5,11 36:3,4 115:5
younger (2) 137:11 197:17
youre (71) 1:14 2:10 7:7 15:21 19:5 21:17,19 22:22 27:24 40:17 42:3,5 52:3,8 53:2 54:18 64:3,16,17 69:9 70:7 71:7,20 73:11 75:16 76:18 83:2 87:25 90:11 93:16,18 105:18,19 106:8,9,24,25 108:15 121:3 128:13 130:18 144:5 148:19 156:4,22,25 157:14,20 158:10 159:18,19 161:13 163:10 166:16 174:17 179:14 180:17 182:22 183:21 184:22,24 185:6 186:5,6,7 189:16 193:20 194:10 195:24 196:1 199:24
yourself (4) 69:8 111:24 140:19 181:23
yousaf (1) 166:21
youve (94) 2:8,21 12:1 18:5,10,11 20:16 21:10,20 22:20,21 31:2 37:7 40:18,20 43:20,22 47:18 49:24 53:7 60:17 63:18 64:11 65:4 66:10,16 68:12 69:11 70:7 71:18 72:25 73:2,24 74:1,15,16 75:17,18,23,25 76:2 83:4,7 88:15 89:5,6,14 92:6,7 93:7,8 94:7,11 95:19,25 96:2,9 97:16,22 98:19 99:23 100:11 102:2,9,10,10 103:9 106:6,16 125:6,8 142:1 143:10 149:12 156:9,18 157:8 158:3,3,6,6 163:5 165:5 166:6 170:22 182:16 184:21 187:4,8 188:18 194:11 195:13,25 197:23

Z

z (1) 194:2
zoom (3) 54:5,9 114:20

0

000002 (1) 156:15

1

1 **(3)** 202:12 204:2,4
10 (3) 179:17 199:5 202:15
101 (1) 138:8
102 (3) 138:9,15 198:14
105 (3) 100:17 204:7,8
107 (1) 101:21
11 (3) 130:5 141:1 174:25
110 (1) 132:14
1107 (1) 63:3
112 (1) 102:9
1127 (1) 63:5
115 (1) 102:20
1173 (1) 129:24
12 (5) 91:6 103:18 111:10 112:3 158:19
120 (1) 130:13
1251 (1) 105:2
127 (1) 193:12
129 (1) 170:10
12hour (1) 72:16
13 (2) 1:1 159:9
130 (2) 104:24 105:4
14 (3) 76:6 129:23 203:7
143 (1) 200:19
144 (2) 105:6 200:19
146 (1) 157:19
14day (1) 130:4
15 (3) 155:17 161:6 197:23
156 (2) 204:9,10
157 (1) 116:2
16 (7) 58:8 79:5 171:11 178:9,14,15 198:3
160 (1) 182:2
17 (1) 108:9
175000 (1) 89:23
18 (2) 40:11 79:22
19 (2) 130:5 163:15
1990searly (1) 183:11

2

20 (5) 13:13 14:20 63:1 142:12 196:7
200 (1) 104:9
2000s (1) 183:11
201 (1) 116:4
2010 (1) 102:12
2013 (2) 107:9,9
2015 (2) 3:21 5:15
2016 (1) 108:20
2017 (1) 3:21
2020 (23) 67:14 83:10 111:10,13 115:12,15 123:15 130:15,16 131:11 132:21,21 142:4,13 143:5,6 146:14 153:16 158:20 159:4 161:5 197:4 202:8
2021 (7) 79:6 93:14 103:14 115:17 123:15 131:11 165:16
20212022 (1) 161:5
2022 (9) 65:22 67:24 75:18 76:11 77:24,24 89:19 101:21 167:23
2023 (2) 156:14 167:10
2024 (3) 1:1 111:12 203:7
2025 (1) 104:4
2026 (1) 86:12
20s (1) 197:18
22 (1) 130:11
23 (2) 32:2 89:19
24 (1) 142:18
247 (1) 17:8
250 (1) 14:22
2500 (1) 123:15
252 (1) 155:20
26 (1) 129:22
273000 (1) 110:24
28 (1) 132:22
29 (2) 84:3,7

3

30 (4) 4:5 6:25 84:4 130:14
306 (1) 155:22
31 (1) 84:13
313 (1) 160:13
317 (1) 160:15
32 (1) 8:20
34 (2) 86:19,22
35 (3) 4:4 71:12 89:20
37 (1) 7:11
38 (1) 201:8

4

4 (2) 68:11 185:23
40 (3) 64:22 82:24 163:9
41 (3) 89:14 199:12,13
423 (1) 203:5
43 (1) 89:14
44 (3) 89:15 91:7 179:7
48 (2) 91:16 191:14

5

5 (2) 8:4 130:1
50 (8) 92:15 94:15 165:20 181:16 191:25 196:7 197:17 200:4
51 (2) 92:9 193:9
53 (1) 92:13
54 (2) 123:8 194:19
55 (1) 91:16
5560 (1) 71:12
57 (1) 196:6
58 (1) 198:5
59 (1) 92:24

6

60 (3) 71:12 94:6,14
607000 (1) 110:22
62 (1) 95:4
63 (3) 148:16 204:5,6
64 (1) 148:16
66 (1) 188:1
69 (2) 188:12 189:16

7

7 (5) 110:20 145:1,2,4,7
70 (2) 7:2 126:16
70s (2) 188:13 189:4
71 (1) 126:16
73 (1) 91:4
77 (1) 109:12
78 (1) 97:19
79 (1) 127:25

8

80 (2) 163:5,9
80s (2) 188:13 189:5
82 (1) 101:25
85 (2) 98:11 99:10
89 (1) 182:21

9

9 (1) 55:20
90 (1) 183:16
91 (1) 99:22
92 (4) 99:22,25 185:18 186:20
945 (3) 1:2 202:25 203:7
999 (1) 190:12