

## **All-Party Group on Coronavirus - Oral Evidence Session 11**

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### **Layla Moran MP**

Well, welcome everybody to this the 11<sup>th</sup> session of the All-Party Group on Coronavirus evidence hearings, so far the All-Party Group has heard from over 40 leading experts, health professionals and individuals whose lives have been deeply impacted by the pandemic and on the 22<sup>nd</sup> of July we had an assurance from Boris Johnson that he was committed to considering the conclusions of our rapid inquiry. Through this inquiry we've had over 2,000 submissions including those from bereaved families, individuals living with Long-Covid, frontline workers, mental health charities and laboratories. We've also heard evidence from Dr David Nabarro from the World Health Organisation, scientists from Independent SAGE, many of the Royal Colleges and of course Local Government and many charities as we are hearing from today. And now we find ourselves moving into that second wave, the very second wave that we very much hoped wouldn't happen, the second wave that we were assured would not happen by the Government and what's clear, sadly, is that the Prime Minister has refused to learn the lessons from that first wave of the pandemic. And since our first hearing in the summer this All-Party Group has gathered a vast amount of invaluable evidence and knowledge that we have been sending into Government and we feel that the Government has chosen to squander this time, so we very much hope that as our recommendations will be released publicly, a summary of them, bearing in mind that a lot of this, all of this has been publicly available for some time and we have been communicating with them, that they now take this opportunity to listen to what we have found and put those changes in place so that the second wave and the second lockdown becomes the last wave and the last lockdown and that they finally learn from the pain that many of us and many people have been going through throughout this time.

So, without further ado I'll introduce our illustrious panel for today and I thank them very, very much for being with us. First we have in no particular order necessarily we have Tracey Loftis who is the Head of Policy and Public Affairs at Versus Arthritis. Versus Arthritis is the largest charity supporting people with musculoskeletal conditions in the UK and they've been heavily involved in supporting people with musculoskeletal conditions throughout the pandemic. So welcome Tracey. We have Paul Edwards, the Director of Clinical Services at Dementia UK. Dementia UK is a national charity that provides specialist dementia support for families through their Admiral Nurse services. We also have Adrian Ivinson, welcome Adrian, who is the Chief Operating Officer of UK Dementia Research Institute, the UK Dementia Research Institute, DRI, is the UK's national dementia research institute and it was founded in 2017. And last but not least welcome to Laura Cockram who is the Head of Policy and Campaigns at Parkinson's UK. Parkinson's UK is a research and support charity currently 145,000 people in the UK are suffering with Parkinson's. So, I thank you all for being with us today, really, really important that we understand the impact that coronavirus is having on these people who would be very much considered in that vulnerable category and what I'd like to do is to start by offering you up to five minutes each to describe what are the key issues that your organisations have seen over the course of the pandemic so far and what have those living, or those caring for people with dementia, Parkinson's and arthritis faced over the course of the pandemic. I wonder, Tracey would it be alright to start with you on that one, thank you.

### **Tracey Loftis**

Good morning, so I'm here to speak on behalf of Versus Arthritis which is a musculoskeletal conditions charity covering a number of different conditions such as osteoarthritis, rheumatoid arthritis, back pain and osteoporosis. I will call them MSK conditions throughout this hearing. These conditions affect 18.8 million people across the UK and they cause pain, they cause fatigue, they cause mental health issues and they also make those everyday tasks that we all take for granted a lot more difficult. Now, when the pandemic happened we reached out to our community of people to find out what are the challenges that you're facing and actually we have 6,000 people with arthritis who spoke to us during a survey, during the months between April and June and what they told us was about the massive impact the pandemic had had on their lives. First of all, we found out that about four out of ten people had had their appointments cancelled. Secondly, we had again four out of ten people tell us well actually I'm feeling lonelier now, I'm feeling more isolated. And critically five out of ten people said to us actually I'm struggling with my pain. I'm struggling with my pain to such an extent that tasks that I want to do around the house is made more difficult.

So, I think the first thing I'd say is that the pandemic has impacted on all parts of a person's life. Clearly some really key things to kind of highlight here, I think first of all people with arthritis are treated in many different places, community care, primary care, secondary care and what we're conscious of is that when all elective or planned care was paused at the beginning of the first wave, this had a massive impact because it meant that actually for really important operations such as hip and knee replacements everybody was paused. Everyone was put on delay. And the second part is about shielding which we know that there were a great number of people with arthritis who shielded actually again for some of the survey data we've looked at it was about 43% of people with arthritis had shielded, only 10% had had a letter and there is something that needs to be really considered about who is shielding, what support is given to them and what communication is given to them and that's clarity of understanding what good looks like. And then thirdly, I think there's something we need to talk about which is the overall health and wellbeing of people who live with disabilities because what we have seen again is people feeling more isolated, more alone and secondly what we've also seen is that for people with arthritis actually one of the great ways of helping them with their health is being physically active and actually we have people with arthritis tell us that they even stopped shielding to be physically active because that's their way of managing the pain. So, I think those are the three areas which I'd particularly like to focus on in my own remarks today.

### **Layla Moran MP**

Thank you so much Tracey. If I can now go to Paul Edwards.

### **Paul Edwards**

Yeah, sorry about the delay, just taking myself off mute. Thanks for the invitation by the way I really appreciate being able to talk to you about the things we've learnt from people with dementia and their families and our specialist nurses. I think I'd just echo firstly what Tracey was saying about the isolation and the nature of that and the impact that that has had on families and people with dementia. We know that things are tough caring for people with dementia and families particularly carry the burden of that caring responsibility and I guess since lockdown particularly we've noticed even more sort of increased carer stress, increased elements of anxiety and depression, restrictions on movement, restrictions on being able to get out. Carers have been particularly worried I think about dealing with their loved ones and their understanding of the situation because very often people with dementia find that really difficult in terms of restricting because you know people with dementia

want to live active lives and then don't fully understand the kind of nature of why we're having to curtail some of their activities.

At lockdown we saw a lot of those usual services just shut down overnight, so some of the day facilities, respite facilities which then it of course just puts more pressure on the family home and family carers and also carers were reporting they were really worried about people coming into their home because of transmission risks and infection risks and things like that. So, a lot of problems. Our nurses on the ground are seeing more complexity as a result, you know more distressed behaviours in people with dementia, more carers tragically sort of at the end of their abilities to cope and then crisis building up which of course ultimately puts pressure on other services which we want to try and avoid at all costs. And I think also what happened at the very beginning of lockdown because people with dementia weren't on the clinically vulnerable lists then ... and I know other groups weren't either, then people were really worried just about getting everyday items like shopping and medications delivered, all that sort of stuff and a lot of that was picked up by the local communities rather than in any organised way at that time.

I think the other thing we're noticing really is more safeguarding referrals because people are actually in a very difficult risky place as a result of some of those services not being around. We've certainly picked up a lot of that both on our national helpline and also with the nurses on the ground dealing with really complex cases where ordinarily there would be other services around to be able to support and refer onto, those things were shut down. And that's just the impact of people if you like living in their own homes and in the community, there's another strand of concern for us and that's about obviously care homes and some of the challenges there have been in that sector, I can't quite explain how difficult that has been for families and people with dementia and also providers too, as we've been through the pandemic. Right now, we're in a stage where people are really struggling because they're not able to see the people they love and that is also having a detrimental effect on people with dementia in the care homes as well.

So, I think just to sum up really, it is about the increasing levels of exhaustion, isolation and frustration that carers are finding when they're already dealing with such a complex issue. The withdrawal of those services that would normally be there, albeit patchy and imperfect in many ways and also then the longevity of this pandemic and the impact that is having on their relationships and also the ultimate impact on people with dementia themselves.

#### **Layla Moran MP**

Thank you very much Paul, lots there for us and I know there's lots of questions around that coming later. If I can ask Adrian to go next and then Laura after that, if that's alright. Adrian.

#### **Adrian Ivinson**

Thank you very much. So, picking up on some of the things that Paul said, dementia is not a disease per se, it's a symptom of several diseases, Alzheimer's is probably the most common cause of dementia but not the only cause. In the UK today, there are 850,000+ people with a diagnosis of dementia and the cost to the UK economy, the total cost of dealing with dementia, whether it's primary or care or whether it's lost work from care-givers and other hits on the economy is currently £34 billion per year, so pre-Covid this was a huge challenge facing the country. When Covid hits that community what it's done is it's highlighted to us in many ways what we already knew and that is people with dementia tend to be very vulnerable, elderly, living at home in difficult circumstances and if you think of what Covid has done it has stressed to us how difficult it is to take care of vulnerable, elderly people at home and the isolation that they feel. Well, you know as Paul said that's sort of the

business of trying to work on dementia as a challenge, so Covid has, if you like, given us a very dramatic stress test of the system and shown us how vulnerable the system is.

Just to give you some idea of that vulnerability, the most common pre-existing condition of those who between March and June died with an official death certificate quoting Covid, the most common other condition they had was dementia, so that tells you immediately about how vulnerable these people were, for whatever reason, that is quite startling. The diagnosis of dementia during Covid and shutdown has dropped significantly, people are not getting that diagnosis which means they're not getting any of the care that Paul referred to. As Paul mentioned, one of the big things facing people with dementia is isolation anyway and when you put on top of that the added isolation of Covid that really can turn the tide for a lot of people.

Another fact just to bear in mind pre-Covid, one in four beds, 25% of NHS beds was taken up by someone with dementia. When Covid hits and there is quite understandably a rush to take people out of hospital and get them back home or to a care home, just the numbers themselves tell us that an awful lot of those people that were moved out of NHS beds to make room for those with Covid were dealing with dementia. And of course, as a result what happened in the early days to go to your question about what might be done differently, in the early days there was not testing before people were returned to their home or their care home, so we inadvertently moved Covid-positive people into care homes, as a result the percentages of Covid-positive residents in care homes was alarmingly high. In one of the studies that our group did where we tested everybody in three large care homes in North London, it was 43%. When we went in and started that testing there was no idea, the assumption was there were a few people that might be positive in this environment. It was 43%. When you don't know that care homes are full of people with Covid and you're not isolating them then of course it spreads very rapidly. Bizarrely we thought we were protecting people in care homes by stopping visitors, in fact the virus was already there, we weren't doing anything other than adding a layer of isolation which made it even worse.

The other thing I would say in wrapping up, we're a research group, not a charity per se, as you said in your introduction we're the UK's largest dementia focused research group and a lot of our research is the basic biology to understand what causes dementia and that of course has taken a huge hit through Covid, we had to close all our labs, we have 650 dementia researchers who were all sent home. They are now back at some level but we must keep these labs open because we have both a short-term need to help people with dementia but we also have this growing long-term challenge. As I said there are 850,000 people with dementia in the UK today but that number will double in the next 20 years based on our predictions. Predictions which have been very accurate up until now. So, we must not take our eye off the longer or medium-term goal of research. And finally, that research includes for example how to help people with dementia live healthier, more satisfying lives, in their homes. When you ask people with dementia and their care givers what they most is they want to stay at home and feel safe there, they don't want to go somewhere else. Well, that is also the challenge when we take a lot of elderly people and tell them they must stay at home to protect themselves from Covid. How do we keep an elderly population at home, happier and healthier for longer? And that's our business as well.

**Layla Moran MP**

Very wide ranging, thank you so much Adrian. And Laura, Parkinson's perspective.

**Laura Cockram**

Thank you very much, thank you for inviting us to provide evidence. Just want to give you a bit of background about Parkinson's, so it's a neurological condition so nerve cells that control movement in the brain die and so it does mean that movement is predominantly impacted. It's the fastest growing neurological condition in the world, most people who have the condition are over 60, but one in ten are under 50, so obviously there's a real impact in terms of the working age, or people of working age, sorry. There are over 40 symptoms of the condition including rigidity, slowness of movements, stiffness, tremor, dementia, pain, fatigue, anxiety, hallucinations and problems with sleep. There's no cure for Parkinson's and currently symptoms are controlled by medication but does become less effective over time. So, that's just a brief synopsis of Parkinson's.

In terms of the issues that people with the condition have been experiencing during the pandemic, very similar to you know what Tracey and Paul have shared around arthritis or MSK conditions and dementia. I think the first thing was around the confusion around the shielding definition. Parkinson's is seen as moderately vulnerable and so not everybody with Parkinson's will be in the clinically vulnerable category and so people were really concerned and confused about how they would get onto the list. There were lots of mistakes in terms of the data and so people were not told to shield and then they got a letter at the end of the shielding process, or the shielding timeline thanking them for shielding when they hadn't been shielding. There's also issues around those people who are of working age who need to be working and their employment status and whether they're able to actually get out and go to work safely, and I think we'll probably cover some of that later in the session. But also, the support that people are entitled to and I think that's something that still is with the new tiers and the new lockdown that's been announced, that's still unclear at the moment.

What we found as an organisation is there is an increase in calls to our helpline and our local advisors were providing more support to people with Parkinson's, particularly about Parkinson's and Covid and what the risks and the links were, about shielding, about how to deal with symptoms, about accessing health and social care systems and like Paul said about trying to get access to medication and everyday essential items. Like Paul said as well, we also saw a massive increase in reporting safeguarding issues because people were in riskier situations. We did our own survey of people with Parkinson's in April and May and what we found, we did that with Lancaster University, and what we found is that there was an increase in the severity of symptoms, so people were particularly having issues with anxiety, stiffness, tremors, sleep problems and we found that about 10% of people were reporting really distressing hallucinations and didn't feel that they had the support in order to actually deal with those. We also found that as symptoms were increasing there was a reduction in the support that was available from the NHS and from social care services, so again our Lancaster survey found that a third of people with Parkinson's had their appointments cancelled and they weren't offered either a phone or an online appointment and a third of people with Parkinson's had their appointment cancelled with their consultant and again, you know, we saw GP appointments cancelled, physiotherapy, speech and language, occupational therapy and mental health support was being reduced and kind of pulled away from people just as they needed it.

We also found that people were really needing that support in terms of exercise, a third of people were telling us that the fact that they were unable to get out and to exercise was having an impact on their condition. Hospital episodes data shows that there was a 20% reduction in face to face appointments, about a 20% drop in emergency admissions and actually for Parkinson's that's specifically worrying because there's a large number of Parkinson's admissions each year due to emergency admissions, due to either dementia, urinary tract infections or falls. And we also saw almost up to 60% drop in elective, so planned procedures as well, so clearly a real impact in terms of people's health and care services. Paul has elucidated the risks in terms of the increased strain on carers and what we saw is almost 70% of respondents to our survey took on more caring responsibilities. Our community also had real difficulties getting access to everyday items including

medication and there were some medications that almost went completely out of stock for people with Parkinson's and that's a real concern because that's one of the only ways of controlling the symptoms. We also found that loneliness was a particular problem for our community and some very worrying calls coming in around people being really afraid to go into hospital because they thought that they wouldn't get critical care because of their Parkinson's. And then the final thing that I wanted to share is around the misunderstandings about the funding for the hospital discharge and since September the lengthy delays that have come in around continuing healthcare funding.

So, I guess to kind of sum up, the real issues for the Parkinson's community are around reduction in services and support, the increase in the symptoms, the increasing in carer strain and loneliness.

### **Layla Moran MP**

Thank you so much all of you and I will be asking people if you see that someone else has said something already please just say you agree with them and move on. We've got another seven or so Parliamentarians who are going to be asking lots of questions and I'll ask the Parliamentarians please can you be clear about who you are directing it to and don't be offended if it's not all four of you every time and feel free to pass on, because we want to get through as much of this as possible and I don't want to leave anyone out. Before I pass to the Chair of the All-Party Group on Dementia, Debbie Abrahams, I've just got a very quick question for Adrian about the research and perhaps this is also one for Laura as well. We understand that there is some evidence to show that coronavirus is accelerating these conditions, is it true just of ... well, dementia is a symptom as you say, Adrian could you expand on that a bit more because I don't think that that's something I'd heard before and it sounds incredibly worrying.

### **Adrian Ivinson**

Yes, it's early days to be able to give any clarity on this so it's an important area of research that frankly we were not aware of a year ago, but there are a couple of things that are emerging, first of all a lot of people who are turning up in hospital with Covid symptoms have very significant neurological symptoms as well. I mean, we tend to hear the headlines and understand that there's a major issue with the lungs and oxygenation etc, what we're not hearing as much is the very common neurological conditions. People who are coming out of Covid treatment successfully, if I can say that, you will have heard this reference to Long-Covid, a lot of Long-Covid is based around neurological complications. We are finding that people who are saying that they feel that they are recovering reasonably well physically and they're active again and they're back up and walking and what have you, are saying but I cannot shake what I can only describe to you as a sort of mental foginess. Well, you know a lot of times people would refer to dementia as a foginess as well, so there is absolutely something there, it needs to be investigated rapidly, we don't know the extent of it and a concern of ours in the community is, is this going to fall on the dementia research community to look into with a limited funding, is it wrapped up in a more traditional infectious diseases community research, is it the lung people who are going to look at this. Where exactly do we put the resources to put the right teams together to investigate it.

### **Layla Moran MP**

Thank you very much. So, unless Laura you wanted to add or someone else wanted to add I'll pass to Debbie Abrahams now, thank you. Go ahead Debbie.

**Debbie Abrahams MP**

Thank you. You've pinched my first question there Layla, but ... given I gave it to you beforehand I'll forgive you. So, in terms of Adrian lovely to see you again, in terms of what you're saying about the incidence and the reductions in diagnosis, what would be your next steps around trying to ensure you get a reliable estimate of how potentially Covid could be affecting all dementias?

**Adrian Ivinson**

Yeah, this should be tractable really, we should be able to meet this challenge. So, what we need to do is we need to identify the places that people who are beginning to get worried or their loved ones are beginning to get worried about them, where they can go where they will feel safe and not as if they're going from the frying pan into the fire. What we don't want is for people to be staying at home and dealing with this, and don't forget that ... I mean of course none of us forget that this has now been going on for eight or nine months, that's a lot of dementia diagnoses that will have been lost. So, there is a backlog now of people who are staying at home and their loved ones are saying no, I don't want to go to the GP, I don't want to go to the hospital because I'm worried that's going to be even worse than what we're dealing with now. And as a result, they are not getting that first level of diagnosis and clarity and let's be clear, reassurance at some level, no one wants a diagnosis of dementia but when you're not sure what's going on you do want a diagnosis, because that gives you a certain sort of clarity, OK at least I now know what I'm dealing with. So, that's our problem. We need to identify the safe spaces for those people to go to, to get that care. And we need to be ... again it's easy to forget that it's not a one-way street, it's not as if you get a diagnosis of dementia, you stay at home for a while and then inevitably you end up in a care home and so it goes, it doesn't always work like that. You might be an elderly person in a care home and you've been there quite happily for a few years and then you get concerns, or people around you are concerned about a diagnosis of dementia. Well, where do they go to get that, it's not as if this is always happening from home, sometimes it's happening in a care home. So, how do we create that space where people can continue to get that very important diagnosis and once they get it can, if you like, retire to an equally safe place knowing that they are not going to simply get a diagnosis by name and then say but I'm afraid Covid means that no one's going to come and see you.

**Debbie Abrahams MP**

Thank you very much, I wondered Tracey, I mean of course Covid doesn't just as we've heard affect respiratory systems, it affects the nervous systems but it also has affected MSK as well, being an inflammatory disease in the response, I wonder if you've also noticed that there has been an impact in terms of the incidence of arthritis and MSK conditions that we need to be aware of.

**Tracey Loftis**

So, what I'm conscious of first of all is that we've had a huge influx of people contacting our helpline in the first wave, again you know people visiting our website has doubled to hear about Covid. So, in the short-term what we're aware of is that people who have MSK pain have been reaching out for help. In terms of the longer-term impact I think we need more information and data to help us with that story. What we are conscious of is clearly in terms of musculoskeletal pain such as that caused, such as through sedentary activity there's a lot more people who aren't as active as they were and that will undoubtedly have an impact on how severe someone's pain is, but also will impact on their overall health. I think for the inflammatory part I think that's something that we can get in contact

with our colleagues and the British Society of Rheumatology to give a bit more of a steer on that specific bit.

**Debbie Abrahams MP**

OK, thank you very much. And I don't know if Paul or Laura want to add anything to that? Paul, in terms of what you were saying about the impact on carers, I wonder if you want to comment on the Alzheimer's Society's proposals around and their campaign on getting family carers to be given key worker status so that they can ... it's often very difficult to separate out the impact on being isolated as you've talked about but also in terms of whether there is the pathophysiological effect of the disease or the environmental effects of the disease in terms of, as I say, the isolation and separation from their loved ones.

**Paul Edwards**

Yeah, I mean I think I just want to go back to what Adrian was talking about as well about that diagnostic backlog that we've got because I think what happens at diagnosis is also where post-diagnostic support kicks in, so it's not only the diagnosis being delayed but also some of the usual post-diagnostic support being delayed too, so I think ... and that of course adds more stress and difficulties for the person with dementia and families, particularly at a really difficult time, you know just after diagnosis. And I think just to your point really about us all as one dementia voice calling for particularly treating family carers as key workers and therefore being eligible to access the same kind of testing or whatever to enable visiting and to be able to live more of a social life, you know we absolutely welcome that. Clinicians like me struggle to understand why it hasn't happened already if I'm honest, you know for all of good clinical reasons as well as kind of emotional reasons too. We have alongside the Alzheimer's Society and others been lobbying Department of Health and Social Care to try and make that happen, we haven't heard enough about it yet. And what that is leading to actually is people becoming more angry, families who are moving from being really desperate to being really angry and therefore not trusting the system and you know taking the advice as it's given to try and provide that level of reassurance and safety and I'm certainly feeling that in terms of what I'm seeing and hearing from families and also people with dementia themselves also wanting to make this change.

But also, when I look at our own helpline the calls that are coming through to that around this issue, around the lack of clarity and the lack of support for them to be treated in a way the same as key workers so that they can carry on looking after and loving in that relationship that they've got and we definitely have to shift that very soon.

**Debbie Abrahams MP**

Thank you and Laura do you want to add anything in relation to Parkinson's and again the incidence that you've noticed changes in terms of diagnosis and support?

**Laura Cockram**

Thank you Debbie. Yes, so at the moment the research that's out there around Covid and Parkinson's is inconclusive as Adrian says. Obviously one of the symptoms of Covid is a loss of smell, anosmia, and that is something that is present in Parkinson's as well, so there are some similarities there. Previous research has shown that some viral infections slightly increase the risk of Parkinson's but currently the

long-term impacts are unknown. So, for instance in the Spanish Flu in 1918 which I won't ask if anybody remembers, that would be too rude, that there was a significant increase in Parkinson's-like disorders so obviously the research and the history is there and so we are investing in some research, some clinical research, with Parkinson's specialists to understand the kind of clinical impact. We're hearing anecdotally is that people who are being diagnosed with Parkinson's they're a lot further forward in their journey, so maybe they're two or three years down the line of their Parkinson's, further than they would have been and very much support the points that Paul was making around diagnosis, the reduction of diagnosis and then the support that isn't then coming through for people. Certainly, with Parkinson's what tends to happen is that people will go to their GPs maybe four or five times before they're then referred to their Neurologist, with the reduction in GP appointments that we're seeing at the moment of almost 30% you can clearly see that there will be that delay in terms of diagnosis and Parkinson's must be diagnosed by somebody with expertise in the condition which most of those consultants have been then redeployed back into the NHS. So, we'll see that delay to diagnosis.

**Debbie Abrahams MP**

Thank you so much everyone.

**Layla Moran MP**

Thank you so much. Lord Russell.

**Lord Russell**

Yes, thank you to all of you, can I start off with Tracey. Tracey, if you look at the Government guidance on shielding how clear is it and if it is not as clear as it should be, how would you like to see it change?

**Tracey Loftis**

Thank you. So, in terms of shielding we are conscious that this has caused a great deal of confusion amongst our communities. First of all, about who should be shielding, secondly also when people are shielding again with arthritis a lot of people use physical activity to manage their pain and therefore how can that be built into the system. I think as a UK-wide charity something that we have struggled with is the fact there's been slightly different guidance in every nation and if there was something that could actually make it really joined up so we're getting one message that we as charities can help communicate that would be really helpful. What I'd say as well is that we speak to our beneficiaries day in, day out although we haven't been able to continue face to face services we have moved all our services online and again we have online communities and so part of this is if the Government can work more effectively with us, so we can also communicate that would be helpful, but that does mean that we need some notice. So actually having, say for example, a week's notice so then we can work with all our information colleagues to work out how to translate this into language that will help and empower people that would be incredibly helpful.

**Lord Russell**

Do you feel that there exists any form of two-way communication that is effective with the Government or is it mostly one way?

**Tracey Loftis**

So, I think there is two-way communication, I think the challenges is the level of complexity here and I think especially about that as our knowledge is growing both of first of all what is someone's individual risk and then secondly what is the risk in different settings and thirdly what is the risk in the area where they live. So that complexity of communication is challenging, clearly there is investment in a risk stratification tool from Oxford that we're expecting shortly which hopefully when that's kind of used with healthcare professionals can really enhance this. But I think part of the challenge here is that for some people with arthritis they haven't stopped shielding and they feel incredibly anxious about what their risk is and what they should and shouldn't do, so part of this is both going forward how can we have stability of communication, consistency and also empowering people who may not have to shield to such an extent as they first thought, that actually these are the risks and this is the information available to you.

**Lord Russell**

Thank you Tracey. Paul do you have anything to add and expand on?

**Paul Edwards**

Not really, if I'm honest. I think the points are well made about getting as much advanced notice as we can so that we can translate that to the people we support and you know we know this has been a very reactive process but it would help us enormously because of the thousands of people that we're in touch with if we had that. Whilst I understand there's this ... it's a really difficult time, I don't feel like we've had an easy two-way relationship just yet with various different departments, if I'm being brutally honest.

**Lord Russell**

Is it getting any better?

**Paul Edwards**

No. And that's because I understand the nature and the pressure, but I think when we are asking for clarity we need that and we've been asking for clarity around shielding and issues like that for quite a while now and actually if that came to us in a timely way we could then make the Government's job much more easy by being able to translate it to the people that we serve.

**Lord Russell**

Thank you. Laura, do you have anything to add?

**Laura Cockram**

Thank you Lord Russell. I think Tracey made the points exceptionally well, particularly about the UK and the differences across the whole of the UK and as a UK-wide charity that was particularly

concerning for us. I think it also wasn't communicated about exactly how you get on or off of the list and there are children that are being taken off the list, everybody is supposed to have a conversation with their GP if they are being taken off the list. I think people with Down's Syndrome and kidney patients are going onto the list now but there are delays in that being communicated and effectively communicated out to the community. So, I think the communications and exactly as Tracey said providing enough time and the process to be added or to have that conversation because the risk stratification tool that is being developed by Oxford is very much for clinicians and for people with conditions to have that conversation, there aren't clear plans at the moment about having a tool for the general public. I think the big issue though is actually about those people who are in employment and since the announcement on Saturday from the Prime Minister that there will be this national lockdown and there will be an extension of the furlough scheme, there hasn't really been a great deal of communication about exactly what that means for people who should be going to work or will be compelled to go to work. So, I think we recognise that things are moving at such a fast pace, but actually being able to keep the communications and to get out to charities so that they can also communicate with their supporters, that's really important and that's currently not working so well.

**Lord Russell**

Thank you all very much.

**Layla Moran MP**

Thank you very much. Wendy Chamberlain.

**Wendy Chamberlain MP**

Thank you very much Layla and thank you everybody for attending today. So, you'll hear I'm a Scottish MP and I suppose my questions are around actually Lord Russell just talked there about shielding but also as we go on to talk about care homes obviously we do have different guidance within the devolved nations. In terms of shielding in Scotland people are advised to follow the general guidance and the tiers that we're now in. In terms of care homes there's been recent developments around the fact that members of the families can visit care homes and that's something that's obviously in progress. I think I'd just like to ask you all your thoughts on what is happening in the devolved nations, different things that are happening and is there lessons that can be learned and are indeed are they being learned? I'll go to Paul first of all, please.

**Paul Edwards**

Thank you very much. So, we have been offering the same advice and guidance that were given to the English MPs in the same way as we've been doing to the devolved nations as well, so anything, any sort of information we put on around, you know shielding or vulnerability or looking after your loved one, that's gone out to the devolved administrations too, that's the first thing to say. It would be really helpful though if there was that, you know, central messaging that we could share across the board because you know we're having to update and amend for different administrations at the moment and that's not always easy because we need to make sure that we give the right information in the right way to people. So, anything we can do to make that much clearer across the four nations would be really welcome, I would say. In terms of care homes, you're right, there is slightly different situation in Scotland than there are in other countries but also in Scotland we've had the same issues

that we have had in other areas, not just about transfer of people out of hospital beds into care homes but also some of the visiting restrictions and all the rest of it.

**Wendy Chamberlain MP**

And some really individual experiences, some of which have been very good and some of which have been particularly poor.

**Paul Edwards**

Yeah, and that is actually that's the nature of care home support, it can be very variable. And I think there's two things for me, one is the planning within the nations and also across the UK around the understanding of care homes probably hasn't been as good as it could have been, let's put it like that, if people at very early stage in the pandemic had the understanding of care homes and how they operated and that was woven into that plan then we might have had different outcomes possibly, if we understood the nature of that a little bit more. And what we're trying to do as a charity is build a consensus of approach around care homes and care home visiting so that we get providers, families, different parts of the kind of public health in those different administrations coming together to work together to build on the plans and what we're seeing in Scotland is some of that planning is being done to allow families to visit. We need to see that much more readily across the rest of the UK because I think that's the only way we're going to solve this issue for families is if we get proper sensible kind of clinical risk management on the ground per care home to enable people to actually carry on visiting.

**Wendy Chamberlain MP**

Thank you very much. Adrian, what's your thoughts in relation to that, it does sound like we need an evidence base.

**Adrian Ivinson**

Yes, we do need an evidence base. The DRI is UK-wide, we have significant labs in Edinburgh, in Cardiff as well as across England. We're not a frontline care provider and so I can't speak in the way that Paul and my colleagues have but what I can tell you is briefly some of the research we did about this in the early days in April and May of this year. As I mentioned we actually found that getting Covid testing up and running, I mean we're a neuroscience group but actually we had Covid testing up and running in 14 days at a time where people were desperate to bring testing online, so we got that up and running, we actually found that we couldn't get the samples through the system, the pipeline of getting samples from patients or suspected patients into the labs was very slow, so what we decided to do was what we do best, we wrote a research protocol that allowed us to go in and do direct testing in care homes and we found very high rates of positivity there. What was interesting though was it wasn't what we expected. 43% of those that we found positive in the care homes were completely asymptomatic. That wasn't what people assumed given it was an elderly population and we generally think of Covid as the worst affected it tends to be age-related. So, there was an awful lot of hidden Covid there. As soon as those care homes knew what they were dealing with internally they could in effect separate themselves into Covid positive and Covid negative wings if you like. We also could test all the care givers, the staff, we actually found very low levels of Covid which was reassuring.

The reason I stress this is evidence base is very important, so what we could do very straightforward, is we could set up weekly testing of all residents and staff and family visitors for care homes and then we would be very quickly, we would be in a position where we could be much more open nationwide about people going to visit their most vulnerable, scared and often demented family. This could be done.

**Wendy Chamberlain MP**

Yeah, so a focus for the 'moonshot' that actually protects our most vulnerable and potentially mitigates against some of the other factors that we're talking about, the isolation adds to.

**Adrian Ivinson**

Exactly.

**Wendy Chamberlain MP**

Thank you very much. Laura, from a Parkinson's perspective have you got any thoughts around where potential learnings could come from the devolved administrations?

**Laura Cockram**

Yeah absolutely I think some of the ... I was just looking back through emails there and one of the things that came out on the 22<sup>nd</sup> of October was a letter from the Welsh Government to all clinically extremely vulnerable people just letting them know where they are, what the plans are and so clearly there's been a move from the Welsh Government and also from the Scottish Government and in Northern Ireland to approach things in a slightly different way. I recognise the scale and the scope of the population is different but I do think that there has been a different approach. Also, on virtual appointments there's been a very useful interaction with Scottish Government and with clinicians and charities around virtual appointments and actually do they work, are they effective as opposed to just the Secretary of State saying we're going to move towards virtual appointments and that's going to work for everybody which clearly it doesn't. So, I think there has been a slightly different approach from the different administrations and again, the fact that the Scottish Government are enquiring into the deaths in care homes, which I think is something that hasn't necessarily come forward and been something that the Westminster UK Government has committed to as yet and I think that would be great. I was really interested in Adrian's comments about the testing and the fact that many residents were asymptomatic, it would be great to get those messages out there but yeah, at the moment that is definitely not in the public domain.

**Wendy Chamberlain MP**

We need a more four nations approach thank you. Tracey any final thoughts from you before I pass back to the Chair, thanks.

**Tracey Loftis**

Yes, just a couple of thoughts to build on what's already been said. I think part of this is learning from cases of best practice, I think a good example is the NHS Golden Jubilee Hospital which has been able to maintain some elective surgery and again has been also talking about how it can support other Scottish [inaudible 1:03:51.2].

**Wendy Chamberlain MP**

I'm smiling because my sister works there.

**Tracey Loftis**

Fantastic. And secondly as well I'm aware that in Wales they had the Bevan Commission which has been looking in particular at shielding and again has put out some best case practice, so what we see is some really good practice happening in innovation, how can we share that, clearly in England, certainly musculoskeletal conditions we've had an NHS Change challenge for MSK conditions where localities have sent in examples of best practice and they with the aim of kind of sharing that innovation across England, so the whole 'pinch with pride' and I think there is something here about how can we take all the knowledge from across the UK and enable people to understand what is innovation that they can take forward.

**Layla Moran MP**

Thank you very much. So, I've got a very quickfire question that's disturbing me. We understand that the Government is going to give £14 per clinically vulnerable person to Councils to help them through this period and as briefly as possible if I may, but I just wanted a sense of are you aware of where this figure might have come from and what kinds of things are you hoping that Councils are going to be able to do for the clinically vulnerable during this time. Perhaps I'll go to Paul and Tracey and then Laura as well and Adrian you are welcome to chip in, but Paul.

**Paul Edwards**

No, I wasn't aware of the exact figure, that's for sure and I think it's still fair to say that people with dementia don't come onto the clinically vulnerable list still, so that's a problem in itself, because actually that does open up the possibility of more support if you're on that list. And so, the one ask, given what people with dementia and their families have been through throughout this pandemic so far, wouldn't it make sense to understand the vulnerabilities that this group has and actually make them available to be put on the list. That's the first thing, and from what we learned last time people were struggling with everyday things, accessing food, accessing medicines, getting the support, getting out, you know those are the kind of things and then there are other layers of support and help such as in-home respite and additional care and support in the home that might be beneficial. But I suppose we're not even thinking about people with dementia as within that extremely clinically vulnerable category at the moment and that could be problematic for us I would say.

**Layla Moran MP**

Thank you. Tracey.

**Tracey Loftis**

Just a couple of reflections. I think first of all you could almost equate a shielding letter to a passport to enable you to access certain services. I think some of the ones that particularly spring to mind I think is first of all access to medicines being dropped off at your home address and secondly access to food and in particular food slots, so I think there's something about how Local Authorities can work with their local communities and indeed employers about how can we make sure some of this happens. I think the second part of this again comes back to the communication piece and actually how we're communicated and then of course we are going to be thinking how can we communicate that to our beneficiaries. And thirdly there will be on-going need for support in relation to loneliness and isolation and that is going to be continuing, I think especially through the winter months. I also think as well there's something we need to think about in terms of resilience because a lot of people may have just thought well OK I'm going to get through the first wave and look forward to Christmas and actually it's really difficult news that they're navigating right now so again I do think there is something important about how local communities can work again with Local Authorities, with Government, with charities about what support we can give people.

**Layla Moran MP**

Yeah, thank you very much. Laura do you have anything to add?

**Laura Cockram**

I suppose we learned the lessons in the first wave that providing food boxes wasn't the way to go for Local Authorities because people want to be able to shop and purchase the items that were appropriate to them as opposed to just get a food box, particularly if you have dietary requirements so I think setting up other ways for people who are digitally excluded to be able to get food and to get medicine deliveries I think is really important. Very much concur with Tracey on the loneliness points because I think that is particularly problematic and also respite, we've talked about carer strain, we've talked about the fact that there really is this sense of, with the winter months very quickly approaching, this sense of people being in their house, we do need to make sure that there is some support for carers and respite and whether there's any way that we can provide that extra support for respite for carers I think is really important. All of the work that has been done by the DWP to set up these extra benefit payments, it's making that really, really clear so that people know what's coming and where it's coming from so that they're able to get access to what they should have access to.

**Layla Moran MP**

Thank you very much. Barbara Keeley.

**Barbara Keeley MP**

Thank you. I'll just take us back to the point, it moves on from Wendy's question about what's happening in Scotland, I wanted to bring out some issues around visiting care homes and social isolations, really building on Adrian's comment about testing. Just how serious is the mental health impact both of lockdown and the lack of social contact, the isolation that's needed for infection control. So, it's two things isn't it, one is that impact in terms of no visits to care homes and then what

people have been feeling at home because that I think for us as Parliamentarians is something that needs drawing out because if this issue is going to be dealt with seriously it needs to be drawn out just how serious is that mental health impact, so could I start with that? I don't know who wants to start, Paul or Adrian or Laura?

**Adrian Ivinson**

I'll leave it to Paul because it's not our expertise.

**Barbara Keeley MP**

Yeah, OK thanks. Paul.

**Paul Edwards**

Yeah, well thank you for the question, it is very serious and I say that as a mental health clinician, it is very serious. So, let me give you an example of quite how serious it is. So, people are ringing our helpline right now and certainly since the extended lockdown was announced telling us that they can't go on anymore because they can't bear not seeing their loved ones. So, I know that's anecdotal but that's how serious it is because they have had to put up with a prolonged period of separation from the people they love and that has caused all sorts of problems, mental health problems of course, but also leading to other problems, carers not taking care of themselves anymore and feeling like things are worthless and so it is really, I would say, that serious. And of course, the impact is also quite serious on the person with dementia in the care home who doesn't always understand why they can't see their loved ones, so who doesn't always understand the complexities of infection control or transmission rates, it probably doesn't mean very much, but what actually matters is the contact you have that makes your world feel better when you live with dementia. So, it also has a detrimental effect on the person with dementia themselves and I don't think we can overstate it because we're getting reports all the time of families seeing their loved ones deteriorate and of course people with dementia do deteriorate over time, we know that these changes can happen but accelerating that because of the usual support mechanisms and loved ones not being around you, that's a very difficult place for people with dementia and their families to be in. And I really want people to understand that, it is not a kind of we're going to sort out the infection stuff and we'll manage that risk because there's another massive risk over here which is the risk of isolation and the on-going damage that that causes people.

But actually there are ways of making this work, there are ways of managing the risk and a very sensible, clinical, pragmatic approach is that we could introduce to actually help that and I think Adrian was pointing out some of those things earlier on, and there are things that we could do quite rapidly if we really wanted to, whether it's testing of family members, making sure that the safe spaces in care homes are there, you know you could put in place all of those protocols pretty quickly to enable those things to happen and nobody is asking for all of the doors of care homes to be opened up widely and all the rest of it, when I talk to carers I don't know of any family carer that wouldn't have a test prior to going to see their loved ones, they are willing to engage and willing to help as indeed are I'm sure the providers too, but actually what I hear from providers is it's still taking too long for the results to come back, so just trying to get a grip on that as a care home manager let alone everything else you've got going on is a challenge.

**Barbara Keeley MP**

OK, thank you. Laura do you want to add to that?

**Laura Cockram**

Yeah, thank you Barbara. We very much started to see an increase in calls and distress around this issue to our helpline recently and I guess there is that sense of balancing risk of infection with the benefits in terms of mental health. We've just issued guidance ourselves to our supporters on this and trying to use some of the guidance that's already out there from care home providers about different ways of being able to engage and continue to have that relationship with a person with Parkinson's in a care home and I think Paul and Adrian have shared a number of suggestions and solutions. I think that the one big thing for us is also about the mental health workforce and the fact that there is a clear chasm in the number of people who are going to be needed to be part of that mental health workforce for the carers as well as people with long-term conditions and a recent Parliamentary question shows that the Government has missed its target by almost 50%, so this is going to be something that impacts the whole of the population and I think it would be wise for the Committee to add something into their recommendations around mental health and how this will prepare the population moving forward.

**Barbara Keeley MP**

OK, thank you. My second question is a slightly different one, the focus in the first wave as we know was to protect the NHS for Covid patients and that did leave care homes exposed in the way that Adrian talked about and all the weaknesses in our care systems and our other systems very clear. Do you as members of our panel today, do you feel that our NHS and care systems are better equipped now to deal with the issues which are starting to hit as the number of cases of Covid rises sharply and effectively what are your biggest concerns? Shall I start with Tracey?

**Tracey Loftis**

Thank you, and I'm going to talk primarily about the NHS, clearly when the Covid outbreak occurred in the UK all elective care was cancelled and this clearly had a profound impact on people with arthritis. What we saw was again in terms of community care, we saw physiotherapy and podiatry I think 60% of appointments have been cancelled, in primary care a lot of the appointments have been moved online so that's incredibly helpful but in rheumatology we're aware that a lot of appointments were cancelled and a lot of operations were delayed. I think in some of [inaudible 1:16:54.1] play forwards from the first phase is that when you look at operations such as hip and knee replacements this is a real bread and butter operation for the NHS, this is the second and third most common operation that the NHS does and yet we know that the decision to restart services in the summer months is now coming under increasing pressure because of the winter pandemic and I think from our point of view wherever possible we would like to see elective care continue.

The second thing I think about in terms of learnings in particular is the importance of communication and the importance of almost having a minimum set of standards that people are communicated to if their appointment is delayed or cancelled, you know we heard of some really not great examples in terms of communication, one person who was waiting for a hip replacement just got told 'don't expect to have it this year' that is clearly not good enough so there's something about compassion in communication and there's something about frequency. Even if the answer is we don't know yet, part of this is if we can be honest with people about this is the pressure that we're experiencing and this is

what we can say so far that is really helpful. And I think that the third thing again, and I think this is particularly important again as we go into the winter months is the importance of being physically active, both in terms of people's musculoskeletal health but also their general health and wellbeing and clearly the fact that during the second lockdown we're able to take unlimited physical activity outdoors is to be welcomed.

**Barbara Keeley MP**

Laura or Paul, could you say what your biggest concerns about how the NHS and care systems are facing this next wave?

**Paul Edwards**

Yeah, so a few concerns really, one is an age-old one if you like now it's about testing, proper testing and getting the testing back on time, particularly I'm thinking about care providers, you know it's so hard to manage infection control in the care home if you don't get the testing data to enable you to plan and also obviously like I said testing for all family members so that we can start that process of unlocking some of those environments so loved ones can see each other. So, that's one of the things. I am really worried about the workforce, we already know that we had problems particularly in the social care workforce and also in the NHS workforce going into this in terms of recruitment and vacancies and stuff but also I'm hearing from our own nurses really is just how difficult it is coping with these enhanced levels of complexities, of vulnerabilities and that takes an emotional toll on our workforce, on our nurses, on our care workers, on our doctors and AHPs in the NHS, so I think that is a real concern because if we lose their level of energy and all the rest of it because they are worn out and emotionally drained and that has a knock-on effect on the way that we deliver care to people for sure. So, we need to be really mindful about our workforces and looking after them and building support and resilience and all that sort of stuff. And I think the third thing for me is I'm really worried about more and more people feeling more and more isolated the longer this goes on, because we know what happens to the experience of caring for a living with dementia when that happens, so three areas of big concern for me.

**Barbara Keeley MP**

Thank you, Laura have you anything you want to add to that?

**Laura Cockram**

Yeah, thank you, very much agree with Tracey's points about elective care, about the communications, absolutely staff are exhausted, we were on a call with some Parkinson's nurses last week and they were sharing when they cared for people during Covid and kind of what's happening now and clearly there is just a sense of exhaustion and there's still a bank of people who are willing to come into the NHS and work but I don't think that has been utilised maybe in quite the way that it should. I think issues around testing very much are a problem for people with Parkinson's, somebody who was going in for a routine leg ulcer appointment wasn't able to go in because they didn't have a Covid test in enough time in order for them to actually get their appointment and therefore then care agencies aren't going to come into their house because they haven't had that negative test, so it's actually having an impact on people's daily lives. I think the final thing is that there are some glimmers of hope, let's try and be positive, there are some glimmers of hope and some of them are around the

technology and the use of technology and remote monitoring, where it's appropriate for people I think that's great and so being able to have those virtual appointments I think is great and it is that opportunity to check in to make sure that people's symptoms aren't getting out of hand. But it's not appropriate for everyone and I think that that's really something that we should be making sure that there is that contact with people, as Paul says, to try and understand the loneliness and trying to reduce the isolation that people are facing.

**Barbara Keeley MP**

OK. Adrian did you want to add to that?

**Adrian Ivinson**

Thank you, yes please. I mean my concerns are two-fold and the first is probably best described as initially with Covid there was very much a sensation that this was an acute challenge to society and we're all in it together and it's going to last a little while and we'll come out of it, it's now clear that it's more of a chronic challenge and I'm very worried that as a society we might accept it as a long-term chronic issue without putting the work behind it to deal with it. Now, that's a different set of challenges than the acute phase of quick, you know let's rally together and try and figure out what to do in the short-term. So that's the first thing. Second thing is given that it's a chronic challenge now and frankly if this coronavirus does get a vaccine that has some long-term benefits there's another coronavirus round the corner, we shouldn't imagine that this is the only virus that could do this to us, so we need to be ready for it. As I mentioned before it's a bit like we've been given a very significant stress test and we've realised where there are vulnerabilities so now we have to work on those vulnerabilities and one of the things that we should be doing more of is as Paul and as Tracey mentioned is we should be ... sorry I think it was Laura ... we should be looking at how we keep the most vulnerable people living healthier and happier at home, there are things you can do in the home. So, we have a test bed of 50 homes that have some of these devices embedded in them, we can tell when a patient with certain stages of dementia has stopped moving around, has stopped going to the loo, has stopped putting the kettle on and therefore is dehydrated, has started putting lights on at 3am because they've got sleep disturbance. There are these technologies, we should be investing in them, they are going to be very valuable for the dementia community living at home but they're also going to be very valuable for other vulnerable elderly people who want to live at home.

**Barbara Keeley MP**

Thank you, thanks Chair.

**Layla Moran MP**

Thank you very much. Baroness Masham.

**Baroness Masham**

Yes, I'm Sue and I'm a member of several of the health groups including arthritis and Parkinson's. My question is could the problem faced by your organisations and those suffering from those conditions have been avoided in the early stages of the pandemic. I also wanted to add about the problem of early diagnosis but I think you've said pretty well you've covered that, but I was very, very worried

about, I think it was Laura who mentioned the shortage of medication, I mean that's really serious and us from a spinal injury field have been very worried about that too, but also carers coming to help in the home, that is really getting very, very much more difficult. I was even rung by somebody who's up in Scotland yesterday who is desperate for a carer for an elderly father and you know it's really getting difficult and Brexit and corona combined is a nightmare. So, I'd be very pleased to hear your comments, perhaps Tracey first.

### **Tracey Loftis**

Thank you, so I think what I'm conscious of is that there has been a real life learning situation here and certainly some of the learnings that we definitely want played forward and to be avoided in future is again for people who are waiting treatment, who may have had that postponed, about improved communication about what is happening. And also signposting to what support is available, I'm conscious that as a charity we have invested in an AI chat port to enable people to ask questions at any time of the day about coronavirus and arthritis and again through the Richmond Group we've been working on a campaign called 'We Are Undefeatable' again to enable people to move and be active in their homes during these times. So, there is something about how we share innovations and how we kind of play those forwards. I do think there is something here about how we can communicate better across the whole UK, especially with guidance which affects people who are extremely clinically vulnerable, I think that's a really important one and again working with the charity sector about how we link through to our beneficiaries.

### **Layla Moran MP**

Thank you.

### **Baroness Masham**

Yes, what do you think Paul? What does Paul think?

### **Paul Edwards**

Thank you, I agree around communication and the kind of need for very clear messaging that we can then translate for the people that we serve, I think that's a really good point. But I think in dementia care having been around it for quite a while, dementia care wasn't in a perfect position before it went into this pandemic, it's probably the most under-invested part of our health and social care really, given the numbers that we've got. So, there wasn't a perfect infrastructure and then if you put a pandemic on top of that it just exposes, I think Adrian was alluding to this earlier on, just exposes some of the issues that we know we need to address, that we knew before actually whether that's a diagnostic time, whether it's post-diagnostic support, whether it's single points of contact, specialist nursing, you know etc, people wanting to stay in their home for longer, all of those things seem to have been amplified by the effect of Covid. So, we did know that this world of dementia care wasn't that robust anyway, so I think that's that. I think we are in this kind of very much learning all of the time and changing and amending and innovating all of the time, I think there will be some things that are better in terms of our information, everybody's got a Covid hub, everybody's trying to help as much as we can, helplines have certainly been expanding and you know, so some things are better and were better prepared but there is the longer this goes on, the greater the amount of needs we're going to have to meet in terms of supporting families. So, yeah very mixed but if we, you know, if we

really think about what was going on in dementia care and the structures and the support and the under-investments that's gone on for so long in this area, actually that could have been quite a different experience if it was on a much better footing.

**Baroness Masham**

What do you think about telephone calls with GPs? I find it quite complex.

**Paul Edwards**

Yeah and you know, and I actually know some GPs who have been still doing home visits in full PPE and going out to people, so we have this very patchy kind of response at the moment but I think two things, one is the digital telephone accessibility issues, you know if you're hard of hearing you know, things like that can be very difficult over the phone rather than face to face. And also, I guess it's about the relationship that you have and the trust you have, that's much more difficult over the telephone line sometimes for people to understand, so I think it is problematic, but at the same time, you know, GPs have to run the services as best they can with the resources they've got and they want to try and reach as many people as they possibly can, but it is more problematic for sure in terms of telephone appointments. But, actually you know we also get feedback from carers who are saying, you know left a message with the GP, he got straight back to me, previously I would have had to wait four or five days just to get into the surgery, so there are benefits too.

**Baroness Masham**

What about Adrian, have you anything to add?

**Adrian Ivinson**

Thank you, Sue.

**Layla Moran MP**

May I just quickly interject to say we've got nine minutes left so if we could be very brief, I'd be very grateful.

**Adrian Ivinson**

Then I'll pass.

**Layla Moran MP**

Are you sure?

**Adrian Ivinson**

Yes.

**Baroness Masham**

What about Laura?

**Laura Cockram**

Just very briefly, agree with everything that Tracey and Paul have said. I think it would have been important for the NHS to have better and more accurate data so that they can base those shielding decisions on. I think also in terms of NHS services having Covid and non-Covid sites so that you could continue the planned, elective treatments I think would have been useful and this pandemic has meant that we have moved in the NHS to using telephone and video appointments more. I think there could have been work in advance to have helped the patient population as well as professionals, a move towards a more digital approach. I'm not saying that it's right for everybody but I do think that there are ways that we could be getting more people seen and using technology in terms of remote monitoring at home, as Adrian has alluded to previously.

**Baroness Masham**

Thank you all so much.

**Layla Moran MP**

Thank you so much. Paul Strasburger.

**Lord Strasburger**

Thank you Layla and welcome to all four of you. Two very quick questions to each of you. Looking backward has the support you've had from the Government been sufficient and looking forward what one thing could the Government do that would be most beneficial to you in your work? So, backwards and forwards. Laura would you like to go first?

**Laura Cockram**

Thank you Lord Strasburger. I think the support that the Government has provided to people with Parkinson's has been particularly around I guess the support around, you know, shielding, the food boxes, the medication pick-ups, the NHS Responder's scheme and whilst it's not been perfect I think it has helped some people to have some support at home. I guess for charities like Parkinson's UK and also for some people with Parkinson's the furlough scheme has helped some people to remain in work and also to get some support. I think what we'd like moving forward is the resumption of NHS services, particularly services around rehabilitation, you know that there's going to be a pull on services around Long-Covid, around mental health and I think also the support for research and for research to keep going because as a medical research charity we don't have a cure for Parkinson's, we want to make sure that we are investing, that the Government is investing in that and so we support the Association

of Medical Research charity's call for support for the life sciences charity research partnership to keep that vital medical research going.

**Lord Strasburger**

Thank you. Tracey.

**Tracey Loftis**

Thank you, so we are aware that there's been some useful innovations during the pandemic, you know a classic example has been the expansion of access to work for home working and also providing statutory sick pay for those isolating before surgery, these are both welcome benefits. I think looking forward I think first of all again just to echo colleagues' remarks, certainly for musculoskeletal care, there were problems before we went into the pandemic for trauma and orthopaedic treatments the waiting time of 18 weeks hadn't been met in nearly four years, so part of this is when we're looking at the pandemic in the longer term we need to work out about how can the NHS run its bread and butter kind of elective care alongside in providing Covid treatment and I would also echo Laura's remarks about the importance of supporting research in the longer term. We are also a funder of medical research and during the pandemic again we've had to pause the vast majority of our research, so clearly thinking about things such as the life sciences charity partnership fund is a way of both supporting medical research but also helping equip us better for the future in terms of our response to future issues in the pandemic.

**Lord Strasburger**

Thank you Tracey. Paul, what's the one thing the Government could do to help you most?

**Paul Edwards**

I think right now there are many things, but right now we need to work on solving the visiting issues for care homes for people, to open that up, that's a priority right now.

**Lord Strasburger**

That's very clear, thank you. Adrian would you like to add something?

**Adrian Ivinson**

Yes, in terms of backward looking I would just say that we all jumped too quickly to close research labs, in fact it turns out research labs are pretty carefully controlled clean places and we shouldn't have closed the research labs down, this time around we're not closing them down so that's one thing. Forward looking, dementia is not ... it's not a lost cause, you know it's not a question that we're just all going to get old and at some point some of us will get dementia and then we'll have to go into homes and what have you, that just is not the case. And so, I don't want the medium and longer term research agenda to be lost to the quite reasonable day to day dealing with Covid, I want us to recognise that the cancer community 25 years ago, cancer often was a death sentence. Today it is not the case, sometimes it is, often it isn't, it's come on leaps and bounds. The whole field of neurodegeneration

and dementia could come on leaps and bounds but we are going to, as Paul said, it's been terribly underfunded and if we don't put the money in we won't get the result out.

Just to remind you Lord Strasburger, as I said £34 billion hit to the UK economy each year, so that's on one side of the equation. Shouldn't we be spending at least 1% of that on the solution, and we are nowhere near?

**Lord Strasburger**

Thank you, thank you all for being so clear. Layla.

**Layla Moran MP**

Well, that's the end of our questions and I just simply want to say an enormous thank you to all of you today, I think it's really highlighted the huge breadth of the issue and how many unresolved parts to it there still are. So, thank you very much for all of you for taking the time today, thank you to Parliamentarians for their insightful questions. We are certainly going to incorporate much of this evidence into our recommendations which will be released very soon. The evidence that you provided will be made public so that people can peruse that as well and so that we can amplify your voices. But last but not least thank you for everything that you are doing to support our wider communities at this very precarious time and I hope that in the future we'll be able to have you back and we very much hope that you'll be able to tell us that all these things that you've raised as issues will have improved and that's what we are here to aim to do. So, thank you very much everybody, thank you everyone at home who's been watching and we will see you all hopefully in two weeks' time where we'll be focusing on cancer care and Covid, so another very important area that has suffered as a result of various lockdowns and that we're deeply concerned about, so thank you very much everybody have a wonderful afternoon, goodbye.