Wednesday, 23 July 2025

(10.00 am)

LADY HALLETT: Ms Cecil.

MS CECIL: Good morning, my Lady. May I please call Professor Sube Banerjee.

PROFESSOR SUBE BANERJEE (affirmed)

Questions from COUNSEL TO THE INQUIRY

LADY HALLETT: Thank you for coming to help us, Professor.

THE WITNESS: Thank you.

MS CECIL: Professor, you have helpfully prepared an expert report on the impact of the Covid-19 pandemic on the care and treatment of people with dementia and their families, and for those that are following, that's INQ000546956, helpfully brought up on the screen.

If I may very briefly just go through your professional background insofar as it is relevant to the matters we will be discussing today. You are currently the Pro-Vice Chancellor at the Faculty of Medicine and Health Sciences, and Professor of Dementia at the University of Nottingham; is that right?

A. I am.

Q. In relation to your experience, you have both considerable clinical and academic experience.

A. Yes, I'm a clinical academic doing both research and clinical work with people with dementia.

Q. And helpfully for our purposes, you were also, at various points, seconded to the Department of Health and Social Care in relation to policy.

A. Yes, on two occasions I was seconded for four to five years, the first as senior medical officer in the research and development division of the Department of Health, as it was then, basically responsible for all mental health research for people of all ages, including older people, and second, I was -- and second, in 2005 to 2010, I was seconded as the senior professional adviser in older people's mental health and dementia at the Department of Health, as it was at the time, and helped prepare the National Dementia Strategy.

Q. Thank you. I just want to flag, for transparency, one aspect if I may; you also hold number of trusteeships, non-executive directorships, memberships, and so on.

A. I do.

Q. One of those was as a trustee of the Alzheimer's Association; is that right?

A. Alzheimer's Society.

Q. Society, my apologies.

A. Yes, I am a trustee of the Alzheimer's Society.

Q. Alzheimer's Society, my apologies. Thank you, and I flag that just for transparency because you may be asked about some of their work or policies papers in due

course.

A. Yes, I did see some of the evidence was from Kate Lee who is the former Chief Executive of the Alzheimer's Society.

Q. And alongside your expertise, the report also draws upon the expertise of Dr Nicolas Farina and Dr Ben Hicks.

A. It does.

Q. Thank you.

If I may begin, then, at the very start, what is dementia?

A. Well, dementia is one of the most serious and one of the most common disorders that we face. It's a major public health and social care challenge. Dementia is a term that is used for a collection of disorders, so dementia is a thing that is caused by various illnesses, the most common of which is Alzheimer's disease. I'll come back to that.

But dementia is a syndrome which is characterised by two things, mainly. Firstly, a progressive decline in one's cognitive abilities, that's your abilities to be able to think and to remember and to do all the things your brain does, so a progressive cognitive decline. But, also, alongside that, there is a functional decline. So that then stops you from being able to do things that you were able to do in terms of activities

of daily living, so -- as that becomes more -- as dementia becomes more severe, there is more impairment that comes from that, and that includes social communication as well as dressing, cooking, eating, those sorts of things.

Q. So we see both cognitive decline and also functional decline?

A. That's correct, and dementia also has two other aspects which are part of the syndrome and are particularly complex and difficult. So the first of those is the social impairments that happen in dementia, which may be a function of the cognition or maybe a function of other brain changes that are there, but that social -- the social problems that happen in dementia are either withdrawal or agitation, and compromising one's ability to be able to be do the things that we're used to, not because of physical reasons, but because of the way we socially interact.

And very importantly, and a very major driver of poor quality of life for people with dementia, and also their family carers, are the development of neuropsychiatric syndromes, which are a part of the syndrome almost everybody dementia -- everybody with dementia, at some stage in dementia, will develop either anxiety or agitation, sometimes even aggression, and

resisting help giving, at times, but things which can also include hallucinations and delusions, beliefs that things aren't real, seeing things that other people can't see, and these in and of themselves are distressing for the people with dementia and for carers and are unfortunately part of the syndrome of dementia, and they can happen either early in the illness, in the middle of the illness, or later in the illness.

Q. Thank you. And is it a terminal illness?

A. Dementia is a terminal illness. A third of people in the United Kingdom die with dementia, and dementia is, as I said, a neurodegenerative disorder, it affects all parts of the brain, essentially, and our brain essentially allows us to do everything that we do, including, you know, breathing and eating and those sorts of things, so dementia is a terminal disorder, though people may well die of other illnesses before they die of dementia.

Q. In terms of life expectancy you describe that as typically being between seven to 12 years post-diagnosis, obviously dependent upon when diagnosis is made and a range of other factors?

A. Yes, absolutely. So it depends upon the age at which one is diagnosed, the earlier one is diagnosed, then potentially the longer one might live. But vitally, it

depends upon comorbidities, other physical disorders, but yes, within seven to 12 years you can expect somebody who is diagnosed early will die.

Q. And you have spoken about a number of different illnesses or causes of dementia, and you touched upon Alzheimer's.

A. Yes.

Q. Just to be clear about that, that is often used, isn't it, as a shorthand for dementia but it is but one type of dementia?

A. Yes. It is the most common form of dementia, followed closely by Alzheimer's disease with other -- mixed in with other forms of dementia.

Yeah, I mean, we have an imperfect understanding of the etiology of dementia as a whole and also of the causes of dementia.

But if I could just -- so the main causes are Alzheimer's disease. And Alzheimer's disease, there is degen -- there is a characteristic degeneration of nerve cells that leads to those nerve cells' death and a characteristic pattern of that degeneration in different parts of the brain.

The second most common aetiology form of dementia will be things that are to do with your vascular make-up. So cerebrovascular health is really important.

So if you have small strokes or you have blocked blood vessels, then that itself can be a cause of dementia, and that's often called vascular dementia. So that would be the second most common specific type of dementia.

What complicates things in dementia, of course, is that almost everybody as they grow older has some element of vascular illness; so people with Alzheimer's disease also have vascular illness, some of that affects their brain and those cases can then be called mixed dementias.

And there's a different pattern that one gets with vascular dementias and with -- because it depends on where the problems are in the vascular system compared to Alzheimer's disease.

There are also a group of dimensions that are associated with Parkinson's disease. Again, that's a different pathology than Alzheimer's disease and we know a little bit more about that. But people with Parkinson's disease are more likely to develop dementia. And there are people who develop Lewy body dementia that can happen before the symptoms of Parkinson's disease happen.

Q. Thank you.

A. There are a lot of other different causes of dementia.

Q. Of course.

If I can just touch upon specific risk factors, age is obviously the predominant risk factor for dementia?

A. It is.

Q. Women also have a higher prevalence of dementia than men?

A. They do.

Q. Fairly comprehensive studies by The Lancet have considered that up to half of dementia syndromes might be attributable to potentially modifiable risk factors. You set those out within the report. They deal with things such as less education, hearing loss, physical inactivity, diabetes, traumatic brain injuries, pollution, all sorts of other matters; and many of those, you say, are more common in deprived and marginalised groups?

A. They are.

Q. So there's a potential connection there with socioeconomic deprivation.

You also set out that there is a disproportionate impact among minority ethnic groups, with a 20% higher likelihood of dementia; is that correct?

A. That's correct, and that is likely -- there may be elements of that that have a complex genetic basis, but a lot of it depends upon social and behavioural

characteristics. So, for example, if you -- if there's greater deprivation and your diet is worse, if there is a higher level of obesity, if you have more diabetes, as some groups do, then those are more likely, and your risk of dementia increases with those comorbidities.

Q. Thank you. And the other group for which there is a significant risk profile are those with learning disabilities?

A. Yes, there are particular groups at risk of dementia. People with learning disabilities form a high-risk group in and of themselves, particularly people with Down syndrome.

Q. Thank you. And what dementia is not, however, is an inevitable consequence of aging; that's a misconception?

A. No, there are a number of misconceptions about dementia and, absolutely, dementia is not a natural and normal part of aging. It is -- and it's -- as I said, it's caused by several illnesses. But all of those are specific disorders.

So the prevalence of dementia, the number of -- the proportion of individuals at any age group with dementia does increase with age. So at about 65 it's about 7% of people, at about 85 it's about 20% of people, at about 95 it's about 33% of people. But that still means that two-thirds of people do not have dementia, and we have

good evidence to suggest that it's not that they -- it's not that if you live until you're 120 you get it. Dementia is not a natural and normal part of growing old; it is an illness in and of itself.

Q. Just to turn to population demographics for a moment, across the UK, in terms of the over 65 population, it's around 7.1% of those individuals have dementia?

A. Yes, there are different -- there are different estimates from different studies using different criteria but it's about that. So we have about -- it's about 7% of the people over 65, if you take that whole population again. If you go to higher age groups, you get a higher proportion.

Q. So, as I say, 7% over 65s and around 2% across the entirety of the population?

A. Yes, about 2% of the people in the UK. That's of all ages, including children.

Q. Thank you.

Care is obviously an important issue for those with dementia. You've described that it's a degenerative disease.

A. Yes.

Q. What follows from that is that there are greater care needs as the illness progresses, as the syndrome progresses. Who provides care in the majority of cases?

A. The vast majority of care is provided by family carers. That's the term that I use because that's the one that family carers have preferred in the research that we carried out. But family carers also includes friends that support individuals as well, in the terms that I use.

But the vast amount of care is provided by families of people with dementia, unpaid family members who support those individuals. If you look -- if you look within that at about who provides most care, it is generally women. Women provide most of the care. The predominant group will be those people that are spouses of those individuals, so that if you are living -- if you're co-resident and live with the person with dementia and that person develops dementia, then you will be very likely -- you will be that main family carer and you will be providing those. And those are very largely spouses. Some of them are -- are the next generation, are sons and daughters, who may or may not move in to do that.

But there are also non-co-resident caregivers, and those are generally sons and daughters or daughters-in-law who are providing that main family caring responsibility.

Another thing about family caring is that it doesn't

fall evenly in families. So there is generally one individual who takes most of the role on. And, you know, there are positive things about caring for people that you love and know, that are part of your family, and there are also negative consequences of looking after people with dementia.

Q. And we'll come on to some of those in terms of some of the pandemic impact in due course.

Just dealing then with the proportion of those with dementia that live in care homes, that's approximately a third; is that right?

A. Yeah, a third of all people in the UK who have dementia live in care homes, yes, that's our best estimate.

Q. And then when looking at the care home population, it's -- the estimates are around 80-90% of those in older people's care homes have dementia?

A. Yes. So if you look at care homes, the normal care homes, not care homes that are specifically for people with schizophrenia or people with learning disabilities, if you look at, you know, the 95% of those standard care homes, between 85% and 90% of those individuals have dementia. Care home care in the United Kingdom, long-term social care, is essentially dementia care. Because that is the reason why individuals cannot continue to live in their own homes.

People with dementia also, when they are admitted, live longer, so they live longer in those homes. People who are admitted to care homes with an acute physical problem out of hospital, and no cognitive impairment, they will often die within the first six months of being in the care home.

So you end up with a care home population being 80-90% made up of people with dementia.

Q. Thank you. I'd like to move, then, to the initial pre-pandemic position in terms of governmental policy and strategy. If I can summarise what you have to say in your report like this: what you explain is that across the four nations, dementia had emerged as a priority over the past 15 years.

A. Mm.

Q. However, for the years immediately prior to the pandemic, that had waned, effectively, the interest and the will had waned in respect of those, there were concerns about a lack of delivery. The question I have is a very specific one, which is: what implications did that have for the pandemic?

A. So the waning was particularly clear in England, but the level of delivery was unclear in all of the countries of the UK, in terms of what was being done. The specific question as to what did that do, it means that we were

less prepared, we had less good care and support for people with dementia than we could have, and that we should have. And that put people with the dementia certainly less in the eye of policymakers, it was less of a priority for the Department of Health, or the Department of Health and Social Care, as it became, because it wasn't -- didn't have the policy priority it once had, and I -- and it meant that the services that were being provided to support people were often fragmented and often -- and that there was major variation across the country in terms of what one might be provided with in terms of both diagnostic and post-diagnostic care.

Q. Thank you.

If I can turn, then, to the guidance at the outset of the pandemic, in England, dementia was not explicitly mentioned with regard to shielding or social distancing, in terms of the March guidance --

A. Yes.

Q. -- the April unpaid care guidance or, indeed, the list of clinically extremely vulnerable that was later published in winter of 2020. It was similar in Northern Ireland, and again, in England and Wales, when it came to guidance in relation to dementia, it was not in relation to risks but with regard to difficulty in

self-reporting symptoms.

Were the risks to those with dementia foreseeable? Ought they to have been included in those policy documents on the basis of what is known?

A. Yes, and yes, they were foreseeable and they should have been included in those documents. People with dementia are almost by definition old and frail with complex comorbidities. They are also, as we've heard, more likely to be living in care homes, so congregate households. It is entirely predictable that almost any pandemic would affect older people and people with dementia disproportionately. And it's very clear that that's what happened within this pandemic. There are few pandemics that would be isolated to children, or whatever, but these are the most vulnerable, physically, in our society, and it is likely that the most vulnerable in society are most likely to be vulnerable to infectious diseases.

So yes, I think that any pandemic, any pandemic planning should have explicitly included those people that were most at risk of being harmed, and I think that any future pandemic planning must attend proportionately to those people who are most likely to be harmed by those pandemics.

Q. If I may pick up on the disproportionality that you've

just mentioned.

A. Yes.

Q. One of the headline messages from your report is that people with dementia were disproportionately impacted in terms of mortality --

A. Yes.

Q. -- death, in short. And that overall, a quarter of all deaths occurred with people with dementia?

A. Yes, and what we've tried very hard to do in our report is to look, as dispassionately as we can, at the various sources of data that are out there. And the data sources are not unequivocal. We have looked at a lot of research from a lot of different places and a lot of routinely collected data. What we also tried to do was to boil it down into understandable messages, which had the weight of the evidence behind them. And yes, we found that 25% of the deaths of people with Covid were in people with dementia, so a quarter of all people who died of Covid were people who had dementia.

And as we said earlier, that's a quarter of all the deaths happening in 2% of the population. That is disproportionate.

Q. Thank you. And I'm not going to take you to the statistics that you set out within your report, but in terms of the four nations, what is clear is that the

same pattern emerged in terms of that, broadly speaking, a quarter figure.
A. I mean, there are variations, there are minor variations, but it's pretty clear that the same experiences were had by people with dementia across the United Kingdom. There are variations in the way that dementia is recorded, there are variations in the way that death may be recorded and other things, which means that there will be variations, but yes, it appeared to us that the same things were happening across the United Kingdom.
Q. And deaths in hospitals, a similar disproportionality, with people with dementia being 38% more likely to die in hospital during wave 1 to those without dementia, and in wave 2, still 34% more likely, comparatively?
A. Yeah, and all of the information holds together. Clearly a lot of people with Covid died in hospitals, and that, you know, that is -- that -- and many of those people were people with dementia, who died in hospital with Covid. There were people who died in hospital, people who died at home, and people who died in care homes, and in all of those settings, if you had dementia, you were much more likely to die than those without.
Q. Indeed. And in terms of excess mortality, similarly,

people with dementia had the highest levels of excess mortality in 2020?
A. They did.
Q. Just to be clear, these disparities were seen even when accounting and adjusting for comorbidities and other potentials causes of death; is that right?
A. That's right. I mean, the data here become, you know, a little more uncertain, but those studies that have been done, that have attempted to control for the effects of, you know, other physical illnesses and other situations, do suggest that that even when you take those into account, that there was an increased mortality in people with dementia, and part of that, of course, will be the effect of care homes that we've talked about, as well, in terms of determining higher mortality rates.
Q. Indeed. And just dealing with -- picking up the point about deaths in care homes, if I may. Obviously, there are a large number of individuals that are not formally diagnosed with dementia.
A. Yes.
Q. But is it right that in your view and, indeed, the research that you've considered, that notwithstanding that, the overwhelming majority of those that died without formal diagnosis were likely to have also had

dementia?
A. Yes, that's the thing, so the 85-90% estimate is based upon those studies that have gone into care homes and actually diagnosed people using research methods. If you simply rely on the GP records for dementia, then only two-thirds of people are diagnosed at any time, so many people in care homes may not have a formal diagnosis but will have dementia.
Q. And you provide a number of potential explanations for these disparities that arose in relation to the pandemic. One aspect of that, in your words, is deprioritisation and differential management of care home residents and people with dementia. Can you just, very briefly, explain a little bit further as to what you mean by that.
A. Specifically in care homes?
Q. Yes.
A. Yeah. So I think that it's very clear that there was worse care provided by the NHS and by the system as a whole to care homes than there was to acute hospitals. There was a prioritisation of acute hospitals over care homes, and that included the sending people back to care homes that had -- without testing, who were Covid -- who were positive for Covid and who therefore spread those things.

So there's a set of reasons why those sorts of things might happen, but they are all based on a lack of priority given to care in -- social care, compared to care in healthcare. There is talk of the, is it the steel boundary, or the ring of steel --
Q. The ring --
A. -- that was put around care homes and just looking at the evidence, you wonder whether that -- well, firstly, there's very little evidence of it, but you wonder if its effect was to protect the NHS from people in social care, rather than to protect those people in social care from Covid.
Q. If I can ask you, please, just in relation to one other aspect, within your report you explain that obviously lots of individual decisions are taken --
A. Yeah.
Q. -- and there are systemic issues then that come into play, as a consequence of that. And one aspect of that are beliefs and misconceptions. Can I just ask in relation to that, what concrete steps should and could have been taken to recognise and address that disproportionate impact during the pandemic?
A. So I think clearer guidance would have been very helpful. I think guidance that made specific reference to older people and to people with dementia, criteria

that were more explicit would have been helpful.
I think that -- and this is absolutely not seeking to make any statement of blame, but it is seeking to understand why one group of people appears to get a worse set of care than another group of people.
And if we look again at the research-based evidence, we see that the general population and healthcare professionals have lower expectations and lower positivity about older people and older people's health than they do about people in -- middle-aged and younger people. And so you have a set of potential biases that enter into clinical decision making, but also enter into the management of hospitals, and also enter into the generation of health policy and delivery of health policy because these misconceptions and negative attitudes towards older people are held by the general population and also by people in healthcare.
So presented with extraordinarily difficult and complex situations, you're, you know, and you are asked to make decisions and you make those decisions according to your internal compass. If your internal compass faces away from people who are old, then you may be more likely to decide that individuals don't get a test, are sent back to their care homes or sent back home, rather than afforded the care that might -- the extra care that

be provided in a general hospital, for example.

LADY HALLETT: Can I just interrupt?

A. Of course.

LADY HALLETT: Ms Cecil asked you about the guidance, and you said clearer guidance with specific reference to older people and people with dementia would have been helpful, and you said, "more explicit criteria". What did you mean by more explicit criteria?

A. I think that decision -- and one can understand why, but clinical decision making was largely left to individuals to make their own decisions in those without guidance. I think that the lack of ... the lack -- so there were a number of conditions that were identified as particular high-risk groups quite early, and dementia wasn't one of those. And I think that that then frames those high-risk groups as ones where you should do things and the rest as ones where you might -- there might be less of a reason to do things. That's the sort of thing I was talking about there.

LADY HALLETT: Thank you.

MS CAREY: If I may turn to other impacts, you also explain that diagnostic services and post-diagnostic care, so effectively people being diagnosed, those services were seriously disrupted during the pandemic. What does that mean in practice?

A. So people with dementia rely on -- they rely on health systems, social care systems, to have their support. But they also rely on those systems being available to be able to tell them they've got dementia. Nobody knows that they've got dementia until you've been through a diagnostic process. And it's complicated, because many people who are developing dementia -- and this is different from other disorders -- do not recognise that they have the symptoms. There's a lack of insight that is one of the features of dementia.
So an individual with a pain in a particular place might come forward and say, "Hi, I've got this pain."
Someone with dementia will not -- is not likely to come forward and say, "Hello, I've got a problem with my memory."
What happened during the pandemic was that the diagnostic services that existed were largely shut down and stopped working.

Q. Those are the -- (overspeaking) --

A. They were largely -- so diagnosis happens in a two-stage process in the UK. The first is that, in primary care, there is a suspicion that something is wrong, and that might be a family carer come and say -- coming to say, "I'm worried about my partner."
It might be an individual saying that themselves.

Or it could be that memory problems were noticed as part of another -- as part of a routine consultation.
Now, all of those things didn't happen. That's that first stage. The second stage is you then refer that person to a specialist memory service, and that memory service then does the more detailed assessment, and not only makes the diagnosis of dementia, ascertains that they have that, but also works out what condition is causing the dementia and what other problems people have. So you can formulate a proper care plan.
So what happened in the pandemic was that both elements of that were shut down. So primary care services essentially became an online service, and online services don't really provide that sort of -- you can't pick something up in a consultation --

Q. In the same way?

A. -- in the same way. And they were perceived as being a scarce resource that shouldn't be disturbed, and so older people are much less likely, in those circumstances, to seek care.
But even if individuals were noticed as having memory problems, the memory services that exist, which are, you know, hard pressed through the country anyway, and of variable quality, they were essentially closed down, because the normal way of assessing people with

dementia is to see them face-to-face and take a collateral history from a family carer, and it's a careful and multidisciplinary assessment that's done face-to-face.

And face-to-face services stopped.

There was some pivoting towards online services, but the volume of people being seen was very much lower. So what it ended up with, was a cohort of people who were less likely -- who either had their -- the opportunity for diagnosis missed, or it happened late, with the consequent problems that come from not knowing you've got dementia. Because the next piece of information is in this -- and it's another misconception, people believe there's nothing you can do about dementia -- there's a lot that you can do about dementia, but you have to know that you've got it in order to be able to do that. And systems and services have to know you've got it.

So there was a cohort of individuals who were -- whose diagnosis was missed, and we still are reaping the problems that come from that, and a cohort of people whose diagnosis was delayed.

It is also likely that those diagnoses that were made were of lower quality and lower accuracy than diagnoses made in the normal way.

Q. In terms of any future pandemic is there anything that you would recommend, for example, where face-to-face appointments cannot be maintained for whatever reason?

A. Yes, there's learning that we can take from the pandemic in terms of how to do it well and how to do it badly.

It was -- it was local, local innovation that happened within the pandemic. And there are things that one can do online. There are things that you can do to try to improve both the quality and the penetrance of people with -- of diagnostic services. So, yes, there are things that one can do differently.

Q. Thank you.

If I can just turn now to needs assessment and care planning, if I can just call up paragraph 73, please, of your statement INQ000546956, that's at page 34, what you explain there is that:

"Comprehensive needs assessment and care planning is core to providing good quality care ..."

It's much more than giving medication.

You explain that it involves a holistic person-centred approach, considering the person as a whole, the family, and the social context in which they live, also considerations of history, preferences, lifestyles.

Again, similarly, you describe a significant impact

on those needs assessments during the pandemic, with far fewer, and certainly not at that level, in short; is that correct?

A. That is correct. One of the challenges that dementia and complex care, like dementia, raises, is that it's not a simple mechanistic process to make a diagnosis. So it's not like you do a blood test and you know that someone's got something. And it's also not that if that blood test is positive you then provide a particular tablet and everything goes away. That's really not what you get in dementia.

So all of the quality, all of the ability to live well with dementia, comes from these sorts of comprehensive assessments, this careful multidisciplinary work that then ends up with people's psychological and social needs being met as well, as their physical needs.

Q. Indeed.

A. And that was compromised during the pandemic.

Q. And you go on to speak about the importance of non-pharmacological care, but what you also then go on to state is that almost all of those modalities of care and support were stopped or curtailed in the pandemic.

A. Yes.

Q. And what impact did that have, briefly?

A. So people with dementia and the -- and their family carers had, and also people with dementia in care homes, had really very major negative impacts in terms of their quality of life and quality of care being provided to those individuals.

It's a complex picture when you have a co-resident person with dementia and a family carer because the consequences -- because family -- again, there's good and clear evidence now, I think, from multiple sources that suggest that if you were lucky enough to be living with somebody, then that person would -- then the person with dementia, in that situation, was more likely to have their life quality maintained, but that would be at the expense of the quality of life and the mental health of the carer of that person with dementia.

Q. Indeed.

If I can then also ask you, if I may, to look at this particular experience, this really deals with the experience of those with dementia.

It's INQ000474426, it's at page 26, and it goes over the page, please, to 27, at paragraph 5.6 to 5.8.

What we have here are the experiences of Cilla Merryweather and her parents Rosemary and Ronald Brown. They sadly died during the second wave of the pandemic in November 2020 and January 2021. What

she explains there is that when the first lockdown was announced -- she recalls that all the additional supports that her parents had begun to rely on started to disappear, chiropody services, but also visits from the dementia nurses, an overworked and under/inexperienced domiciliary care service was utilised which sadly, for obvious reasons, resulted in Ronald rarely being seen by the same care worker.

So the continuity of care that you speak to, the familiarity of routines, and the like, were obviously not present.

It continues that after Rosemary had passed away, his health also then declined. And due to his decline in his health and his needs not being able to be met by those levels of domiciliary care, he was moved into a care home.

How common were those types of experiences, in terms of the research that you've undertaken?

A. So, it's a very familiar story. It's a familiar story, it's actually a familiar story out of pandemics as well as within the pandemics, but clearly these sorts of things became much more common within the pandemics in terms of the, you know, the very difficult circumstances that both carers and people with dementia found.

So the networks that support people, that we put

together, that families put together, that services put together, to support people with dementia in the community to enable them to live well with their family members, we talked about the assessment process, but they are fragile and they require attention to keep them working, and they do work better when there is continuity of care and understanding. That's why family carers are so important, because they don't change in the middle of that care framework, and they require -- they require management.

In the pandemic, those sorts of things broke down, and when you -- and if your main and your most important support is your family carer, co-resident carer that lives with you, the loss of that individual will often destabilise someone living within their own homes and then it becomes difficult to provide the care that's needed within that home, and so there may need to be a transition to a care home.

Now, what's important is to do that really carefully, because it's one of the most, you know, it's one of the biggest changes anyone will have. If you've got dementia, it's very difficult to learn to be in a new place. There's a need for support that wraps around that happening, and in the pandemic that support and wraparound wasn't there which means that you're less

likely to settle into the care home and you're less likely to be -- to have a good care plan generated and less likely to be properly supported in that environment.

So I think these normal stories of tragedy were very much exacerbated and increased during the pandemic.

Q. Thank you. Turning, then, to medications that were utilised, so pharmaceutical issues. You explain in your report that up until 2020, levels of medication prescribed for the treatment of dementia, so dementia-specific medications --

A. Yeah.

Q. -- were rising year on year, but in 2020 there was a significant decrease in those prescriptions. Set against that, you explain that there was an increased use of antipsychotics during the pandemic.

A. Yes.

Q. So firstly, turning, if I may, to the dementia-specific medication, in a nutshell, why would that have been?

A. So just a word, I think, before about what I mean by those two sets of medication. There are a set of medications that were licensed some time ago for dementia, that kind of make the best of what you've got. They do not stop the dementia, they do not slow the dementia, but they give people the best function they

can have at that time, and those are the anti-dementia medications that I've mentioned in the report, including donepezil is one of those.

There are very few quality markers for care of people with the dementia because there's been no investment in quality care markers, so we simply use things that are available and one of those is the prescription of anti-dementia medication because, you know, it is a good thing to receive these medications if you have dementia, and we had -- and this had been monitored since the medications were introduced, and there had been a really heartening increase in the prescription of those medications since the publication of the National Dementia Strategy, that's very nicely -- that's a very good increase that happens there. So this is a positive thing that we were doing across the United Kingdom in terms of providing these medications.

It's a marker of a diagnosis having been made, and that having been made in secondary care, made well enough for the medication to be prescribed.

During the pandemic what we see is that number drops off markedly, so the numbers of people with -- receiving anti-dementia medication decreases markedly. Part of that will be to do with the mortality of people with dementia during the pandemic that we talked about, and

part of it will have been that the services that people were receiving, the diagnostic services stopped so new people were not being initiated on anti-dementia medication.

Q. Thank you.

LADY HALLETT: Can I ask you to slow down, Professor.

A. Oh, sorry.

LADY HALLETT: A lot of us are responsible for speaking too quickly, including me.

A. Sorry, would you like me to say that again?

LADY HALLETT: No, no, not at all, I'm just thinking I don't want the stenographer putting down the pen in protest.

A. Yes, sorry. So I will much more slowly talk about antipsychotics.

MS CECIL: Indeed, and perhaps I can summarise it in this way: the dispensation of antipsychotics is another indicator of quality in terms -- (overspeaking) --

A. But of poor quality --

Q. -- but an indicator of poor care quality in relation to dementia patients, and you explain that over a decade or so the use of those medications had decreased by half, but in your words, when presented with the stress of the pandemic and the removal of non-drug options for care, the system fell back into its old ways.

You describe within your report why antipsychotics

are inappropriate and that certainly for certain types of dementia, they can significantly exacerbate or cause different or new symptoms such as hallucinations, have the opposite effect, in short, and mask actual need; is that correct?

A. So that's correct, apart from the causing hallucinations. As I said before, hallucinations can be part of dementia, and delusions can be part of dementia, and behavioural disturbance like aggression and agitation can be part of dementia, and they're immensely distressing for the person with the dementia themselves and for carers. So it's entirely legitimate that we should wish to treat those symptoms.

The most common drug that was used -- set of drugs that was used in order to do that were antipsychotic medications, and antipsychotic medications unfortunately have been proven over the last two decades to have some really important negative effects in a lot of groups, but positive effects. In people with dementia it's been shown to have even more of a negative effect than you'd expect.

So there is an excess mortality associated with antipsychotic medications being taken if you have people with dementia, and that's of the order of a 1-2% increase in mortality for every three months that you

take those medications, so it's a big risk. And also the effectiveness of these medications is low.

And we had a good news story in the United Kingdom, which was that we had -- we had identified it as a problem, there'd been great work done in primary care and in general hospitals, and in mental health services, and we've driven down the prescription of these drugs, we've halved the level of prescription of these drugs.

Now, some people will require them because it is so difficult and complicated, and because there are no other treatments, drug treatments, for these behavioural problems. So we'd managed to drive this down really well. But presented with the -- and replaced them with non-drug treatments, with sensible monitoring, with care and support that enables people to live well without those drugs.

But presented with the problems of the pandemic, people fell back, I believe, on the old ways, that -- firstly, there was more agitation and more problems for people in homes and in care homes. So there's a greater need. And then, secondly, there were a lack of other options, or a perception of the lack of other options, and so the level of prescribing of these medications increased. And that, again, will have contributed to the increased mortality seen in people with dementia in

the pandemic.

Q. Indeed. And if I may then turn to other aspects, the Inquiry has heard significant evidence in relation to there being a decline in cognitive function?

A. Yeah.

Q. And -- in terms of -- following from lockdown or from -- in relation to visiting restrictions, isolation and the various restrictions that were put in place. Is that something that is -- that also arises from your research?

A. So we looked carefully at this, and there is no definitive research because there is no control group of people that didn't have a -- that weren't exposed to the pandemic at this time. But actually, there is good evidence, from different sources, that during the pandemic, people with dementia experienced greater cognitive decline than you would have expected outside of that. So greater cognitive decline. Greater functional decline as well, so that people's abilities to look after themselves and do things for themselves decreased in the pandemic more than we would have expected over that period of time had there not been a pandemic.

And there are a lot of plausible reasons why that might be, which include the virus itself, in some cases,

but also includes decreased social stimulation and decreased encouragement of people to actually do things for themselves and the social limitations that came from the pandemic and the lack of stimulation that came from the pandemic.

Q. And similarly, in relation to the Every Story Matters report that's been prepared for this module and for the Inquiry, there were also themes emerging that the lack of visits or care by a loved one would have physical consequences too, such as drinking less water, which is obviously an important factor for individuals of that age with that condition.

From one care worker, who says:

"I'd say those residents with advanced dementia ... [for those] loved ones used to come in, and it would prompt them to eat ... they knew that person ... [and as a consequence there was] weight loss through lack of stimulation ..."

Would that accord with what you would expect?

A. It would indeed.

Q. Thank you.

A. You can't underestimate the value to a person with dementia in a care home or in their own home, but particularly in a care home, of visits from people that they know and love, because people that they have known

their own lives and who they continue to recognise, people who spend time with those individuals, you know, social time talking about things, going through things, you know, encouraging people to eat and drink, as you say, but also enabling people to be socially stimulated and to continue to, you know, use the memories that they have and enjoy those moments with those individuals.

There is something, you know, very specific and very special about the care and support that can be given by family carers in that way.

Q. Indeed.

A. And the loss of that is one of the things that will cause a deterioration in those individuals, either through things like prompting people to eat and drink, or through people developing depression, or through people's dementia itself progressing more quickly and therefore people losing skills that they had beforehand.

Q. Indeed.

And with regard to those restrictions that were put in place, the Inquiry similarly has heard evidence of confusion in people with dementia in relation to why an individual, their loved one, could not visit or could not come into a room, had to stay outside, those sorts of issues.

If I can just call up INQ000109754, page 2, please.

It explains -- and this is one example:

"I feel extreme guilt that I can't visit my mother properly, she can't understand why I won't enter her care home. I feel distraught watching her cry or refuse to come to the window to see me."

Similarly, staff members describe individuals within the care home wanting a hug or to sit with them, to hold their hands. They couldn't do that, and it was very distressing. And further, that the consequence of that for some was that actually those residents no longer recognised their loved ones where they were unable to visit over a period of time.

A. Yes.

Q. Is that something that was predictable?

A. It's entirely predictable in that -- and again, one of the reasons why one might pay particular attention to the -- there are a million people with dementia in the UK at the moment. It's that kind of number that we're talking about.

So, one of the reasons why you might pay particular attention to people with dementia is that, you know, people with dementia have a disorder of memory, they cannot remember things, which means that if you tell people that they need to wear a mask, they will not remember they need to wear a mask. If you tell people

that you can't come in because there's a bug around and that's why your relatives are not visiting, then they will not remember that. It will be, you know, continually being in a state of wanting to see a person that's not coming or wondering why they're not coming any more. And not being able to, you know, do the things they used to, be that a hug or whatever.

You know, it is not possible for many people with dementia -- it will not have been possible for them to understand the rules and not possible for them to comply with the rules, though they would be potentially sanctioned for not complying with those rules.

And there are heartbreaking -- there's heartbreaking testimony that one reads from care homes and from people in their own homes about, you know, the difficulties caused by the entirely predictable cognitive impairment that people with dementia have, and a lack of ability to understand that on the part of the general public and respond to it on the part of services.

Q. One of the innovations that was put in place during the pandemic was the greater use of digital technology to try to compensate for some of these issues, and for many it was a very good innovation, but for others, and in particular those with dementia, you describe it as being a weak mitigation.

If I could just call up INQ000474426, page 20, paragraph 4.40, please.

This speaks to the experience of Arthur Argyle, a gentleman with dementia, who was described by his daughter Sarah as being visibly scared when using Facetime.

A. A cardinal element of having a dementia is the inability to learn how to do new things. You can remember stuff from ages ago, which means you can still have a great conversation about those sorts of things, but you can't learn new things. One understands why there was this switch to digital, and there were digital solutions, but actually, you need a lot of human help to be able to use a technology that you've never seen or used before. And that the sad reality is that -- you'd mentioned a weak mitigation, I think what we created is a set of digital, digitally-excluded people and that's not just people who can't afford the stuff, it's actually people who can't learn to use it. It's about people who are frightened by -- they don't know what these images are about or what they're for, they can't understand why there's somebody in that.

There are so many ways in which digital technologies can be really helpful for all sorts of people in all sorts of situations, and for some people with dementia,

there's some, you know, there's some nice examples of things that worked very well for certain people, but for a very large number of people with dementia, particularly those with more severe dementia, particularly those within care homes, you know, the answer to every problem being "Well, there's an app" is not an answer that actually helps individuals.

Q. And if I may turn to other challenges that care homes were facing, an English care home manager described residents with dementia as not understanding the need to stay in their rooms, for example --

A. Yes.

Q. -- but wandering. And that's also a theme that similarly comes through the Every Story Matters report --

A. Yes.

Q. -- with residents becoming very upset, explaining that: they did inform infection prevention control, who just basically said, well observe and what will be, will be.

Another account from Every Story Matters, a resident admitted with Covid in a dementia ward where everybody is mobile, everybody is moving around, and it spread through the home like wildfire.

And similarly in the corporate witness statement of Covid Bereaved Families for Justice, the experience of

Roy Staples, an elderly gentleman, spritely nonetheless, who took up dancing, having been inspired by Strictly, at the age of 84, was in a care home, his family had concerns about patients being discharged from hospital and in particular a new resident who had dementia and wandered into his room.

In terms of that wandering, does that pose particular challenge within this cohort and demographic of people?

A. So it does. Wandering is one of the behavioural problems that can develop within dementia, so it's not that people are, you know, purposefully seeking to invade other people's space or seeking to leave the home in a way that is dangerous. That is part of what happens in dementia, both wandering and getting lost, as well. And I mentioned earlier that it's quite difficult for people with dementia to learn the geography of a new home, if they are moved in their homes. So you would also have the confusion that comes from having no idea where anything is, and not being able to learn where anything is.

Now, of course, the way to mitigate this is to have sufficient staff around to be able to help individuals and to be able to divert people and to, you know, try and stop these things from happening. But again, it is

predictable that there will be such things and what you can't rely on is an individual understanding the rules and therefore complying with them, and it's not a wilful act, it's an act of -- (overspeaking) --

Q. It's a consequences of the illness.

A. -- and a consequence of the disorder. And if you feel agitated, then you may wander. If there are, kind of, wander pathways for you to go around outside the care home, that can be quite helpful. If all you can do is walk the corridors of the care home, that's more of a difficulty.

And a final issue with that is that quite often, the wandering happens at inconvenient times. There's a phenomenon called sundowning whereby people are more likely to be agitated or to wander at night rather than during the day when there is traditionally lower levels of staffing and therefore lower levels of being able to deal with that.

So yes, it's absolutely part of -- it's an absolute part of managing people with dementia and a predictable risk.

Q. Thank you.

Another aspect was the use of face masks. Just very, very briefly, it revealed that many people, actually, with dementia relied on lipreading but there

are also the lack of social cues, communication, and one recommendation you make is to consider the use of transparent masks in any future pandemic and indeed, that's something that's been acknowledged by the UK Government in guidance.

A. Yes, a lot of the cues that individuals will get are lost when you cover a substantial amount of the face, particularly the bit that smiles and has emotion associated with it.

Q. Thank you, Professor Banerjee.

You set out at length within your witness statement the impact on family carers and, indeed, you've covered it to some extent already today, so I don't propose to deal with that, save as to say that the impacts were, as you have already described, profound.

A. Profound and negative.

Q. Thank you. Then finally, in terms of recommendations, you similarly set out at the end of your statement a comprehensive list of practical and focused recommendations in relation to the pandemic. If I may, just because of the limitations that we have, just draw on one in particular, which would you say is the most significant and most important message to take away?

A. So if I may steal two, the first would be that we really do need clarity and specificity in communication that is

inclusive of dementia and that acknowledges the care home system as being, you know, of profound importance in dementia care and therefore having particular challenges. We needed that before the pandemic, we certainly need it now, moving into any future pandemic.

So clarity and specificity of communications is absolutely there. And that includes public messaging during pandemics. And that can be prepared beforehand.

Q. Yes.

A. And I think the other thing that I would say is that we've really got to have better, improved understanding and improving health and care professional attitudes and beliefs about dementia. We are running systems and services that fundamentally believe -- happily believe things that are not true about dementia, that it's an inevitable part of aging, that there's nothing you can do about it, that having dementia is worse than being dead in some ways. So what is the problem with all of this?

Those are the sorts of things that underpin the problems that we had in planning for the last pandemic, in dealing with -- with that pandemic and that continue to be a problem in the way that we provide services and would be a problem in the next pandemic. And there are good, clear, simple things that we can do in education

and training that would change that and it would change the system for the better for older people who are the main people who use health systems wherever, and would be the main people who are affected in any plausible forthcoming pandemic.

MS CECIL: Thank you, Professor Banerjee. Those are my questions.

LADY HALLETT: Thank you, Ms Cecil.

Mr Weatherby.

Mr Weatherby is just there, Professor

Questions from MR WEATHERBY KC

MR WEATHERBY: Good morning, Professor. I represent Covid Bereaved Families for Justice UK which represents bereaved families, including some of the families whose accounts were very helpfully put to you earlier.

I've got four very short and, I hope, very straightforward points to put to you.

At page 81 of your report, you refer to both inequality and inequity in the section dealing with care and outcomes. In Module 1, the Inquiry heard from Professor Marmot, who told the Inquiry that the word "inequity" was used to describe, and I quote "avoidable differences in health which are judged to be avoidable and are not avoided, are unfair, hence inequitable."

Am I right that you've drawn the distinction between

inequality and inequity in the same way?

A. I have drawn a difference between inequality and inequity. Professor Marmot has clearly been working on this his whole life. I have a more simple way of looking at it, which is that inequalities happen because there are differences and there are all sorts of reasons why there may be differences. Inequities are where there are difference that are not fair. Now, whether or not they can be addressed by different changes and addressed by that is a different matter but they are things there are not fair.

In dementia we have profound inequalities but we also have profound inequities also.

Q. Which can be changed or challenged?

A. There are things that one could do to address a number of those -- (overspeaking) --

Q. And is that why it is important to examine the care and outcomes for people living with dementia through the lens of both inequity and inequality?

A. Yes, it is. I mean, one of the major research projects that I lead is called DETERMIND and that is all about the outcomes of care and inequalities and equities in dementia care and outcomes. So yes, it is absolutely important to look at it through both of those lenses.

Q. Yes. In Module 2, experts on discrimination highlighted

a lack of research and data on the impacts of discrimination on particular groups, including minoritised ethnic communities and the LGBTQ+ community. Is this is an issue with respect to dementia research also?

A. It absolutely is. We've got far, far, far less research on people from minority ethnic groups and from LGBTQ+ groups. One of the -- that's one of the reasons why in my DETERMIND project, that I was talking about, has recently been funded to look specifically at those groups.

Q. Yes. Now, earlier you mentioned the statement of Katherine Lee from the Alzheimer's Society. I'm not going to go to that, the Inquiry has that, but do you agree with the Alzheimer's Society's recommendation for dementia-specific planning for future pandemics?

A. So I need to just reiterate my potential conflict of interest, as a trustee of the Alzheimer's Society, but yes, I do agree with that, there should be dementia-specific planning and that was one of the two things that I chose as the recommendation.

Q. Yes, indeed, I'm not going to go to them but I think there were six specific recommendations. But the bottom line is there needs to be proper pandemic planning for -- that includes -- specifically includes dementia.

A. People with dementia are predictably a group that will be disproportionately -- that could be disproportionately affected by any future pandemic, and are certainly a very high-risk group, and so you would expect that group to be part of planning.

Q. Yes.

Final point. In a footnote on page 15 of your report you say:

"... it is remarkable how little things varied across the UK for people with dementia and their family carers. Wherever one lived things were very difficult indeed."

And I think you've repeated that in evidence this morning.

In Northern Ireland, the system is one of integrated health and social care, and this is sometimes held up as an advantage because the particular position and vulnerabilities of people in social care can be integrated into decision making.

Given your evidence, would you agree that you've found no evidence that the integrated nature of the health and social care system in Northern Ireland had an appreciable difference in terms of outcomes for people with dementia and their families?

A. So there's relatively little research that looked

specifically at the Northern Irish context, and enabled us to be able to care between places. But if you look at an indicator like mortality, there's very little variation across that, and certainly there are -- there is evidence of people in each of those areas having difficulties and problems.

Integration is a problem, and also a set of -- really an -- interesting possibilities for improvement, across our health and care systems.

MR WEATHERBY: Indeed.

Thank you very much, Professor.

LADY HALLETT: Thank you very much, Mr Weatherby.

Mr Stanton.

He is right over there, Professor.

Questions from MR STANTON

MR STANTON: Thank you, my Lady.

Good morning, Professor.

A. Hello.

Q. I ask questions on behalf of the Covid Bereaved Families for Justice Cymru. I just have one question. It relates to one of the recommendations with your -- within your report, that the care home sector needs to be involved in emergency planning in the future.

A. Absolutely.

Q. Something which you've just touched on in your answer

with Mr Weatherby.

Given it was well known that care homes -- care home residents are particularly vulnerable to a pandemic event, again as you described fully earlier, are you able to offer a view as to why the sector was not properly engaged prior to the Covid-19 pandemic? It seems such a glaring and obvious omission.

A. Well, I can think of at least two things. The first is that health systems very often forget care systems, and that is a major problem and they're often seen as a lower priority, and as different. And we need to be -- we need to get rid of that distinction. It's a system -- one bit cannot live without the other bit, and we're seeing that in the pressures in general hospitals today.

I think the second reason, a second reason is potentially that the -- the care system is often perceived as being provided by independent companies, and therefore you can't deal with it because it's lots of different little bits and it's very difficult for you, therefore, to get information or whatever. And I think one of the papers submitted on Operation Cygnet or whatever suggests that.

I agree that it is difficult, potentially, to get information, but it's such a critical part of the system

that actually just because it's difficult should not be a reason not to do it.

And a third -- sorry, half of the money that care homes are provided with in the UK is money that comes from local government. It is essentially governmental money that gets paid to them. The ability to stipulate that information should be given should be part of that process, and therefore one could more meaningfully involve care homes.

MR STANTON: Thank you very much.

LADY HALLETT: Thank you, Mr Stanton.

Ms Jones, who is just over there. Sorry to point to everybody.

Questions from MS JONES

MS JONES: Thank you, my Lady.

Thank you, Professor Banerjee. I ask questions on behalf of John's Campaign, The Patients Association, and Care Rights UK, all of whom work extensively with people with dementia and their family carers.

You've said in your evidence today and in your report that government guidance was confusing and clearly not prepared with people with dementia in mind.

A. Yes.

Q. I'm sure that links to the recommendation you highlighted about the need for clearer communication in

future.

In your view, what difference might it have made if government had consulted with people with dementia or their family carers or representative organisations before producing the guidance?

A. Well, had they done that, they would have had a better idea of what the potential challenges are, and you would have hoped that the information would have been more comprehensive and also more inclusive of people with dementia.

One of the main problems is that people with dementia were not mentioned in any way in anything for quite a while in the pandemic. And had they been included, it is likely that there would have been a better and more effective advice in terms of helping people with dementia.

Q. Thank you.

You've also said in your evidence today that you can't underestimate the value to a person with dementia of visits from a person they know and love, and I know that's a position that those I represent would strongly endorse.

And you've also addressed the many negative impacts that people with dementia and their family carers suffered by the exclusion of visitors and carers from

care settings.

You may be aware of the ongoing campaign for a statutory right to an essential care supporter, sometimes known as Gloria's Law, through which people would, in all circumstances, have a legal right to the presence of a chosen care supporter who could be with them, advocate for them, and provide them with individualised care and support, regardless of the care setting that they live in.

In your view, what difference would a legal right of this sort of have made for people with dementia during the pandemic?

A. That's a difficult -- I mean, so, firstly, there is no data that I have available for me to be able to make that, so it would simply be an opinion that I would be giving on that.

I think that if people with -- if people during the pandemic had had more access to their main family carer and had been able to see those individuals, then their quality of life would have been better, and it is likely that their -- that the progress, the negative progress of their illnesses may have been mitigated. So it would have been better for the person with dementia.

If those individuals were in care homes, for example, it is likely that those individuals would have

been more easily managed and more happy and contented within the care homes, and therefore required less care. So it would have been good for those care homes. And one could imagine the same things pertaining within general hospitals also.

MS JONES: Thank you very much, Professor.

Thank you, my Lady.

LADY HALLETT: Thank you, Ms Jones.

That completes the questions we have for you, Professor. I'm sure there are many very distressing aspects of medicine, but yours, I suspect your specialty is particularly distressing for some, who aren't used to it.

Do you find any difficulties in recruiting people to your specialty?

THE WITNESS: So, yes. And we do because -- and that's one of the problems about there being societal and professional prejudices against older people. When people come into medical training and nursing training and other things, they have quite a low level of enthusiasm and positivity and knowledge and -- about working with older people and working with people with dementia. When they leave training, they have even lower levels of positivity, even though 75% of the people that they're going to be dealing with are old and

frail, because that's the nature of the hospital population.

The thing that -- it can be depressing and difficult, but it can be immensely exciting working out how you can try to deal with these things in order to make things better. So one of the things that I refer to in the report is a programme that we generated, which is now being rolled out across the whole of the south of England, which basically -- it's called Time for Dementia. People -- students meet a family with dementia. They work with that family, they are taught by that family what it's like to have dementia, over a two-year period. They start to identify with that family, and they end up with much more positive ideas about older people, much more positive ideas about what family carers do, and they end up as little change makers who want to make sure that the system is not -- the system is changed so it is more positive for people like their family.

So that relational learning can make a big difference. There's things that we can do to make this better. They're not being done at the moment; they need to be.

LADY HALLETT: Thank you very much indeed, Professor. By the sounds of it, they may be little

change makers but if you have your way you're going to be a big change maker, so I wish you luck.

THE WITNESS: There's a lot of change that needs to be made, but thank you.

LADY HALLETT: Thank you very much for the help that you've given to the Inquiry and for the work you're doing so far as dementia sufferers and their families are concerned. Thank you.

THE WITNESS: Thank you very much.

LADY HALLETT: Very well, I shall return at half past.

(11.15 am)

(A short break)

(11.31 am)

LADY HALLETT: Ms Shotunde.

MS SHOTUNDE: My Lady, please may I call Cathryn Williams.

MS CATHRYN WILLIAMS (sworn)

Questions from COUNSEL TO THE INQUIRY

LADY HALLETT: Thank you for coming to help. I hope we haven't kept you waiting for too long.

MS SHOTUNDE: Can you please confirm your full name.

A. My name is Cathryn Williams.

Q. And thank you for providing the Inquiry with your witness statement dated 16 August 2024. And for the record, that's INQ000571608.

I'm going to just briefly ask you some questions

about your professional background and then I'll give you a moment to give some preliminary remarks.

So you were previously the chief executive of the Association of Directors of Adult Social Services.

A. Yes.

Q. And you held this position between January 2015 --

A. Mm.

Q. -- until June 2024.

A. **(Witness nodded)**

Q. You have previously worked for the Local Government Association, as well, haven't you?

A. Yes.

Q. And prior to that, you worked as a director of social services?

A. Yes.

Q. So therefore, in terms of your chief executive role in ADASS, which is what I'll call it from now on, you were in post at the time of the pandemic.

A. Yes.

Q. Now, I understand there are some brief preliminary remarks that you would like to make. Please feel free to do so now.

A. Thank you. So first of all, I'd like to express sorrow for everyone who died needing social care and support during the pandemic. There were tragic mortality rates.

I also want to pay tribute to the paid and unpaid carers who did so much, and again, there were disproportionate mortality rates amongst care staff and social workers. And finally, I want to pay tribute to everyone who worked excessively long working days for months on end trying to address the issues that were before them.

Q. Thank you.

So the Association of Directors of Adult Social Services, it's a charity whose members are current and former local government directors of adult social services; is that correct?

A. Yes.

Q. And its objectives include furthering comprehensive equitable social policies and plans which reflect and shape the economic and social environment of the time, furthering the interests of those who need social care services, regardless of their background and status, and promoting high standards of social care services; is that correct?

A. Yes.

Q. In terms of the role of directors of adult social services, am I right in saying that they are responsible for leading, commissioning and delivering adult social care work and social care in local authorities?

A. Yes, in England.
Q. Thank you. Their remit includes older and disabled people, people with learning disabilities, unpaid carers, people with mental ill health, and those needing care and support who are experiencing abuse and neglect; is that right?
A. Yes.
Q. And state-funded adult social care services support over 1.1 million people in England; is that right?
A. Yes.
Q. I'm going to ask you some questions about pre-pandemic planning. Now, there was some work undertaken by ADASS, commissioned by the UK Government on future pandemic planning.

If we could just turn to your witness statement, that's INQ000571608, page 25, paragraphs 7.2. If we could just scroll up a bit please. Thank you.

So for that work that was commissioned, there were a number of reports that were produced by ADASS prior to the pandemic, and I've got them listed up here, such as:

"Key message from the survey of Directors of Adult Social Services ...

"Critical information and data needed for [Directors of Adult Social Services] and local partnership decision makers to plan for and make timely and rational

decisions about the reprioritisation of services ...

"The Communications and Support Infrastructure ...

"Recommendations on regulatory and process easements that Directors of Social Services require ..."

And:

"Proposals to support local areas to prepare now for a future pandemic."

Did the work identify any gaps in pandemic planning for the adult social care sector?

A. So we produced reports for each of those sections that you have in front of you. And we also produced a guide for directors of social services, and I will refer to them as DASSs from now on. Apart from the guide for directors, which we distributed to our members across England, the other reports all went into the Department of Health and were, in effect, private reports.
Q. Did -- sorry, go on, please.
A. So we did, in our guide for directors, identify a number of recommendations for people locally, our members, and we also identified a number of recommendations for the Department of Health, many of which were in the separate private reports.
Q. And I understand from your witness statement that, other than the guide for pandemic flu planning for directors of adult social services, ADASS, and yourself

particularly, were unsure what use the Department of Health and Social Care had for these -- (overspeaking) --
A. No, we do know that during the pandemic, for instance, when we were talking about Care Act easements, that Department of Health civil servants mentioned that they'd been looking at the plans, but whether they'd looked at them prior to the pandemic, I couldn't say.
Q. Do you think some of the work on easements may then have been used in the pandemic in this instance?
A. I think it was. I think the fact that there were easements probably demonstrated that. But I'm very conscious that, whilst we were doing the pandemic flu work, we had anticipated that social care wouldn't be able to deliver all of its responsibilities because of staff shortages, and we were working on there being 20% of staff not being -- not functioning.

But we hadn't really anticipated that other sectors, like hospitals and schools, also wouldn't be able to fulfil all their duties.
Q. So essentially you were looking at it from one perspective --
A. Yes.
Q. -- but you weren't considering all the other sort of services, public services, that went down as well?

A. Yes.
Q. In terms of pandemic planning, who or which organisation was previously responsible for checking the adequacy of pre-pandemic planning in the adult social care sector?
A. So, to the best of my knowledge, there wasn't anybody, either nationally, regionally or locally.
Q. And just so I'm clear on this, this is also -- this is including all planning, so planning on the local authority level and also planning on the provider level; is that right?
A. Yes. To an extent, the work that we'd done on Brexit, which was led and closely monitored by DHSC, had looked at things like staffing, supplies, fuel, transport, but it hadn't looked at the infectious nature of a pandemic.
Q. Do you think there was a role for local authorities in respect of pre-pandemic planning, other than of course its own plans?
A. Well, local authorities and social care providers have the unique knowledge about how care works on the ground. So certainly, pandemic planning is necessary, whether that's for tomorrow or 20 years' time. Whether -- I can't answer the question solely in relation to local authorities. It's -- clearly involves many more people.
Q. And prior to this pandemic, other than the work that was commissioned by DHSC, was there any other role that

ADASS had in pre-pandemic planning at all? Guidance that was provided for local authorities, for example, or anything like that?

A. We weren't part of Operation Cygnus, if that's -- if that's what you're asking me.

Q. So, in evidence last week, Michelle Dyson told us that in February 2020 there was a plan to revise local authority plans and that the Minister for Social Services wanted to see a copy of a good local authority plan so that it could possibly be replicated across other local authorities.

And in evidence, it was noted that at a meeting, that the Local Government Association and ADASS did not have the assurance skills to do -- to review plans, but that they might be able to help make a checklist with questions to ask when checking the plans are fit for purpose, so that local resilience forums can be confident.

Is there a greater role that you think ADASS could undertake regarding pre-pandemic planning to assist local authorities?

A. Well, I think that we can certainly contribute the experience of ADASS members of the pandemic to future pandemic planning, definitely. And certainly with our partners in -- care providers and others, I think that

would be essential.

Q. And in evidence last week Helen Whately suggested that the CQC could check whether providers have got pandemic plans. Do you agree with that suggestion, that that's something that the CQC could check?

A. So I have consulted with someone from the CQC about that, and apparently in the regulations there's no explicit requirement for providers to have pandemic plans, although they do have to have contingency plans.

I think the view is that there could be a case -- it might be possible to do it at the point of registration, and at the point of inspection, but to ask the organisation to assure 18,000-odd pan flu plans would be -- in one go would be unrealistic.

Q. Just so I've got it correct, there was no requirement in the regulations for care providers to have specific pandemic plans, just contingency plans?

A. There's a requirement for them to provide safe care, which might incorporate that, but not specific pandemic plans, to the best of my understanding.

LADY HALLETT: Well, that depends on one's definition of contingency, doesn't it?

A. Of course.

MS SHOTUNDE: Which body do you think should be responsible for assuring the plans, making sure that they are fit

for purpose? If you think there is any. If you think they should be done at all.

A. So possibly a combination of CQC with social care expertise, public health, and some representation from an organisation like ADASS in a sort of panel system. Perhaps not every single plan, but some kind of selective process.

Q. Do you think there were any other organisations that should be consulted or involved in planning? So, for example, representative bodies of care providers, recipients of care or unpaid carers.

A. Definitely. I think the interface with local resilience forums is a critical one as well, and it was -- the juxtaposition of local resilience forum, NHS structures and local authorities, together with national organisations, was -- worked sometimes very well, particularly where there was coterminosity, like in London, but was inherently problematic for some other DASSs.

Q. Other that regulations, how else do you think pandemic planning can be embedded into care providers? Is there a role that you think the local authority could or should play in respect of that, and in particular in respect of the services that they're commissioning?

A. So, prior to the pandemic, I think none of us had an

idea of how difficult a pandemic and how disastrous a pandemic could be. Now we do. And it's probably important, while there is still a degree of freshness in people's minds, to look. And certainly local authorities and others would have roles in that.

Q. Do you think that providers' pandemic preparedness should be a factor that influences local authorities in respect of which providers they should be commissioning services from?

A. So, local authorities will want to take a number of things into account, and that could be one of them. However, I think the real challenge is marrying up the underlying fragility of providers in terms of their ongoing work with requirements to make robust plans for the future, and there is a significant gap in many instances between that.

Q. Thank you.

In respect of key decisions that were made by the UK Government, you've stated in your statement that acute and intensive healthcare needs were the focus of decision making during the pandemic.

Was there any focus on the adult social care sector at all? And if so, when do you think that focus started?

A. So in my witness statement I describe social care as

being an afterthought. I think that there was probably -- there could have been a degree of knowledge that we weren't aware of, and it was a deliberate decision, as the then Secretary of State has said, to make the least worst decision making, and I couldn't comment on that, but it certainly felt as though decision making for social care came afterwards and once we, with all our partners in the sector, were alerting DHSC and senior politicians to the actual impact of the pandemic on people needing and working in social care.

Q. In your statement you mentioned that there was a lack of understanding by the UK Government of the adult social care sector in England. How do you think the lack of understanding impacted the UK Government's response to the pandemic?

A. So, the hospital discharge decisions were an obvious one. Decisions around testing for social care coming afterwards. PPE, more or less all of the protections were secondary, and more complex for social care across such a diverse sector. I think there were also issues about status, inequalities, the care workforce being very low paid and account not having been taken of the complexity of giving them time to get PPE, tests, vaccinations, and the fact that if you work in a hospital it's relatively easy to go to a room and get

a vaccination, whereas you're talking about thousands and thousands of people sometimes travelling two hours.

I think that there was very little understanding of the size and the number of people working and needing social care, and actually the workforce was larger than that of the NHS. And the complexity and wonderfulness, really, of what family and unpaid carers contribute to keeping us all alive and working and living.

Q. An example you used was the decision to discharge patients from hospitals into care homes without testing. I want to ask you some questions about the Prime Ministerial meeting on 18 March 2020, and for your reference, in your statement it's paragraph 8.2.

In your statement you note that there was a Prime Ministerial meeting on 18 March at which ADASS attended, and you state that:

"... the principal discussion in relation to social care was its role in assisting the NHS with discharges, but which did not address social care concerns about the safety and resilience of its main services, and its capacity to undertake the discharge task."

And in an email, which I won't pull up on screen, but it was from James Bullion to you and others, summarising the meeting, he states:

[As read] "Complete focus on assisting the NHS and

acute hospitals, in particular the 30,000 discharges, not for reasons of politics but because it is health collapse, that is what is killing people in Italy."

At the time do you think that was the right approach by the UK Government, the focus on hospital discharges, because it's a health collapse, and this is what they saw in Italy?

A. So I completely understand the anxiety about acute hospitals and intensive care, and recognise that, but in other parts of my submission in the witness statement, I did make representation that, actually, you can't just look at acute hospitals; you have to look at the whole health and social care system and its capacity and resilience, and I also felt very strongly and mentioned that it was necessary, it should be looked at, the NHS community, primary, and mental health capacity, as well, because they sit so closely with social care.

Q. On that point, I'm going to ask for your statement to be pulled up on screen.

That is INQ000571608, paragraph -- so page 51, paragraph 12.14. Just take a moment because I'm skipping. Okay.

At this paragraph you've stated that:

"In the afternoon of 16 March ... [NHS England] (with DHSC copied in) asked ADASS to comment, within an

hour and a half, on the draft hospital discharge guidance," and that it was shared that evening with ADASS trustees, and on the morning of the 17th, you returned initial comments.

And those comments include that it:

"... only looks at discharge and unless you look at the capacity of the whole system -- including primary, community health care, social care and the inevitable additional needs if unpaid carers cannot function, then there is a serious potential to make things worse."

You also state that:

"There were ... a range of comments about increasing care in the community, for rehabilitation and reablement ... [and] that care homes might not be the best place, in a pandemic due to [the] risks to others ..."

And you emphasise that people needed information.

You also state you don't believe that many of the comments were incorporated into that discharge guidance. Did you receive any feedback from the UK Government about this?

A. I received feedback from one civil servant in DHSC who stated that social care would be looked at at a later date.

Q. Do you think that, with time, there was any work done by the UK Government to mitigate or alleviate any of the

concerns that you raised?

A. Well, certainly around that period there was an intensive amount of work undertaken, not just in relation to hospital discharge, but the growing awareness of transmission and its impact. And certainly, the work that was going on across DHSC, ourselves, care providers, the Care and Support Alliance, which included carers and Age UK and organisations like that, started to ramp up very, very significantly.

Q. So the response that I've read out in the paragraph 12.14 was actually from an email, and I'm going to pull that email up now, please.

It's INQ000103763, page 2.

The last substantive paragraph, which starts with "Secondly", you state that:

"... this is ostensibly a 'systems' message -- though actually it reads as a directive from NHS [England] to social care. Social care is part of the system. It hasn't been co-produced. I have already had email heat from people alerted to at least one webinar for NHS staff. There are 22,000 social care providers. Communication in this form is like to cause chaos which is the absolute last thing we need right now for local systems."

Do you feel that that was the overall culture when it came to hospital discharges during the pandemic? Did it feel like it was a directive from the NHS to the adult social care sector?

A. So, yes, the systems were there for the NHS, and they weren't there in terms of systems and infrastructure for social care.

There was also a habit of NHSE sending out letters that were addressed to trust chief executives or primary care, and also to either directors of social services or to chief executives of the councils. But there were no addresses. So we often heard from our members that they'd been shown an email from NHSE by one of their NHS colleagues locally, but we weren't aware of it.

And we'd offered to NHSE to distribute such communications if they'd wanted us to.

And that email was rather more abrupt than I would normally have been, but it was done in great haste.

Q. It was. In a note here, you say:

"Unfortunately we couldn't meet your (unreasonable) requests for comments within [the time]", et cetera, et cetera.

Now, we've heard numbers of concerns from various witnesses about the hospital discharge policy and, in particular, issues in respect of how the adult social

care sector could deal with that, with the lack of PPE, testing, et cetera.

If I could pull up your statement.

That's INQ000571608, page 53, paragraph 2.21, please.

I just want to ask you about a particular point that is here. You state that:

"On 31st May we responded to an enquiry from a DLUHC civil servant about rapid hospital discharge."

And your response in the email chain includes the first paragraph, but on the second paragraph you state:

"As hospitals emptied, many to 55% occupancy at one point, some local systems made their own local arrangements not to further discharge people to care homes that couldn't isolate and didn't have PPE. We heard of other hospitals continuing to discharge rapidly."

So, as I've mentioned previously, at the beginning of the pandemic there were concerns regarding the ability of care homes to be able to look after residents, both coming in from hospital and also their current residents, due to lack of PPE, testing, et cetera.

In this context, do you think that rapid discharges from hospitals to care homes should have continued to

take place when occupancy rates in hospitals were low?

A. So I understand the anxieties, and work closely with people in acute hospitals, so I completely understand their anxieties about treating people and retaining capacity. But certainly, rapid discharge without consideration about whether the environment that people are going to is suitable, whether it's safe, whether they actually wanted to go there, and certainly our work on discharge to assess, as the following paragraph highlights, had worked on the model that 95% of people would go home, that there'd be reablement and rehabilitation to enable people to get back on their feet, and at least that people, even if they needed long-term care, would have had the time to consider which options were right for them and whether they could afford them, whether they were suitable, and so on.

Q. And before we go on to that paragraph 3, which I will ask you a question about, do you think that consideration of the ability for local care homes to safely care for residents should be factored into decisions on discharge and especially when occupancy rates in local hospitals are low?

A. Absolutely. And their capability and whether they're the right place for people, because one care home is very different from another, and there are other

options, as well as care homes.

Q. Now, you mentioned the discharge to assess model, and the fact that the discharge plan describes 95% of people going home, 4% of people to reablement, and 1% of people to nursing care, and you state in this email that you've heard of 30% going to nursing homes in one area, but you state that that might not be at all typical.

Overall, do you think that this particular aspect of the discharge plan, the amounts of people that are supposed to be going to their home, nursing home, and reablement, do you think that was largely followed during the pandemic or do you think it was a bit of a mixed picture?

A. I don't think we had evidence that it was and certainly we raised that concern with DHSC and with NHSE. I think the function that social workers had in hospital was to have a conversation with individuals about what would be right for them on discharge from hospital so -- or their representative, if they lacked capacity to make such decisions.

I think the anxiety about getting people out quickly and the fact that Capacity Tracker was a model whereby -- and was advertised by NHSE as a model whereby trusts could discharge people to care homes and, indeed, care homes were invited to advertise vacancies, made that

a route for people that was more convenient for hospitals than was necessarily right for the individuals concerned, and their families.

Q. In Michelle Dyson's evidence session on 16 July, she was asked questions about discharge into care homes that were rated as inadequate and specifically whether the Department of Health and Social Care knew how many people were discharged into care homes, that were considered inadequate.

She confirmed that the UK Government did not know how many people had been discharged into care homes rated as inadequate. However, she also said that in this regard, local authorities have an important role as they have statutory duties regarding their local care markets, there might be issues that local authorities are aware of, but the CQC are not, and that where the CQC is aware of the issues, local authorities may have undertaken their own assurance checks to make sure that those issues have been resolved.

Do you think there is a role for local authorities in either ensuring or monitoring the people discharged to care homes rated as inadequate by the CQC?

A. So prior to the pandemic, we had worked with CQC and DHSC, and organisations of people with disabilities and older people on quality matters. In that, we took away

two recommendations which we communicated with our members. One was around using data in relation to quality, and the other was in relation to not taking up new contracts for people with services that were rated inadequate. And particularly in the context of hospital discharge, clearly many of the people discharged from hospital had more intensive needs than they might have had otherwise, and we had a point of view that "inadequate" might indicate that providers might be unable care for the people they were caring for already.

Q. I'm going to ask you a question about the designated settings policy.

If I could just pull up a document. It's INQ000514882, page 4.

I believe these are minutes of a meeting, and in respect of designated settings, the second bullet point:

"... there were challenges in finding suitable premises/providers, getting CQC approval in a timely [manner], and a difficulty for providers in obtaining insurance. The scheme to support this was cumbersome and often not used. Designated settings were expensive, late in the process, and not all capacity was used."

Did ADASS support the designated settings scheme and if so, why?

A. We contributed and were present at meetings where it was

discussed. I remember personally asking Jenny Harries more than once whether there was evidence that this would provide better outcomes by way of infection control. I don't think that she was able to respond then and I don't know whether that's -- any research has been done since.

I do think that the principle of asking people whether they think that the risk of getting an infection during a pandemic is more important to them than the risk of not having contact is very important, and I know providers bent over backwards to try to make safe areas, such as they could within care homes, and that homecare providers did absolutely the utmost they could in relation to going to home to home.

I think in principle, to refer back to what you were asking originally about the discharge plans, our understanding in the early meetings was that NHS would be supporting people who had tested positive, and that clearly didn't take shape in the actual discharge guidance that was produced, and was challenged later.

As I say, I think there is a notion of trying to introduce some form of choice for people and if that needs to be in a separate establishment then I can see the justification for it, but of course another pandemic might be transmitted in very different ways. So, yes.

Q. And just on your point on your understanding on the early meetings that the NHS would be supporting people who had tested positive, how were they supposed to, or, you know, suggested to have been supporting people or should have been supporting people at the time?
A. So the original suggestion, I think, was in community hospitals or in the Nightingale hospitals.
Q. Yes. So, in respect of the designated settings policy, and in particular, where local authorities had to provide a list of care homes that had the ability to take on Covid positive patients, would you support a similar scheme in the future?
A. If the context is right.
Q. You may not be able to answer this, but do you think that that scheme, when it was up and running, was successful?
A. It's difficult for me to say, because it was up and running quite late in the progress of the pandemic. Perhaps, if it had been up and running sooner.
But of course, if you were to establish something from scratch, unless the country has addressed the issue about workforce, that would be very difficult to set up.
Q. So do you think, in respect of pandemic planning, the concept of designated settings should be included in that, so that if there was a future pandemic, it could

be started up quite quickly?
A. The concept where there is a place for people to go who need care and support, that minimises the risk of infection, is definitely a sound one.
Q. I'm going to ask you some questions about visiting restrictions, and I'm going to just hone in on the issue of blanket bans, on restrictions of visiting by local authorities and other organisations.
Were you aware of those taking place?
A. I wasn't aware of blanket bans by local authorities. I'm aware of some localised bans where there were local outbreaks by health protection and public health teams because of community and other issues or local outbreaks in homes.
Q. Do you know if directors of adult social services were involved in decisions on blanket bans?
A. Not to my knowledge.
Q. So you think it was more of a public health sort of decision but on a localised level?
A. So I think that some care homes took their own decisions to ban visitors based on anxieties about transmission. But as I say, I'm not aware of directors being involved in those decisions. Though no doubt their local director of public health would have been in dialogue with them.

Q. I'm going to move on to ask you questions about restriction of staff movement between care settings. What did ADASS think about the concept of restricting staff movement between care settings?
A. It makes absolute sense in an ideal world. In the world we were living in, care staff were, as you know, low paid and often dependent on more than one job to put food on the table.
So issues like staff pay, furlough, or compensation for not doing more than one job was absolutely necessary, as well.
Q. Do you have a view, or does ADASS have a view, on whether there should be legislation restricting staff movement?
A. Well, it should certainly be discouraged, and could be part of a new deal for care staff, positively. Whether it should be legislation, I'd need to consider more, and I would need to be in discussion with more people about that.
Q. And I presume from what you've said previously, you'd also want to ensure that proper remuneration is in place for the care staff? Is that a yes?
A. Yes, that's a yes.
Q. Thank you.
If I could ask you some questions about Care Act

easements. What, if anything, did ADASS or the -- oh, gosh, I can't remember the name of it, give me one second -- the National Advisory Coronavirus Group -- what, if anything, did ADASS or the National Advisory Coronavirus Group do to assess the impact of Care Act easements on people in need or in receipt of care and their family members?
A. So NCAG, as we referred to it as, commissioned Think Local Act Personal to do a review of the Care Act easements, and they talked to those who had enacted them, and people involved in their local areas, including disabled people's organisations.
We had also decided that we would ask our members more about the impact they'd had, both those DASSs who had enacted them but also a wider group of directors.
Q. And I believe that ADASS produced a document called *'Themes and Learning from ADASS Members on the Local Response to COVID-19 in Spring and Early Summer 2020',* which discussed the use of Care Act easements. And it's clear from that document that they were not used to a great extent. My understanding is around eight out of 151 local authorities used Care Act easements during the pandemic.
Do you think Care Act easements would be necessary in a future pandemic, given that they were not used to

a great extent in this pandemic?
A. So I think that the fact that there were amendments to legislation in relation to social care and not in the same way to schools or hospitals or other public services meant that it was possible that disabled and older people needing care and support felt that they were unfairly singled out in terms of their rights having been reduced.

I think that the -- there is a very painful juxtaposition for us as an organisation in relation to the easements, because we had been reporting via our members surveys for many years on the lack of confidence that our members felt in delivering their statutory duties, and that continued, and worsened, during the pandemic.

So I think that it caused a great deal of distress for directors not to be able to deliver the Care Act and Mental Capacity Act, because they were felt to be good legislation.

I think there would be -- need to be a -- I think what I'm saying, briefly, is there would need to be a broader look at how public services function rather than just social care in the context of another pandemic.
Q. And the Inquiry has heard some evidence where people

have, and organisations have, alleged that local authorities -- some local authorities did not invoke Care Act easements but reduced services or acted in a manner with which they should have declared that they were invoking Care Act easements.

The Inquiry has also heard that some local authorities were using flexibilities in the Care Act to provide less services without turning on easements. Was ADASS aware of this, and if so, how widespread was this issue?
A. So to answer you, I think that councils and DASSs had for many years been considering how they were able to enact the Care Act and deliver rights to people, and that they had, certainly our members had an impossible, in my view, job to do in terms of balancing the number of people to whom they provide care and unmet needs, the price that they paid to providers, the quality and the choice that they were able to fund and facilitate, and to balance as part of councils, to meet their legal requirement to balance their budgets. I think that's a very difficult equation to make the right decisions on, and I think that people were having to flex over a number of years, and the pandemic certainly made that worse.

I don't -- I'm a hundred per cent confident that

nobody did that maliciously or in an underhand way. They were simply trying to juggle the staffing and the resources that they had.
Q. What, if anything, did ADASS do to ensure that the system of easements were being used correctly by local authorities?
A. Sorry I didn't hear the middle bit of that.
Q. What, if anything, did ADASS do to ensure that the system of easements were being used correctly by local authorities?
A. So we had regional structures and met with our regional chairs regularly, and within our regions there was a degree of both support and challenge for each other. And we regularly communicated with our members but it wasn't an assurance process.
Q. If we have a future pandemic and if we have Care Act easements in it, would you agree with the suggestion that the CQC should monitor the use of Care Act easements in a future pandemic?
A. It's possible. I think the people who did use the easements were intensely scrutinised both by DHSC and rights groups, and locally, and some described it as bombardment when they were trying to juggle the actual impact of the pandemic, as well.

Again, there's a context, isn't there, about do you

do this just for social care or do you do this elsewhere? And certainly there's a role for all public services to be challenged in crisis.
Q. But during this pandemic was there a mechanism where recipients of care and their family members could complain about the use and impact of easements during the pandemic?
A. So there wasn't a single process but certainly the existing procedures remained in place, and certainly locally, I know there was a lot of discussion with Disabled People's Organisations. But I'm also very conscious, having worked in social work and social care, that it's extremely difficult for people who are frail, isolated, excluded, or, as -- not everybody clearly in receipt of, drawing on social care, is in that position. Some are very much not. But it's very difficult to engage with complaining.
Q. So my next question is, do you think there should be a specific mechanism for recipients of care or their families to be able to complain about the use of easements in a future pandemic?
A. It's difficult for me to answer that one specifically. People should always be able to make representation, of course.
LADY HALLETT: It's also another possible way of draining

the local authority resources in responding to individual complaints at a time when everyone is under enormous pressure. It's a really difficult balance, isn't it?

A. Yes.

MS SHOTUNDE: I'm going to ask you some questions about infection prevention and control and in particular PPE. And I'm just going to hone in to the initial, sort of, drops of PPE.

If I could just pull up your statement, that's INQ000571608, page 63, and paragraph 14.3.

You state here that:

"The initial drop to [local resilience forums] was inadequate; they were the wrong mechanism for social care in a period of prolonged emergency, though possibly the only option at the time."

What would have been a better option, do you think?

A. So I think in conclusion to my thinking in relation to pandemic, not just in relation to PPE, but also in relation to testing and planning and responding, that there needs to be a significant review of how LRFs sit alongside NHS structures and government infrastructures, and the Inquiry's report to the first module, which set out what I think you called the spaghetti diagram, just demonstrates absolutely how well and how disconnected

social care was from that, compared to the direct lines of the NHS.

So I would suggest that there's a review of that, and how national systems, regional and local systems, work together, because LRFs are composed of individuals who have big full-time jobs and can respond to short-term emergencies but clearly it was an unrealistic expectation that they could do that over a long period of time.

Q. And later on in your statement you state that work was undertaken to address the issues in respect of PPE provision. How successful was the national supply mechanism of PPE during the pandemic, in your view?

A. Eventually, when it became functional, I think that it was extremely appreciated by directors, by care providers, by unpaid carers and by personal assistants but it took a long time to get established -- understandably, because part of the challenge, of course, at that point of time, was global supply.

Q. And speaking of unpaid carers, what efforts did local authorities undertake to ensure that they had access to PPE?

A. So the supply of PPE to unpaid carers came later in the day, in line with guidance. And I know that councils made very big efforts to remain in touch with carers and

to support them in such ways as they were able, but I'm also aware that many carers were behind closed doors and unknown. So I think the issues were similar to other forms of support and protections.

By the time of vaccinations, we and carers organisations had managed to imprint the significance of unpaid carers, such that we were able to advocate for, and contribute to, the standard operating procedure for vaccinations for unpaid carers. But again, that took a while to get under way.

Q. My understanding is that data in respect of unpaid carers, who they are, where they are, is not complete. Is there sufficient information today -- because I know there wasn't enough in the pandemic -- for local authorities to be confident that they know as many unpaid carers in their areas as possible? And would be able to provide PPE for them in the future?

A. I'm reasonably confident, though I'm speculating, to say that they wouldn't know who all unpaid carers are, and I'm also reasonably confident that there are people in this room and listening to this who wouldn't identify themselves as an unpaid carer, and some people would be very grateful to be identified in one form or another. Another would feel -- others would feel that it's an intrusion.

So, in terms of data, I know that ADASS members did an awful lot of work to put together the data that GPs had, which was patchy, their own data about where carers had been in contact, and data from local carers' organisations, but again, that would only be a proportion of the numbers of people caring in the community.

Q. I'm going to ask you some questions about funding during the pandemic and in particular the Infection Control Fund and other funding that the government gave to support local authorities and care providers.

We have heard evidence from witnesses, including the National Care Forum, who have stated that there were difficulties in the funds reaching the front line, reaching the care providers, and that happened not just at the beginning, but it also happened with the second tranche of funding.

Was this is an issue that you were made aware of during the pandemic?

A. So we were working closely with the Care Providers Alliance association and others right the way through and prior to the pandemic, and so we were aware of the context. Of course the initial funding for councils was to spend at their discretion, albeit that care provision was expected to be a part of that, that councils were at

that point in time covering shielding and rough sleeping and various other initiatives as well.

Certainly we heard from our members and from our care provider colleagues that the requirements of the grants were making things slower than they might otherwise have been.

Q. And if I could just pull up on the screen INQ000587670, page 76 -- sorry, page 86, paragraph 361.

This is a statement from the Homecare Association for Module 6 in which they state that:

"75% of the Infection Control Fund went to care homes. Local authorities distributed the remaining 25% based at their discretion. Homecare services received roughly half of the remaining 25%. Some local authorities gave none of this funding to homecare. Others gave it only to providers who contracted with them."

Were you aware of issues with domiciliary care providers receiving funds during the pandemic?

A. So we were very conscious of domiciliary care providers generally, in that there was a major focus on care homes.

In relation to funds, we, alongside other colleagues, advocated for the 25% to be at the discretion, to enable at least some funding to go to

domiciliary care as well as to care homes.

I can't answer for local authority variation and MHCLG or LGA may be able to give you more information on that. We didn't keep that data specifically.

Q. Do you think that the split, so 75% of the funds going to care homes and 25% to home care, was proportionate?

A. So I think no, it wasn't, but there was an anxiety about how infection had impacted on people living and working in care homes that was visible in a way that people in their own homes wasn't visible, but clearly, the impact on people receiving home care, the impact on unpaid carers, and people who had employed their own personal assistants was very significant.

So starting again with experience, I think the split should have been different, but that was the decision that was made.

LADY HALLETT: Can I press you on that? Basically, it was the care homes where you had -- they'd become hotspots of infection where you had the problems with staff movement, you had a lot of people in the closed community. Surely the considerations for care homes were very different? I appreciate the problems that people caring had at home, please don't get me wrong, I'm not underplaying that, but doesn't that explain why, at the beginning, the care homes were the particular

focus?

A. Yes, I understand that focus, and I think you're right about that, but I think that the issue around community infection and the impact on people who were behind their own closed front doors was less recognised, as well.

LADY HALLETT: Now that I understand, but that's a different point from whether the proportions should have been different, isn't it?

A. **(Witness nodded)**

MS SHOTUNDE: I'm just going to move on to ask some final questions on the enhanced sick pay scheme.

The Inquiry was informed that the money was not reaching staff and we've heard that from various different witnesses.

Was ADASS aware of this at the time?

A. So we were aware that most providers were making significant efforts to ensure that their staff were able to take time off sick with pay or to isolate with pay. But we were also aware that there were small -- much, much smaller proportions of providers who weren't paying their staff sick pay, or an equivalent to their normal wages.

Q. And what, if anything, did ADASS do about it at the time?

A. So we contributed to discussions about it, we raised it

with our regions, but we were not close enough to, or would have been appropriate to address it with necessarily individual local authorities, but I am conscious that through the data that DHSC had in their regional assurance people, together with our regional staff, they were making enquiries of those employers.

Q. Thank you. And then my final question is: are there any recommendations that we haven't covered in our evidence today that you want to raise today?

A. So firstly, I think I've implied this but I think there needs to be, for a future pandemic, a consideration about the infrastructure for social care, including nationally, regionally and locally, and the engagement of social care from the very beginning at the very highest level, in the same way that Secretaries of State, for instance, regularly engage with the chief executive of -- or NHS England, or whatever succeeds that body, because certainly we would have been able to complement something to those decisions, and there were discussions that we now know, partly as a result of this Inquiry, of considerations, for example of asymptomatic transmission, even if it wasn't likely, that we weren't aware of at all and might have been -- behaved differently as a result.

I don't expect the Inquiry to be able to resolve the

underlying fragility of social care, but certainly, I think that had a very significant impact on the pandemic itself.

So I would personally suggest that there is something akin of a reservist taskforce that meets perhaps annually to review pandemic preparedness, and to challenge plans and operational issues of the time.

Q. Would that -- sorry, if I could just ask a question on that -- would that be a national taskforce, or would it be like a taskforce in each local authority?

A. My comments were in relation to the taskforce that Sir David Pearson chaired, for example, that can be stood up rapidly at a point of it looking like there's an emergency.

And finally, I would recommend that in a future pandemic, there is an equal consideration given to both our social and psychological needs as well as our medical and clinical needs, and that any view of capacity is closely aligned with quality, safety, safeguarding, and other issues in relation to people needing care and support. And particularly that we don't just look at the closed doors of a care home, but also people behind their own closed doors, who were experiencing more domestic abuse.

And I think that of the people I've spoken to,

there's a collective hope that the Inquiry might make a mark in recognising just how essential social care is for all of our lives, and to start to build towards a new social contract so that we can all live and work and care.

MS SHOTUNDE: Thank you, Ms Williams.

My Lady, those are my questions.

LADY HALLETT: Thank you very much, just a few more questions.

Mr Weatherby is first. He's just there.

Questions from MR WEATHERBY KC

MR WEATHERBY: Thank you very much.

Ms Williams, good afternoon. I ask a few questions on behalf of the Covid Bereaved Families for Justice UK. Can I return to consultation, first of all. You've touched on this before.

In your statement -- and just for the record, it's paragraph 9.1 -- you describe being given an hour to comment on a near-final document in relation to the hospital discharge policy, and you describe that as "derisory".

And on 14 April, you were given 25 minutes to comment on the draft adult social care action plan. That's your paragraph 12.18.

So, firstly, was 25 minutes long enough even to read

through the draft action plan?

A. So, to put that in context, we had been invited, again with very short notice, to a meeting to discuss the phrasing in the action plan particularly --

Q. By short notice, I think you say 20 minutes in your statement.

A. Yes, and then we'd been given the opportunity to comment on it. So it clearly wasn't enough, but everybody was working at great pace, and at least we were engaged in that, and we were cognisant of the content of the plan, whereas we hadn't been cognisant of the discharge guidance.

Q. No, indeed. Just picking up from that, then, looking forward and appreciating, as you've just adverted to, that guidance may need to be produced at speed, what can be done, in your view, to ensure that important stakeholders like ADASS are given sufficient time to properly consider and contribute to guidance in an emergency?

A. So I think first, let's not lose the guidance we have so that we're not starting always from scratch.

Q. Yes.

A. And it might need to be significantly adapted, but at least we're not starting from the beginning as we were then.

Secondly, I think the contribution that we can make but also that care providers and other people engaged in the taskforce is more significant, and there needs to be a wide range of people attempting to contribute to it. But I guess preparation rather than trying to make it up as you go along is the key message, really.

Q. Yes, and what about --

A. -- despite the best efforts of everybody involved.

Q. Sure. And what about being embedded within government or having a closer relationship with government so that you don't get 20 minutes, you get a proper period to look at things?

A. Well, I think in fairness, we have always valued a degree of independence such that we can serve our members and make statements but we've always worked very collaboratively with government, so I think, having social care expertise within government, which there has been in the past, and maybe in the future, but there wasn't to that extent at the time, and by expertise, I mean operational expertise as opposed to policy expertise, would be valuable.

Q. Yes. Sure.

Now, guidance on the requirements for the hospital discharge policy was issued on 19 March, and then sector-specific guidance on admissions was published on

2 April.

Bearing in mind the email that you referred to earlier, throughout this period, was there a sense that care homes were being pressured or forced to admit patients from hospitals?

A. I don't think that was the intention, though they were very strongly encouraged to.

Q. Yes.

A. But certainly, I know there were parts of the country and parts of the national system where the pressure was intense to make what was phrased as their "contribution" to the pandemic.

Q. Yes, so maybe not the intention, but it was certainly the perception?

A. I'm sure that perception was real.

Q. Yes. And was there a point at which providers felt less pressure in that sense? And if so, can you give us some kind of time frame?

A. So I can't describe to you actually having any specific direct national feedback on that, but I think that as the social care action plan and then the taskforce report, and then the subsequent winter plan progressed, there was a degree of extra recognition.

Q. Right, so it got progressively better?

A. So -- yes, I think so. But the second year of the

pandemic, when there was Omicron, there were different challenges --

Q. Sure.

A. -- because of staffing.

Q. Yes. Now turning to the hospital discharge policy, but still in the area of consultation, you weren't consulted before the announcement of the hospital discharge policy that was made on 17 March 2020. If you had been, and you'd known how little information ministers had about what was going on on the ground, what would you have advised, in one sentence or as shortly as you can?

A. Some greater safeguards for people needing care and support. I think by then the bandwagon was rolling, so actions in relation to social care would have needed to have taken place in the -- I think it was in the middle of February when people were starting to seriously alert to the pandemic.

Q. Yes. And finally, changing the subject, quality, safeguarding and regulation, at your paragraph 2.2(i) in your statement you say this:

"Lockdowns in care homes effectively resulted in a seismic increase in the number of closed institutions which coupled with pre-existing staff shortages and staff sickness significantly increased the risk of neglect, even in the best run establishments with the

most competent and committed staff."

And you go on to expand that later in your statement at 13.7.

In your view, was an increase in the risk of neglect an obvious risk at the outset of a pandemic or emergency such as this?

A. It certainly appeared so to me and to ADASS members in every conversation that we had.

Q. And were sufficient measures put in place by central government, and specifically the CQC, to mitigate this risk?

A. So I think that the emergency framework that CQC introduced was perceived as difficult for our members, because they'd relied on CQC data complementing their own contracts, information, and safeguarding work, and we certainly said so to CQC at the time.

I'm not sure -- we did try very hard to get safety and safeguarding on the government agenda on a number of occasions, but I'm not sure that we -- that we either articulated it clearly enough or that it was heard.

Q. Yes. And do you think there should have been additional funding provided earlier, as it was perhaps later in the pandemic, to ensure that safeguarding was instituted earlier?

A. Yes. And I think the issue is just as acute in terms of

people at home, because --

Q. Yes.

A. -- in a care home at least you know there's a building with people in it, whereas we know from previous safeguarding concerns that it's very possible, for any reason, for a care -- home carer not to be able to turn up to somebody who is not able to articulate their concerns, and that can have as -- catastrophic consequences.

Q. Yes. Finally, does it -- is it a concern that the CQC apparently didn't collect data during the pandemic on the number of patients discharged to residential settings, that were judged to be inadequate before the introduction of designated settings?

A. So I think the whole discharge process, as I've mentioned, could have been better managed. And yes, a CQC measure would have contributed to that, perhaps, but I would need to engage in discussion about that.

MR WEATHERBY: Thank you very much.

LADY HALLETT: Thank you, Mr Weatherby.

Ms Jones, she's over that way.

Questions from MS JONES

MS JONES: Thank you, my Lady.

Good morning, Ms Williams. I ask questions on behalf of John's Campaign, The Patients Association, and

Care Rights UK. I have two questions for you today. They're both on the topic of the under-recognition of the adult social care system during the pandemic.

Firstly, you described adult social care as being an afterthought, with the NHS prioritised and there being inadequate coordination between the two systems.

What, in your experience, was the overall impact of this context on adult social care and its ability to perform the role it needed to during the pandemic?

A. So, just to clarify, you are asking me to comment on the lack of recognition?

Q. And the prioritisation of the NHS. What were the practical impacts on that of the adult social care sector's ability to do its work?

A. Yes, so I think the lack of recognition demonstrated itself in numerous ways but particularly in the public messaging. So, if you recall, the 5 o'clock Prime Minister and/or Secretary of State broadcast every day. I think, and I may be wrong, but I only recollect seeing care -- the care lozenge alongside the NHS lozenge on one occasion, and the messaging was very much: protect the NHS, save lives, and 'Stay at Home'.

And we did communicate as often as we could with civil servants about trying to encourage more constructive messaging around the value that care staff

and people needing care and support have.

I think we had limited success in that, but certainly, there wasn't the recognition and thanks, and if you will also recall, what was originally "clap for carers" became "clap for the NHS", and I think that led to everybody feeling less valued. And as a consequence, I think the strong messaging about the NHS possibly countered what I believe to be -- can only believe -- it's absolutely true -- that there were no direct messages, for instance, that PPE was to be diverted to the NHS by suppliers or border control, but I think that that message was so strong that the NHS was the priority, that actually, people needing care and support and working in it were a secondary consideration.

Q. And can I just ask in respect of that, what were the consequences for them, of being a secondary consideration? How did you see that manifest in how people were able to perform their work and the care that was provided?

A. So the action plan was produced, in effect, after the first month of that instant initial transmission rather than prior to it. It meant that care staff and carers were secondary in relation to the supply of PPE, secondary in relation to testing, and the ultimate impact of that was on morbidity and mortality and to

this day in -- a disproportionate incidence of Long Covid in care workers.

Q. And finally, if I may, do you think there's been any improvement in recognition of the social care system, given the important role that it played during the pandemic?

A. So I think that there was recognition during the pandemic, thanks, partly, to some conscientious journalists who made the public more aware. There was also, very unfortunately, some negative recognition when the message about care staff spreading the virus occurred, which led to some vilification of care staff and some even needing protection from the public. Has that continued? I'm not sure that I see evidence of that yet, and I'm not sure that contributors to this Inquiry would say that things are better now.

Certainly the underlying issues about long-term funding, recognition and reform haven't been addressed for, I'm sure, a range of reasons.

MS JONES: Thank you very much.

LADY HALLETT: Thank you very much, Ms Jones.

That completes the questions we have for you Ms Williams, I'm really grateful to you for the help you've given to the Inquiry and if you want to reassure your members, if I've got one message during the course

of this module, it is the importance of recognising social care. So you've helped, with others, to get that message very firmly across.

THE WITNESS: Thank you.

LADY HALLETT: So thank you very much for your help.

I shall return at 1.45 pm.

(12.47 pm)

(The Short Adjournment)

(1.45 pm)

LADY HALLETT: Ms Shotunde.

MS SHOTUNDE: My Lady, please may I call Alwyn Jones.

MR ALWYN JONES (affirmed)

LADY HALLETT: I hope you were warned that we wouldn't get to you until this afternoon. I hope you weren't waiting too long.

THE WITNESS: That's fine, thank you.

Questions from COUNSEL TO THE INQUIRY

MS SHOTUNDE: Could you please tell us your full name.

A. My name is Mr Alwyn Rhys Jones.

Q. Thank you for your witness statement for Module 6, dated 17 December 2024.

You are the immediate past president of the Association of Directors of Social Services Cymru; is that correct?

A. Yes. I mean, there is a new president now, so I'm --

yeah, there's been a further president since we came to this stage, so, yes.
Q. And I will refer to it as ADSS Cymru throughout.
A. ADSS Cymru, yes, okay.
Q. Your substantive role is as chief officer of social care for Wrexham County Borough Council; is that right?
A. Yes, that's correct.
Q. And in respect of ADSS Cymru, you took up your role as president in December 2022?
A. That's correct.
Q. And your term of office ended in March 2024; is that correct?
A. That's correct.
Q. And I understand that you have some preliminary remarks that you would wish to make today?
A. Yes, if that's okay.
On behalf of ADSS Cymru, I would just like to note our sincerest condolences to any families that were affected by bereavements during the pandemic, and commit to doing all we can in terms of supporting and understand.
[Welsh spoken]
Diolch. Thank you.
Q. Thank you.
ADSS Cymru is the national professional leadership

organisation for social services in Wales; is that correct?
A. Yes, that's correct.
Q. And my understanding is that it represents the collective view of all 22 local authorities, social services departments; is that right?
A. Yes, that's correct.
Q. And the aims of the organisation are to ensure that adults, as well as children, in need, experience wellbeing and achieve what matters to them by accessing the right care and support; is that right?
A. Yes, that's correct.
Q. And just to confirm, in Wales, adult social care and children's social care are dealt with by one person essentially?
A. Yes, generally there is a director for social care, who covers both adults' and children's services.
Q. Thank you. And speaking of that, it's a statutory appointment in each of the 22 local authorities and my understanding is that it is responsible -- sorry, directors of social services are responsible for services quality and driving delivery of improved outcomes, safeguarding service and performance management, et cetera; is that right?
A. Yes.

Q. In terms of the role of ADSS Cymru during the pandemic, I understand that you worked closely with the Welsh Government and other stakeholders and you also were involved in communication, for example disseminating key messages to stakeholders and other matters; is that right?
A. Yes, we did play that role.
Q. I'm going to ask you some questions about pre-pandemic capacity of the adult social care sector in Wales and in particular, resilience.
If I could pull up your witness statement on screen, please. That's INQ000528094, page 20, paragraph 3.13.
In your statement you mentioned that:
"Issues about the resilience of the independent care sector also surfaced. Unlike England, Wales has few large care home chains where staff can be redeployed between homes. Many are family-owned and their capacity to manage during the pandemic was severely limited. Some local authorities did what they could to help, [for example] in one area, the local authority's catering department provided cooked food for residents of an independent care home because the home's catering staff were absent due to illness."
In terms of Wales having few large care homes compared to England, how did that affect care homes in

practice during the pandemic?
A. I think how that affected care homes during the course of the pandemic is they were -- they had smaller units in terms of resilience, in terms of being able to depend upon during periods of staff sickness, isolation. They also had a different sort of models in terms of the buildings they operated from. Generally they were from different types of buildings, generally older buildings that had become care homes. So I think it made them less resilient in terms of that ability to move staff and that they had very little additional capacity to move into.
Q. How would you describe the level of consultation with the Welsh Government on the adult social care sector during the pandemic?
A. During the course of the pandemic, we had regular consultation with Welsh Government during the course of the pandemic, very, very strongly in early days, and then depending upon the stage of the pandemic, it would vary depending upon the level of intensity in terms of lockdown decisions made at Welsh Government level, but certainly in the early days we had very regular meetings, weekly and some colleagues were meeting more than once a week. We had directors' meetings which then fed into those meetings with the Welsh Government, and

we were involved in a number of key groups.
Q. And from paragraph 2.20 of your witness statement, my understanding is that the first prime contact that ADSS Cymru had with the Welsh Government about the pandemic was in February 2020, and that was a meeting with Albert Heaney and Sue Cooper who was the then president of ADSS Cymru.
Do you think that was the right time, in terms of communication with the Welsh Government about the adult social care sector, or do you think it should have happened sooner?
A. It's difficult for me to comment in terms of the science of the pandemic. Clearly, sooner rather than later would have been the best. Clearly, that's the first opportunity Welsh Government felt they had to start having that conversation about the pandemic with us, and obviously the level of seriousness with which it was being considered.
Q. In your witness statement you described the social care sector as the "Cinderella service", like several other witnesses that we've had for this module. You mentioned discharge and lack of medicine support in care homes as an example of how it was shown to be the Cinderella service during the pandemic.
Are there any other ways in which you think the NHS

was prioritised over the adult social care sector in key decisions by the Welsh Government during the pandemic?
A. I think consideration of social care in the context of a number of decisions was always later than the NHS. So when discharge was considered, it was clearly considered initially with a focus upon supporting the NHS and having a platform within which they could cope with it with the pandemic.
Similar areas around when decisions were made around testing and decisions were made around protective equipment, it always felt that actually social care was considered slightly later. It was considered, but it was not immediate. It felt like the initial narrative was around the challenge within the NHS.
Q. On the discharge of residents from hospitals to care homes, ADSS Cymru were consulted on the discharge guidance at the beginning of April 2020 and I presume that the decision to discharge without testing had already been made by the Welsh Government at the point where ADSS Cymru were consulted; is that right?
A. I mean, I think there was some initial -- there was a period of time where there was not clarity around the testing and discharging. I mean, clearly the guidance referred to needing to be tested prior to discharge. So, yes, it would have been better to have immediate

consultation in that regard.
Q. And in your statement you set out the overall view of ADSS Cymru, which was that discharge without testing was irresponsible. At the time, at the beginning of the pandemic, as I'm sure you're aware, there was a lack of testing capacity. Then. Do you think that in a future pandemic, there should any be discharge into care homes after a negative Covid test, or if there is a positive Covid test, that the person be put in step-down facilities before being discharged into a care home?
A. Clearly in the case of Covid, and given the restrictions that was put on society, clearly the natural indication -- the natural place to take this to is that there should have been testing prior to discharge.
I can't comment on the nature of a future pandemic because it could well be a very different nature to Covid. But in terms of the pandemic which we faced, should there have been negative testing prior to discharge, my answer, simply, is yes.
Q. What about testing before discharge for people who are going to be discharged back into their own homes in need of domiciliary care or care by unpaid carers? Do you think the need for a negative test before discharge is perhaps maybe slightly less acute than in care homes?
A. I think there needed to be testing. I think potentially

as long as domiciliary care agencies had the required protective equipment to support their staff, and we have to recognise that, that maybe it could have been slightly different. But clearly, there are lots of conditions that needed to be in place for that to be different at all. Clearly in a care home it's in a restricted environment with lots of other people around, and actually I think it's important that there were negative tests.
LADY HALLETT: If you had a shortage of tests -- forgive my interrupting -- if you had a shortage of tests and therefore couldn't test before discharge and you had to -- or you had decided you had to make space in hospitals, is the alternative to ensure that anyone discharged is put into isolation in their own room --
A. Yes.
LADY HALLETT: -- or in special isolation facilities?
A. Would that have been the ideal?
LADY HALLETT: Yes.
A. Yes, I think it would have been. But it does make the assumptions about care homes having the right protective equipment in terms of supporting them. But yes, agreed.
LADY HALLETT: So it's not just isolation; it would have to be on the basis there was PPE as well?
A. Correct.

LADY HALLETT: Thank you.
A. Because I think you put staff in a very difficult position in terms of caring should you not have that PPE in place.
LADY HALLETT: Then the staff get infected, and --
A. Correct.
LADY HALLETT: -- circle of infection, right. Thank you.
A. Right.
MS SHOTUNDE: In your statement you've mentioned various issues in respect of discharges that did not take place in a manner in which it was in conformity with the guidance.

If I could just bring up your statement on screen.

That's INQ000528094, page 22, paragraph 4.6, please.

You've stated that concerns -- this is the middle of the paragraph:

"Concerns for the health and wellbeing of existing residents and staff meant many directors were not prepared to sanction ... discharges without testing. This resulted in tension and confrontation, and in many parts of Wales, a significant breakdown of trust between care homes and hospitals. The situation was exacerbated by the delay in the Welsh Government publishing its discharge guidance, was some two weeks after the UK published its guidance for England ..."

What was the role of directors of social services in sanctioning discharges during the pandemic?
A. I think what you'll find is that the directors of social services, through their commissioning teams, have quite a good relationship with care homes. And where there was concern around admissions either being expected from residential homes, they drew in the director of social services in terms of that conversations, and directors of social services gave that clear guidance: no discharges without a negative test.
Q. Is this a role that existed prior to the pandemic, so, for example, would directors of social services be involved in the decision of discharge or not discharge?
A. On an ongoing day-by-day basis today is that happening? No. But obviously were there to be an outbreak of diarrhoea and vomiting within a hospital ward or some issue, they may be drawn into things where things become acutely difficult in terms of those discharges coming out. So, on an operational day-to-day basis, no, ordinarily a director of social services is not involved in that, but they will be drawn in where there are acute problems.
Q. If I could turn to page 32 of your witness statement -- that's INQ000528094 -- you give an example of an issue with discharges in this part of your witness statement.

You state that:

"The overwhelming focus on protecting the NHS did on occasions dismiss any notion of the safety and wellbeing of staff and residents in adult social care. For example, a doctor in an emergency department sending a patient to a residential care home without testing for Covid-19 and demanding that the home takes them. This resulted in a heated argument with the Director of Social Services who backed the home's refusal to take the person into care."

How common or widespread was this issue in the pandemic?
A. I think in the early days of the pandemic it was reasonably common. Once the discharge guidance came out, it was less common, although still happened at periods of high pressure, and there are a number of anecdotal examples here, there are others which are not listed here, as well.

So in terms of beyond when the discharge guidance, as I say, it was significantly less common, but still happened on occasion.
Q. We are going to look at one of the other examples which is in an email.

Can I pull up INQ000511731, page 1, please.

This is an email from a Director of Social Services

saying that:

"Swansea has experienced discharge to dom care where we weren't informed that [the] patient had been tested. Subsequent result of test was positive. Was back before we had much of a grip on PPE. Risked infection of a number of staff and other care recipients. 8 staff ended up in isolation."

Do you think there was a widespread issue of discharge without testing into domiciliary care?
A. In the same regard, early in the pandemic, yes, I think there was.
Q. Do you think that issue of discharge without testing into domiciliary care was adequately considered during the pandemic?
A. I think, actually, early in the pandemic, the health partners tended to see residential care as the main area of discharge and therefore the wider economy of care was not considered adequately, no. There was a perception that you had hospitals, and you had care homes, and that wider economy which is large in terms of the amount of people we delivered care for in the community was not adequately considered, no.
Q. And just sticking on this email, point 2:

"Patient discharged to a care home. Were tested as positive. Not symptomatic. Care home weren't aware

until after the individual died and GP turned up in spacesuit saying that they could see on the records that the individual was positive for Covid infection."

Was there a widespread issue of care homes not being told of the Covid status of the person discharged?

A. I think, again, we go back to the earlier of the stages of the pandemic, prior to some of the discharge guidance coming out. It became significantly less frequent after that point.

Q. And there was another example I wanted to pull up on screen. It's INQ000511732, page 2.

This is from another local authority, where it says:

"Please advise. We have received a referral ... for a gentleman ... where the home are not willing to accept [them] back as no Covid status [was] confirmed. However it seems following various calls to the ward, the home and social services that regardless of the results, they are unable to carry out the 14 days isolation precautions post discharge within the home as the gentleman is cognitively impaired and walks about and they do not have the staffing to carry out '1:1" as they do not want to bring in agency cover."

And then underneath, there's another example:

"I have now received a call from ED ... about another resident from the same home admitted today due

to not eating and drinking. Prior to today, they had been [somewhere] and have since tested [Covid positive]. All tests carried out in ED today, ie, chest X-ray and bloods are normal. I have been informed that she has taken fluids for them without concern and there is no clinical reason to stay in hospital. Again this patient has cognitive impairment and is wandering. The home has refused to have this resident back as well."

Do you think consideration of residents who are cognitively impaired and the ability to implement IPC measures on discharge was adequately considered by the Welsh Government during the pandemic?

A. No, I don't think it was. I think we were ill prepared for individuals such as those two noted here, because, and the nature of the care homes, and the fact that there were not good isolation facilities within those care homes for individuals such as these.

Q. And in your statement -- I'm not going to ask to pull it up on screen -- you mentioned that:

"... there were incidences of health boards trying to use what might be termed 'technicalities' to bend or to work around the rules. For example, a care home resident taken into hospital might have spent time, often a lengthy period such as overnight, in a hospital assessment unit as opposed to being admitted to a ward.

The hospital then insisted that as the person had 'technically' not been admitted, they should be able to return to the care home without isolation or without the use of a step-down facility. There also seemed to be inconsistencies between some hospitals with different timescales applied ..."

How often did this occur, hospitals using technicalities, as it were?

A. How often did it occur? I think there were instances in every council across Wales. They were not regular but it did happen in most areas of Wales.

Q. On 29 April 2020, the Welsh Government issued updated guidance on the step-up and step-down care arrangements during Covid, and in it they described two options as regards to discharge, with the first being discharge back to an existing placement or care package where the individual has received a negative Covid-19 test prior to discharge, or a step-down or step-up within a designated NHS facility where an individual has received a positive test for Covid-19 prior to discharge, are still symptomatic, or within the 14-day initial isolation period.

What are your views on how useful the step-up, step-down arrangements were in Wales?

A. I think in practice -- I think, listen, it would be

useful to give guidance. I think you referred there to the second option of a specific step-down facility. I think in practice very few of those came into being in Wales. So the idea of the Nightingale wards were floated in all areas of the country and a couple of locations agreed upon. I don't believe they were significantly used and I think partially -- that was partially because there was not enough resilience in terms of the staffing required to do that, so I don't believe that happened to a great extent.

Q. So, just to clarify, do you think it's more of a -- that there's a lack of staff rather then a lack of need?

A. I would say, in terms of those sort of Nightingale facilities, yes, it would have been very difficult to staff them.

Q. Now, in England, the UK Government create a designated settings policy where local authorities had to list care homes that were capable of taking on Covid-positive patients before -- residents before moving them into their facilities or home that they ordinarily live in --

LADY HALLETT: I'm sorry, I missed that last bit.

MS SHOTUNDE: Sorry, that they ordinarily would live in. In terms of designated settings, it's like a step-down sort of facility but it's in respect of care homes.

Seeing that you've stated that the step-down

facilities weren't really used that much in Wales, do you think a similar policy like designated settings would be useful in Wales or do you think the step-down would be sufficient in a future pandemic?

A. No, I think they would be useful in Wales, so long as we've considered how we staff and resource them in terms of them being able to be practical. I think as a concept and an idea it's really, really good. There does have to be some practicality to it around how we staff, how we make sure that they actually work.

Q. And in terms of pre-pandemic planning, do you think that this is something that should be considered?

A. Yes, I do.

Q. In terms of visiting restrictions, I'm going to pull up your witness statement on screen again.

It's INQ000528094, page 24, paragraph 4.13.

And in it you state that there were some inconsistencies in visiting restrictions across Wales because of questions about the guidance, differences in local interpretation and application, and who was responsible for decision making. And you state:

"For example, the managers of care homes asking for advice on what they should do whereas the Responsible Individual, it was their responsibility to decide."

We heard evidence from the Older People's

Commissioner for Wales, who also mentioned difficulties when it comes to visiting restrictions because of a lack of understanding of who was responsible for decision making.

Who do you think should be responsible for decision making when it comes to visiting restrictions in a future pandemic?

A. My general view here is there should be some general principles that should sit above this in terms of end of life and ability to see your relative. And I think then, depending on the local situation, ultimately the care home and registered individual has that responsibility.

However, I would see it as local authorities and in -- and local partners being able to give some guidance in terms of actually what is our view around -- for example, in Wrexham, what is the current position in terms of spread, what's our current view in terms of -- and collectively that that is agreed.

So I think there should be some general principles nationally with some local interpretation based upon the situation going on.

Q. Now I understand it from some evidence in the Inquiry, there were some blanket bans imposed in Wales on visiting restrictions by incident management teams,

which went against government guidance. How do you think this could be improved in a future pandemic?

A. I think the way that could be improved in a future pandemic is having good solutions but for how people can visit safely. There are examples, I think, within my statement of where some homes had particular arrangements to meet outside, specific ways of doing that. I think what we need to do is define what is a safe area to meet so that even in the worst of circumstances, a person who is in a care home can have contact with their family and friends in a way that is safe.

Q. We heard evidence from Albert Heaney for Module 6 where he had been asked about there being at least two local authorities who had imposed bans on visits without the incident management team input or any input at all. And he was asked whether he had written to local authorities and he said he did make it very clear what was supposed to happen.

In your view, do you think, if there are going to be any local decisions in respect of visiting bans, let's say because there's an outbreak in a local area, do you think that incident management teams are the ones that should be the ones making the decision?

A. Yeah, I think working alongside the care home

ultimately, the care home -- the registered individual has to have a role because I suspect their insurance says they have to have a very key role in it, but I think they should be advised by the local incident management team, yes.

Q. On PPE, you said in your statement, which I'm not going to pull up on screen:

"Initially, there appeared to be questions whether care homes should have PPE as care homes are not hospitals."

Who was making that question? Was it the Welsh Government? Was it Public Health Wales?

A. I think that question emanated from the fact that there were poor supplies at first, and somewhere in the order of priority, care homes were not quite as high priority as the NHS.

So I'm not sure that was ever verbalised or officially said, but it was something that was the feeling that we had, those of us who were linking in with care homes, that they were not given the same level of priority.

Q. If we could pull up an email exchange INQ000511730, page 1.

I think this is where examples of issues, when it comes to discharge were asked about:

"The clearest cut example is someone who was discharged from hospital (no PPE), became ill, and was readmitted a few days later and then was found to have Covid-19. Even when the diagnosis came through it took a couple of days to provide PPE. More generally, the issue, is that people are discharged to care homes untested and it is not clear if they have the virus or not."

Do you think that in a future pandemic, PPE should be one of the main focuses in ensuring that care homes have PPE before discharges take place?

A. Yes, I think it should be one of the main focuses.

Q. In Albert Heaney's evidence, he was asked a question about PPE shortages, and in answer he said there was always enough PPE in the system. Do you agree with that?

A. In the early period of the pandemic, no, I don't entirely agree with that. The situation did become better and Welsh Government supported us significantly, and we -- supplies were passed down to local authorities to pass to their providers, but in the early period of the pandemic, no. I recall being in Anglesey at the start of the pandemic when we were doing everything we possibly could to source PPE, and it simply was not available. So no, I wouldn't agree that there was

sufficient PPE initially.

Q. In your witness statement, I won't put it up on screen, but paragraph 6.17(iv), there was an email that you mentioned from the Welsh Government about issue reported by an independent care home in Cardiff where existing PPE suppliers appeared to be restricting supplies to providers in England, and there's questions about actions done by Public Health Wales. Was it a common occurrence that there were providers of PPE that decided to restrict their PPE provision to other nations other than Wales?

A. I think there was -- it was clear at first that there was a priority being associated with providing certain sectors with PPE, yes.

Q. In terms of PPE and unpaid carers, what, if anything, did ADSS Cymru do to support unpaid carers and access to PPE?

A. My recollection is this isn't significant but I do think that we did make PPE available to unpaid carers in due course.

Q. Do you think they have enough data in Wales on unpaid carers to be able to ensure that they receive PPE in a future pandemic?

A. No, I think our data about unpaid carers needs to be strengthened.

Q. Do you have any ideas of how that could be strengthened?

A. I think there are efforts being made for people to self-register as carers and I know that Carers Wales are making efforts to increase that awareness of carers as to why it's important to register as a carer, but I think there are still some people who prefer to remain private as carers and obviously in a period like a pandemic, that makes it more difficult, does it not?

Q. I just want to see if you can help me with this. Testing was initially not very widely available for the adult social care sector, but then it became available to social care staff and there was a scheme developed between the Welsh Government, the WLGA, ADSS Cymru, and Data Cymru for local authorities to identify 15 members of staff per council to be tested. Are you familiar with that scheme?

A. Yeah, I think when we say -- from the council, I think we mean from the council services, probably care homes and domiciliary care, if I've got that correct. They weren't just -- they weren't just local authority staff, were they?

Q. In terms of that scheme, we heard from the WLGA that it covered both local authorities, social care staff and staff employed by commissioned providers. What about providers that were not commissioned by local

authorities? Do you know how they maybe had access to testing at that point?

A. I don't, no.

Q. In a future pandemic, where there are limited, let's assume there are limited numbers of tests, for whatever the pathogen is, at the beginning, do you have any recommendations on how testing in the adult social care sector could be implemented?

A. I think, however limited they are, those tests do need to be made available and I guess we need to co-produce how we're actually going to prioritise who receives those tests, and that there is at least that early dialogue around, actually, how do we work within this limited number of tests?

Q. And my final question on this point: from the WLGA, we had heard that the process of identifying social care staff able to be tested was complex and time consuming during that 15 members of staff per day period. I understand that there is currently now a register for adult social care workers held by Social Care Wales. Do you think that would assist in terms of identifying social care staff in a future pandemic?

A. I think it would and it will also help in terms of records as to who has been tested, yes.

Q. In your statement, you state that when testing became

available to social care, the focus was on care home staff and that there was concern about a lack of access to testing for domiciliary care workers. Do you think, in a time there may be a shortage of testing, priority should be given to care homes or do you think it should be looked at differently?

A. I think it probably needs to be looked at differently, and we need to consider how the priority works across both care homes and domiciliary care, as well. Listen, I mean, also in terms of social care, it's not just domiciliary care. We've also got a network of people who go out to see people within social care, both visiting -- you know, we have staff within supported living environments, and others, so I think there needs to be an exercise to prioritise across the sector.

Q. May I pull up the Care Forum Wales -- no, I don't need to pull up the statement, actually, I'm going to read it instead because it will be quicker.

A. Okay.

Q. We've heard evidence, in the Inquiry, of issues in respect of funding, funding provided to care providers in order to cover the costs, the associated costs of the Covid-19 pandemic. We've heard from Care Forum Wales in their witness statement that there were issues in respect of the funding going to care providers, that

there was a lot of delay in it reaching the sector. Do you think that there's anything that could be done to rectify this in a future pandemic?

A. Yeah, I think probably some relaxation of the ... I guess, being able to provide money in advance to support care homes while they're right in the crux of the financial difficulties, with some accounting which happens afterwards, would probably make it easier in terms of passing those funds down. We as a local authority, we obviously have to have an audit trail in terms of this is where we're passing it to, this is the evidence in terms of actually that provision. I think -- I would suggest some relaxation of that would make things easier, yes.

Q. Do you think that the additional funding should be paid directly from the Welsh Government to care providers or do you think it should still be funnelled through local authorities in a future pandemic?

A. I think the reasoning behind funnelling through local authorities is -- the nature of provisioning in every local authority is different, so the nature of provision, and whether it's across the independent sector, voluntary sector, the nature of the care home provision and the domiciliary care is different. And in actual fact, that allows local authorities to target it

to the correct places.

I don't deny, though, that it maybe shouldn't be done -- we should ensure that it goes faster.

Q. In terms of data, we've heard evidence that there was insufficient data on matters for the pandemic, but just to focus on ethnic minority groups, you stated in your statement that there was insufficient data on transmission and mortality rates for ethnic minority groups and other protected characteristics. When you were referring to that, were you referring to recipients of care, care staff, or both?

A. I think both, and the population more generally, as well.

Q. Has the situation improved to date in respect of data?

A. I'm not sure, is the answer to that. I'm not sure.

Q. If it hasn't, do you think that's a potential work programme that --

A. Yes.

Q. -- the Welsh Government should -- (overspeaking) --

A. Yes, absolutely, where there are vulnerabilities for particular parts of society, we need to make sure we've got good data all round.

Q. In terms of the changes to the regulatory inspection regime, and in particular Care Inspectorate Wales' decision to pause routine inspections, at paragraph 9.1

of your statement, you state that you think the decision to pause routine inspections for registered social care providers was appropriate.

As you're aware, at certain points in the pandemic, especially when there were outbreaks, et cetera, care homes almost became what people call closed institutions. There was no visitors from loved ones, hardly any visits from other professionals, so for example medical staff or social workers, and then now no routine inspections by Care Inspectorate Wales. What about safeguarding for residents in the care homes? Were there any concerns about safeguarding for them?

A. Okay. Clearly that level of inspection means that there was less oversight in terms of safeguarding. I think it's really important to note, though, that safeguarding structures within the local authorities continued to work, meaning if we did receive concerns, whether that be from a staff member or others around safeguarding within a particular establishment, we did make enquiries. We did work with a care home to address whether there'd been a safeguarding issue, and those things continued to happen.

So whilst oversight will have been less, I do inherently believe in the good -- that, actually, most staff go into care for the right reasons and if they

observe anything that they have concerns around from a safeguarding perspective, they do, and will report that, and we then still have the structures in place to actually investigate and do the work.

So was there less oversight? Yes.

Was there still a level of oversight and support in event of safeguarding concerns? Yes, there was.

Q. I'm just going to pull up your statement in respect of the impact of the pandemic on unpaid carers.

It's INQ000528094, page 69. Thank you.

As I understand it, ADSS Cymru conducted their own research into the Covid-19 experience for unpaid carers in a study commissioned by the Welsh Government, and the findings captured the lived experiences of unpaid carers during the pandemic.

If we turn to the next page, we have a list of harms that unpaid carers said they faced: social isolation and loneliness, mental health concerns, financial and economic impacts, deterioration in conditions on the cared-for people, and other matters as well, including delays in assessments.

What did ADDS Cymru or local authorities do to alleviate the impact of the pandemic on unpaid carers?

A. On an individual basis, we tended to work with our voluntary sector in terms of how they could support

unpaid carers, whether that be through getting them medications, supporting them in terms of getting food, and that was the main actions we took to liaise with the voluntary sector in terms of that work.

Q. Thank you.

And a final point that I just wanted to ask you some questions about is pre-pandemic planning. In respect of local authorities in Wales and just the Welsh methods generally on planning, who's responsible for plans in the event of a pandemic?

A. Ultimately I think the responsibility should lie with Welsh Government but then devolve down to local authorities and local health boards in terms of individual plans in terms of responses. Clearly that overall strategic needs to come from Welsh Government, then the operational practice that we need to put in place is by those very key institutions of health and local authorities.

Q. And currently is there any requirement for care providers in Wales to have pandemic plans?

A. I believe they do have to have business continuity plans. How specific that is about pandemics, I'm not sure.

Q. Do you know if they are reviewed by anybody?

A. Yes, CIW and our contracts teams would go in and review

any business continuity-type plans that care homes have.

Q. And plans for local authorities, are they reviewed by the Care Inspectorate Wales as well?

A. Yes, they -- we do get reviewed by Care Inspectorate Wales. I can't remember them focusing on those, but yes, Care Inspectorate Wales do review their business continuity plans we have in place for services.

MS SHOTUNDE: My Lady, those are my questions.

LADY HALLETT: Thank you very much, Ms Shotunde.

It's now Mr Stanton, who is that way.

Questions from MR STANTON

MR STANTON: Thank you, my Lady.

Good afternoon, Mr Jones.

A. Good afternoon.

Q. I ask questions on behalf of the Covid Bereaved Families for Justice Cymru. I just have two topics to cover with you. The first relates to the issue of PPE. And at paragraph 6.15 of your statement, you refer to a letter that ADSS Cymru sent to the Welsh Government on 31 March 2020 which raised a number of concerns, one of which was that the PPE guidance for the social care sector was tailored to supply constraints rather than the risks to staff and vulnerable people. And I should say the client I represent shares the view expressed in that letter.

Please could you explain and expand on the particular aspects of the guidance that you say was tailored to supply considerations rather than safety?

A. I think it's -- in looking specifically at it, I'm not sure I can, but the overall feeling that local authorities had was that the level of PPE that was being diverted towards the care homes sector was insufficient towards the start of the pandemic, and that clearly our calls to Welsh Government was to address that.

Caring for an individual who had Covid in a care home was actually not that much different to caring for them in a hospital, and actually, in some care homes, they were in more difficult environments, where maybe infection control space was at a premium, and therefore the overall view was that it didn't cater sufficiently for that.

Q. You may not be able to answer this question, but could I ask, were your concerns around the quantity of PPE, or was it more around the type and adequacy of the PPE being provided?

A. Certainly in the early stages some of the PPE was not adequate. As supplies got better as time passed, that became less of an issue. We do refer in the statement to a couple of examples -- you know, there were some issues with quality. Over time, that became better.

Q. Thank you.

My next topic concerns testing on discharge. You dealt with that already at length in your evidence, but my question concerns the situation in December 2020.

A. Yes.

Q. At paragraph 4.28 of your statement you refer to the Welsh Government's changes to hospital discharge guidance, which included the ability to discharge patients who were testing positive, albeit at a low level.

A. Yeah.

Q. And you set out the concerns of some of your members in connection with this change, including that the guidance was written purely from a hospital discharge perspective, and did not reference the risk for the care homes.

Immediately following this change, in January 2021, there was an alarming increase in Covid-19 infections and, sadly, deaths in care homes in Wales. At this point, were you able to revisit the concerns that you'd expressed in December? And if so, are you able to indicate the response from the Welsh Government?

A. I don't think we did particularly revisit. It was seen that the science was indicating that there needed to be a change in the discharge and I don't believe we did

revisit them significantly, no.

MR STANTON: Thank you.

Thank you, my Lady.

LADY HALLETT: Thank you, Mr Stanton.

And then it's Ms Jones, who's that way.

Questions from MS JONES

MS JONES: Thank you, my Lady.

Good afternoon, Mr Jones. I ask questions on behalf of John's Campaign, The Patients Association and Care Rights UK.

My first question in fact is on the same topic that Mr Stanton was just asking you about: your observation that the guidance on hospital discharge was written purely from the hospital perspective, but it did not reference the risks for the care homes and residents. And in fact earlier, in response to a question from Counsel to the Inquiry, you said that the hospital discharge policy was an example of the NHS being prioritised over social care.

In respect of that, do you agree that the government's failure to take account of the risks of the hospital discharge policy on adult social care settings could have been avoided if you or other key stakeholders had been consulted about that policy before it was introduced?

A. Yes, I think we could have minimised the risks, yes.

Q. Thank you.

My next question is about the problems with data relating to the adult social care sector, problems which you identified and talked about in your statement, for example that the data on registered care settings in Wales held by the Office for National Statistics is woefully out of step with data held by Care Inspectorate Wales, and you also talked earlier today about the need for data on unpaid carers to be strengthened.

Do you agree that it would be helpful in this regard for a centralised database of care sector data to be established which could be accessed to support understanding of the care sector and inform decisions that are made about it?

A. I think that would be really good. I think obviously you'd have lots of sources coming into that central database but I think one central database would be really, really valuable and useful, yes.

Q. Thank you. Then my last question. At paragraph 4.10 of your witness statement you say that:

"The Welsh Government shared its thinking with ADSS Cymru in advance of lockdowns, but that care recipients and care workers heard about them when the public announcements were made."

Do you agree it would have been helpful for those two cohorts, care recipients and care workers, or the stakeholder groups that represent their interests, to have also been consulted or given advance notice of such decisions?

A. I think it would have been helpful. I think it would have had to be done in a managed way so that that -- so that any spreading of the message wider to the public was managed, but yes, I do think it would have been helpful to have that level of consultation, yes.

MS JONES: Thank you very much, Mr Jones, those are all my questions.

LADY HALLETT: Thank you, Ms Jones.

That completes the questions we have for you. Thank you very much indeed for your help, we are really grateful, I appreciate with all your other responsibilities -- you said you had two successors, since you -- is it a year or two yearly post.

THE WITNESS: No, we tend to do a year as the president of ADSS, so I think I finished in 2024, there was one person in '24-'25, and there's one person now. So I am two back.

LADY HALLETT: So you have got to go back to your day job?

THE WITNESS: Yes, indeed.

LADY HALLETT: Which you were doing anyway, I'm sure, at the

same time as running the association.

Thank you very much indeed for your help. I am really grateful, and safe journey back to Wales.

THE WITNESS: Thank you.

LADY HALLETT: I have been asked if we could break now before the next witness because I think counsel may be meeting the witness. So if I return at quarter to or ten to, let me know. Let's say 2.50. Thank you.

(2.37 pm)

(A short break)

(2.50 pm)

LADY HALLETT: Mr Beech.

MR BEECH: Yes, good afternoon, my Lady. Thank you for your forbearance.

Please may we call Mr Eddie Lynch.

MR EDDIE LYNCH (sworn)

LADY HALLETT: Thank you for coming back to help, Mr Lynch.

THE WITNESS: You are welcome.

LADY HALLETT: Coming here to help, as opposed to last time.

Questions from COUNSEL TO THE INQUIRY

MR BEECH: Thank you.

Good afternoon, Mr Lynch, I'm going to ask you some questions today arising out of your witness statement which is dated 17 February 2025, and for everyone's reference, that's INQ000474926.

You took up your role as Commissioner for Older People for Northern Ireland on 13 June 2016, being appointed for an initial four years and was subsequently reappointed for another four-year term on 13 June 2020, and then filled that role in a caretaker capacity until 12 December 2024 before moving on to pastures new; is that correct?

A. That's correct, yes.

Q. And the Inquiry is familiar with the role of the office but just very briefly, the commissioner is an independent statutory role set up under legislation from 2011, and you set out at paragraph 11 of your witness statement that:

"The Act affords me promotional, advisory, educational, and general investigatory duties and powers. Their purpose is to enable me to champion the rights and interests of older people [in] Northern Ireland."

Is that an albeit high-level summary of the role?

A. That's correct, yes.

Q. And just, if I may, in terms of your remit, the 2011 Act defines an older person as normally being aged 60 years or over; is that right?

A. That's correct, yes.

Q. And that in line with census data from March 2021,

Northern Ireland had an over-60s population of approximately some 439,000 and roughly 23% of the population?

A. Yes, that's correct, too.

Q. If I could just then move towards the subject matter of this module which is the impact of the pandemic on the adult social care sector. And again, you set out in your statement that approximately 60% of the requests for individual assistance to your office relate to health and social care, the highest proportion of issues raised relate to care homes and that during the pandemic, the government's response dominated your engagement on behalf of older people; is that correct?

A. Yes, it is.

Q. If I could pull up, please, on the screen INQ000237831, and this is taken from a briefing which you prepared in October 2020. And just if we could look at the first bullet point under paragraph 5. In October 2020 you felt it important to emphasise that:

"When considering care homes we are talking about the homes of around 14,000 older people in Northern Ireland. These settings are their homes."

And then, again, at the final bullet point there, you state that:

"Northern Ireland needs to stop talking about Care

Homes as buildings and care home residents as numbers. [They] are our parents and grandparents who remain part of our society."

As I say, that was October 2020. Why did you think it was important to emphasise those points at that time?

A. I think it was important to emphasise that because sometimes we do lose the fact that care homes are people's homes, and that is something that needs to be considered when decisions are being taken that affect care homes, particularly in the instance of a global pandemic. And I think it's really important that they're at the forefront when we're talking about older people, we're not seeing them as being placed in a care home for the end of their lives but, actually, that is their place where they are entitled to family visits, to live as happy and as fulfilling a life as possible. And I think that, you know, it is important to have that at the forefront of some of these discussions in relation to actions taken during the pandemic.

Q. Thank you.

If I could have up on screen, then, your witness statement which is INQ000474926, page 17 and paragraph 56, you state there that:

"The pre-existing structural weaknesses in the system for delivering adult social care in Northern

Ireland were horribly exposed at the outset of the pandemic."

I'm well aware and the Inquiry is well aware that you've done an awful lot of work in this area, and perhaps we don't need to delve into the full nature of those pre-existing concerns, but in terms of the impact on the adult social care sector during the pandemic, how did these pre-existing concerns impact?

A. Well, my office had released a series of reports over many years, both preceding my time as commissioner and since then, as well as a number of other reports into the health and social care system in Northern Ireland over the last ten years and beyond, which -- report after report highlighted some of the key weaknesses in our system: issues around recruitment, staff shortages, terms and conditions of staff, and also linkages between how the health system and the social care system would link up and link together, and I think what Covid exposed in early 2020 was some of these problems that were in the system led to a serious impact, unfortunately, in many of the older people who were living in those homes.

Q. The former Health Minister, who is quoted quite a bit in this Inquiry, described the adult social care sector as the "Cinderella service, undervalued and

under-recognised". Is that a description which you recognise?

A. Yes, it is, and I think it's worth pointing out, as well, that sometimes Northern Ireland is held up as an exemplar in discussions within the UK as having an integrated health and social care system. But both myself, my office and many others organisations have, for some years now, been raising concerns about how those two parts of the system link up together and work up.

Q. And before we descend, perhaps, into some specifics of policies or guidance during the pandemic, in terms of a brief overview from your perspective of the impact of the pandemic on older people in receipt of adult social care.

A. Well, it was devastating. Unfortunately, Covid-19, the main -- the people at risk were older people and people with underlying health conditions, and that has swept through Northern Ireland, as it swept through many countries before it reached our shores.

Unfortunately, in relation to the likes of care homes, the nature of the virus was just extremely difficult to control once it got into those settings, and the system and the sector was ill equipped to deal with what Covid brought. And as a result of that,

unfortunately, many people lost their lives and many older people spent their last months of their lives in dreadful circumstances.

It also affected the wider social care system, where older people were locked down, where people, you know, reliant on domiciliary care packages, became a big problem in many areas as well.

So these were all issues that were being brought on a regular basis to my office. And I think it was -- you know, devastating is the word, when you look at the loss of life and the experience that many older people and their families had over those few years.

Q. If we could start, then, a bit of an exploration of what happened in Northern Ireland, and if we could start with what became the 17 March 2020 guidance entitled *"COVID-19: Guidance for nursing and residential care homes in Northern Ireland".*

And for everyone's note, the final version of that guidance appears at INQ000120717.

I understand that you were invited to attend the meeting on 16 March 2020, but it was ultimately attended by your chief executive; is that correct?

A. That's correct, yes.

Q. Prior to that meeting, a draft copy of the guidance was shared with your office, and in your witness statement

at paragraph 102 you describe how it was viewed as unrealistic and impractical.

I'd just like to explore first of all, is that the view of COPNI, and how did that -- how was that view formed, that it was unrealistic and impractical.

A. I think that whilst we did receive consultation on some of the guidance that was produced in those first six months and beyond, the timescale for receiving that guidance was very limited. We believed, as did other organisations that were consulted upon, felt that there was very little opportunity to influence the guidance.

We saw issues in terms of the implementation of the guidance that we felt needed to be talked through, particularly in terms of the care home sector.

And, you know, that meeting that was held on 16 March, I clearly remember my chief executive coming back and reporting back to me on some of the concerns within that guidance, but also reporting that the department was very clear that they wanted to issue it the next day.

Q. If I may pick up that point, then, the department, you say, were keen to issue it the next day, and this is obviously reported back from your chief executive.

In your opinion, was there a need to urgently issue guidance to the adult social care sector?

A. I appreciate that it was an urgent and an emergency situation, and we were looking for quick and decisive action on all of these issues. However, the strong feeling of myself and colleagues and others within other organisations was it would have been better to take more time to consider the real implications of that guidance. There was clearly concerns being raised from the care home sector in particular about the practicality of some of the guidance that was being introduced.

And also, concerns about -- from the sector, in terms of their resources, about their ability to actually implement the guidance. So, in my view, it would have been better to take some more time to try to get the guidance right, and also pave the way for its introduction. And I think that would have led to a more effective implementation of it.

Q. I appreciate that you represent older people, you don't represent the care providers, but you've mentioned at least twice there that they flagged issues with implementation. Can you recall at this juncture what the issues they were raising were?

A. A lot of them was down to resources. You know, there was a lot of new issues that were coming on the scene very quickly as a result of the pandemic. So a huge level of increased, you know, infection control

measures, for example, was being asked. How the new arrangements were going to be managed in terms of actually running a care home. How, you know, the social distancing was going to be managed.

This was also the time when the homes was raising major concerns around PPE provision as well. So there was real concerns that they were having about their ability to care for their residents as effectively and safely as possible.

And obviously that concerned me as the Commissioner for Older People, that it felt that this guidance, whilst it may have looked good on paper, if it wasn't going to be implemented on the ground, then I didn't have much confident that it was going to be effective in what it was set out to do.

Q. For the avoidance of doubt, I raised with you the draft guidance you viewed as impractical and unrealistic. The final guidance was then issued on 17 March. Were those issues addressed between the draft and the final version?

A. No, I don't believe so. There was very little, if anything, changed, which was frustrating for both myself, my wider team, and also other organisations.

Q. The first page of the guidance, the final version, states it's been developed in consultation with a number

of representative bodies. If the consultation relied on was that meeting on the 16th, does COPNI think that was -- or does the Commissioner for Older People think that was sufficient?

A. No, it clearly wasn't.

Q. I appreciate that you weren't at the meeting on 16 March 2020, but you report that your chief executive formed the opinion that there was an air of unreality expressed on the part of either officials of the Department of Health or the Public Health Agency that what was seen on the TVs happening in Italy wouldn't happen in Northern Ireland. Is that a general impression that you picked up during those times in March 2020?

A. Yes, I have to say it was. We had several conversations raising concerns about care homes. We had seen, on the news, what had happened in places like Italy and Spain weeks before, and there were some horror stories that had emerged. So I had major concern about -- with my limited knowledge of Covid at this stage, I was no expert in it, but it was clear from hearing and listening to the experts that this was a virus that spread widely. It was a virus that was targeting older people, particularly. So those conditions alone made me very, very worried about protecting care homes, and to

liaising with the authorities to see what steps could be taken to better protect people.

And whilst I appreciate this all came at breakneck speed to the department, I do think more could have been done in consultation to try to get that guidance better and more realistic, in terms of its implementation.

Q. You state, then, perhaps a more general point, that is at paragraph 100 of your statement that:

"There ... seemed to be a high level of reliance on what was being published in England in relation to the NHS, and I was concerned that insufficient time and opportunity was being provided to consider the implications of its effectiveness when applied to Northern Ireland's very different system ..."

Can I ask you for an example or a specific. How did this reliance on English guidance impact on what was happening in Northern Ireland?

A. Well, we didn't have the exact same system, as I said, we had, you know, albeit an imperfect integrated health and social care system, so we were different in terms of the set-up, the linkages between the NHS and the social care sector. I think there was also a difference in the size and scale of the operation. I think Northern Ireland, being a much smaller place, we probably did have opportunities to work together, and in

collaboration more effectively in those early weeks.

And in my view there was a great willingness from the different organisations to do that and it's just a regret that we didn't have some of those conversations earlier on, and I think if we had the opportunity to feed into that at an earlier stage, we may have got the guidance in place more effectively earlier on, as well.

Q. We're talking about guidance at the very outset of the pandemic here, so it's 16 and 17 March. Did the picture improve at all over the coming months and years?

A. I think there was a gradual improvement but I think there was still a feeling that new plans that were being drafted within the government came to us at a fairly late stage. So when they developed, for example, the Care Partner scheme later that summer, I still think there could have been a more early engagement on the details of that scheme, both with my office, but again, with the providers, because there were a lot of concerns raised by them, a lot of care homes were contacting my office at that time, saying that whilst in theory they were in favour of the scheme, they felt that in practice it was going to be very hard to implement, given the lack of resources.

So again, I think there would have been an opportunity to feed in and have a more collaborative

approach at an earlier stage, because the feeling was that certainly my organisation and others wanted to work constructively with government. As commissioner, one of my statutory duties was to provide advice to government, and I felt, you know, that that could have been taken on board at an earlier stage.

Q. If we could just delve into, then, some of the more specifics. In relation to PPE, the 17 March guidance set out the trusts will continue to work with nursing and residential homes on the provisions of appropriate PPE where they're unable to source their own supplies.

So the position was that where private providers couldn't source supplies, they were to go to the trusts. In your opinion, was that an appropriate position?

A. I don't think it was -- in those early -- early stages, it was very clear that the PPE stocks were being held for the hospitals and the NHS. We were inundated with many care homes coming to us in those early weeks who, despite receiving assurances from the minister and officials in the Department of Health who said homes can go to the trusts and get that equipment, homes were reporting to me that that wasn't the case on the ground: that they had been contacting the authorities and getting nowhere in terms of getting PPE stock. So that was a major issue in the early weeks and it was

something that put extra stress on the care homes themselves.

Q. Specifically, then, in March 2020, what alternative should or could have been put in place to ensure that providers received the PPE they needed?

A. Some of this was happening really when, you know, the hospitals were pretty empty. You know, in those early stages we didn't get a surge on the NHS for quite a number of weeks. There was a lot of reports back at that stage, you know, of a lot of the facilities not being under any pressure. So I think more could have been done in those earlier stages.

I think it was clear that the care homes particularly were more vulnerable in those early weeks than the hospitals. The hospitals at that stage seemed to be well stocked, seemed to have plenty of free beds, but the care homes were the ones really in the firing line in those early weeks. And despite the pleas of many homes to get that equipment through, it did take some time for that to happen, and I think that could have been delivered to them more quickly.

Q. You said it took some time. So the guidance was amended on 26 April to ensure that providers would have a buffer stock provided to keep them going, and in a briefing which you provided on October to the Health Committee,

which again we've already looked at, you talk about how these issues continued into late April or May. Is it fair to say that the PPE position improved after that change to the guidance and the requirement to provide the buffer stock?

A. Yes, it did gradually improve. You know, I know there was several conversations that both myself and my team had with Department of Health officials where we went back a couple of times saying that we were still hearing problems on the ground. I know the department issued -- agreed to issue a statement again to the trusts reminding them that they should be providing this equipment to the social care sector, but it was clear from what we were hearing on the ground that still took some time. It did improve but it did take several weeks before we seemed to have that sector being properly supplied.

Q. If I may move on, then, to just briefly discuss the discharge policy, and this was the policy of patients being discharged from hospital without testing in the early months of the pandemic to care homes. And you set out in your statement that concerns were being raised with your office both by families of residents in care homes and by providers, both through the independent health and care provider organisation, and also

individual providers.

What concerns were being raised with the commissioner in, say, March, April 2020?

A. Well, exactly that: there was a number of people had contacted our office directly, and also had contacted the independent healthcare providers raising concerns about the discharge of older people from hospitals back into care home settings without evidence of -- that they were tested for Covid-19.

Now, that raised real alarm bells, both for myself and for a lot of the providers, because there was no way of knowing if that person was positive or negative. And obviously at that stage we knew the vulnerability of care homes. So it was very difficult for them to manage that situation not knowing if somebody had could have or not, and what, you know, what actions they could take.

So that was an area of concern. There was family members also contacting my office at the time raising concerns about that as well. They had been aware that people had been discharged from hospital.

And this -- obviously, you know, in these early stages, this was the time when everyone living in care homes -- there was no vaccine, so people were extremely vulnerable, and a lot of care homes were managing the situation as best they could, but they did feel that it

was unfair that they were having to take people in without getting that reassurance around the testing of them.

Q. And what do you think caused or contributed to this issue where people were being discharged without testing?

A. Well, it seemed to be that this -- that the focus on the NHS was -- there was a major concern that there was going to be a surge in Covid cases to hospitals. It seemed at that time to me that, you know, the NHS was trying to clear out as many beds as possible to create space for that expected surge.

However, you know, at the time, you know, you would have to question: did all of those people have to be discharged as quickly as that or could there have been tests done on more people at those early stages when the NHS wasn't under siege? It would seem to have made sense that people would have -- there would have been extra steps taken to try to prevent the unnecessary spread of Covid back into care homes.

Q. You say there, did all of those people have to be discharged? I think we're going to come on to visiting shortly and, in the context of visiting, I think you accept that ultimately a visiting restriction was necessary in the early stage of the pandemic. But what,

if any, alternative could there be to this situation which arose regarding testing, especially whenever the Department of Health would say that the capacity was so severely limited that these people couldn't be tested?

A. Well, I think there was still -- it was, I think, a very grey area, the testing in the early stages. It was something that concerned me quite a lot. You know, as I spoke to some of the experts, the virologists, the epidemiologists, to try to get a better understanding of this disease, and, you know, the implications and how quickly it would spread, it was very clear to me when I asked them in several meetings around, you know, test and trace, whether that was -- should be part of the strategy to try to monitor the virus and control it, and all the experts I spoke to in those early months were very clear that that had to be part of the approach.

Now, I think it took a while for testing capability to be ramped up, but there still was some initial testing in those early stages and I think there could have been more testing done for those people being discharged.

Q. Just for everyone's note, you said it took a while. The -- version 3 of the interim protocol on testing from 19 April and that's reflected in the 26 April 2020 guidance, basically mandated or required testing prior

to discharge. It's your position, however, that that intervention or change in policy was too late?

A. I think it could have been brought in earlier, yes.

Q. A couple of discrete points then around the discharge policy. To what extent do you understand that individual care homes can safely isolate residents who have been discharged?

A. I think that was a real difficulty for a lot of the care homes. Certainly many of the care homes that were coming to my office were being very open and honest about their capability. They hadn't dealt with anything like this before, albeit they had experience of infection control but not on this scale. So some of these actions, like the discharge, were extremely hard for many of the care homes managers who were trying to manage the situation, an already very difficult situation within the home, and I think the fact that there was already people being brought in back from hospital not being tested at that stage, they struggled to know about what sort of steps and actions they needed to put in place.

And I think that was something again, until we got more of a proper testing programme in place, that continued to be a constant worry for the providers and the families.

Q. And is there anything that could be done in the future, apart from, as you say, perhaps greater capacity or prioritisation of testing to avoid this situation happening again?

A. Well, I would like to think that some of the learnings of this will be that we need to be better prepared for a future pandemic. We need to be planning the resources that we have in place. We need to be able to put that in place a lot more quickly than previously. And I accept it was new to everybody and people didn't know, and a future pandemic could be different, but I think there are basic steps that can be taken and resourced that can at least put you in a better position if you're faced with something like this again -- not just in PPE, but testing and, certainly, a better plan to facilitate visiting and human contact with people in those situations.

Q. Can I just explore perhaps one of the basic steps, then, in that briefing to the Health Committee you say that "it is imperative that any lessons which can be learned from [the use of step-down facilities] are applied". What lessons could have been learnt from the use of step-down facilities in Northern Ireland?

A. I think the whole -- the health service can be reviewing all the steps and all the decisions it took at the time,

and look at how effective they were. They will know better than me how their different areas that they put in place, how well utilised they were, how effective they were. But I think, for me, it's about putting those resources in place and putting enough emphasis on preparing for a situation like this again.

Obviously, we all hope that this doesn't happen, but a lot of the experts predict that it could well happen, well within our lifetimes again, so I think there just needs to be more of a focus. I think the Covid-19 pandemic just identified how ill prepared we were as a society for something like this, and I think, you know, it would be terrible if we didn't learn those lessons and at least put in place an action plan and resources that would allow a swifter response if we're faced with this again.

Q. If I could move on, then, to the issue of testing, and I appreciate the two are heavily connected.

We've perhaps discussed testing policy in March and April, however you set out in your statement that you issued a briefing on 4 June 2020, and your primary focus was to obtain a rollout of a proper testing programme for the adult social care sector. So that's 4 June.

What was lacking, in your opinion, in terms of testing for adult social care as of the start of

June 2020?

A. It was just the programme of testing didn't go far enough. I thought it was too slow to get up and running. Again, I was no expert in this, but I had had several meetings with experts at this stage and a very clear picture emerging of how this needed to be tackled. The care home situation by this stage, we knew in the first couple of months just the devastating impact it was having, and all the experts were saying the same thing to me: that, you know, testing and tracing the virus was absolutely critical for homes to get a handle on it.

So, for me, it was far too slow in coming in in the first place. In fact there was several statements made that seemed to say that a testing system in care homes wasn't needed, which was of deep concern to me at the time. And I thought -- you know, eventually the department did come up with a testing programme. Initially I welcomed its introduction, but I also pushed to ramp it up as well, so that the amount of testing happening could be increased as it went along.

So I think eventually we got to that stage where there was regular testing but, again, I had deep frustration at the speed of that, and what I saw as maybe a lack of urgency about how important that was in

the response to the pandemic.

Q. Northern Ireland reached then August 2020 and the position was that there'd be a rolling programme of testing with residents to be tested 28 days, and staff every 14. Do you consider that that was appropriate?

A. Again, speaking to experts, it was clear that it wasn't sufficient. It was an improvement, it certainly was something, but it wasn't going to be enough to give the level of protection that I was seeking at the time.

I realise that there was limitations on the number of tests, and the programme had to be ramped up, and that's what -- some of the feedback that I was getting. But I was getting clear expert guidance that the testing system should have been testing staff and residents on a more regular basis and that's what I was pushing for at the time.

Q. Perhaps if we could call up on screen some correspondence from yourself from 8 October to the Minister of Health.

If we could have INQ000250250, on the second page, please. I think it's the third paragraph, you say, and this is again October:

"I am very concerned to see the rising number of care homes recording outbreaks in Covid19 infections, and while this may point to the testing system working,

I believe we are now at a stage where the testing must be increased to weekly if we are to identify more positive cases before they have time to spread."

So on 8 October, then, you're calling for weekly testing, and you feel that's important in order to identify more cases before they spread further?

A. Yes, that was the case, and again, as I've said, that was based on several meetings I had with experts, virologists and epidemiologists, and it was clear their advice to me was that, you know, really the more regular testing programme that you have, the more you can catch the virus at an earlier stage. You can identify outbreaks at an earlier stage, and then hopefully put in measures that can contain those outbreaks. So at that stage, I was very keen that the minister consider that, and, you know, introduced that as a matter of priority.

Q. Thank you.

Now, in fact, weekly testing of staff was introduced on 3 November 2020, so roughly a month later. What do you consider about the timing of that change? Was it sufficient or appropriate?

A. Well, I think in all of these, I think we were playing catch-up. You know, I think all of these things could have been introduced at an earlier stage with testing.

It did feel -- it did feel that, for quite a while,

there was quite a bit of pushback on this, and I just felt that throughout the testing programme it could have been introduced earlier, it could have been ramped up earlier, and that was my frustration. And I think, you know, whilst resources may have been one of the issues, I don't believe it was entirely about resources.

I think, you know, in the early stages there was certainly -- there didn't seem to be a huge appetite for testing and particularly in care home settings.

So I think that set everything back and I think all of this rolling out of the testing system could have been done weeks earlier.

Q. As you say, we're primarily discussing care home settings, but that same correspondence goes on, please, if we have a look at the final paragraph:

"I have also raised with you and officials on a number of occasions about the need for domiciliary care workers (home care workers) to be included in the regular programme of testing. It is not reasonable to expect these workers to go and arrange tests for themselves, in the same way as a member of the public does."

Was there any meaningful engagement from the Department of Health on your suggestion that domiciliary care workers required testing?

A. Again, I think this was an area that, you know, was behind the care homes, I think, in terms of being looked at.

I think it's fair to say we were still receiving some concerns raised from family members and older people about domiciliary care workers not being tested. But not on the same scale as the care home setting, because I think the feeling was that the risk was less in those settings, whereas just the nature of a care home and the number of people living under one roof that the focus was on trying to ramp the testing up on to that because they felt -- it -- it seemed like they were under a much higher level of risk.

However, we had conversations and obviously that letter was raising the issue about ramping up the number of domiciliary care workers to be tested as well, because the concern there as well was obviously these care workers were going into many different people's houses on a daily basis. So anyone who was positive for Covid was a danger of exposing quite a number of older people to that if that hadn't been picked up in a testing regime.

So again, yes, it seemed to come after, it seemed to be further down the line in terms of urgency, but it was certainly an issue of concern.

Q. While the intricacies of exactly when testing for domiciliary care workers can perhaps be worked through with other witnesses, it would appear it was not until at least early 2021 that tests were available, and perhaps even as late as August 2021, until regular testing was extended to all independent providers of domiciliary care. In your opinion, what was the impact of that not being introduced until 2021?

A. Again, I mean, it's obvious that, you know, Covid was widespread in the community. You were always going to have some of those domiciliary care workers who would have been infected, and the lack of testing for them means that wasn't identified. You know, particularly with the nature of Covid, you know, if somebody had obvious symptoms, that was one thing, they could take action. But the nature of this virus obviously was that you could have no symptoms at all and still be positive.

So that was certainly a risk to the people that they were going to visit every day, and the longer it took to introduce that testing, the more people were exposed to that restrictions.

Q. If I may move on to the issue of visiting of residents in care homes. I did allude to this a couple of moments ago, but I believe it's your position that at the outset in March 2020, there was a need for some form of

visiting restrictions in care homes. Is that correct? And can you explain why you think that?

A. That was correct. I took a position at the time, it was a very, it was a very difficult decision, one of the most difficult decisions, I have to say, throughout the pandemic. And there was no good decision to take here. It was clear from the outset that, you know, I was aware of the impact that this was going to have on people, but at that stage, it seemed like the right -- people's right to protect their lives trumped everything else.

So at that stage it was seen as the best way to protect people's lives was to create what was called a ring of steel, you know, that it was -- that we restricted access to the care homes as much as possible. The experts had advised me, you know, the less people going in and out from the community, you know, the less risk for people in those care home settings.

So, you know, certainly in the early stages, I supported that the policy. I think over a period of time, you know, I realised that the negative side of that policy was very serious and probably more serious than we initially expected.

I think also the other reasoning behind taking that approach in the early stages was we didn't know how long this was going to take. We didn't know what -- how the

virus was going to continue at that early stage, so we didn't know how long we were in a position of lockdowns like this.

But clearly, by, you know, by the mid to late summer, the level of concern raised by families to my office was really significant and the stories that we were hearing about individuals and the decline and deterioration of older people in those settings was very distressing, and I think that certainly this was one of the areas that I think the learnings from this Inquiry can actually put into place really concrete changes to how care homes could cope with this in future, because it was clear to me that for many older people, that that system meant that they, you know, didn't see family members face-to-face for the last weeks or months of their lives.

It was a very awful position to be in, and I think in the future, we need to weigh up the risk associated with contracting the virus and putting in place measures that allow continued social contact and direct human contact with family members.

Q. If I may, then, just actually turn to what you say about the concrete changes or recommendations which you think could be made here. At paragraph 117 of your statement you say:

"... in the future, decisions will have to be taken for cohorting those older residents of care homes who choose to live with the risk of infection, with all the potentially tragic corollaries, but who value daily contact with loved ones above the risk to their longevity. And conversely providing more rigidly isolated care homes for those whose preference is to protect themselves."

If you just expand on that, are you proposing, in effect, more resident choice going forward in how this would all apply to them?

A. Yes, I am. I think, from reflecting on this issue particularly over the last few years, I think measures need to be introduced into care home contracts that make care homes have, whatever you want to call them, isolation rooms, visiting pods, but some sort of physical capacity to enable face-to-face visiting that reduces the chances of wider infection.

I believe something could be done on that front. At the time, the minister announced some funding that homes could look into visiting pods, and I know some homes took that up, and I think the homes that did take it up, it worked quite well. And I actually think this is actually a really key issue going forward, because what the visiting raised -- has raised real fears amongst

older people and people of all ages, I suppose, who are looking into the future and thinking if that was me, you know, by far the most people I speak to say they would want to still see their family and have human contact even if it exposed them to greater risk. And I think something that changed the contract, changed the -- that put the resources into providing that within the care home setting, so if we're in this situation before, that we don't have to have a total lockdown of visits. I believe that that social contact is just too important to lose.

And I think, speaking to a lot of the families who came into the office, and I've, you know, the families of the bereaved, I think that, you know, was a cruel end to their loved ones' lives and I actually think there's -- putting steps in place like that would be really important for people's end of life. And also for people going into homes in the future. I think we need to get increased public confidence and trust that people wouldn't be faced with that situation again.

Q. You've mentioned two issues there, the first being a resource issue, the second then being some type of protection for residents' rights.

I'm curious, you mentioned twice there that the care home contract you see would be the way to do that.

In England, regulations which the regulator enforce have been changed to guarantee visiting, and in Scotland there's legislation working its way through the Scottish Parliament, in Anne's Law. Do you consider that it's the care home contract, it's that level at which intervention needs to be made or is it a more legislative or regulative change?

A. Well, I think -- you know, I wouldn't have a firm position on that, and I think, you know, Northern Ireland should look at what's happened in other jurisdictions. The key for me would be that the system put in place is effective, and whether you need legislation to do that or whether the contracts can cover that, but I do think we need a situation where -- that care homes must provide that facility, and that's up for government to look at the best way to do that.

I think if you had that in place, you would also address other issues that came up, not just the visiting, but also access. For example, GP access to care homes that was cut out, and also access for the likes of the RQIA in Northern Ireland, the inspection regime. I think it would provide a lot more support for homes if you had that facility.

Q. Before moving on to RQIA and care partners, do you believe that the decision makers understood the crucial

role that family carers play in care settings for the residents and loved ones in care homes?

A. I think that became more clear after a few months of the pandemic. You know, I think the Public Health Agency started to have regular meetings with family members, and I think most of the authorities got that that restriction in visiting was having a huge detrimental impact on the residents.

So I do think people realised, you know, when they listened to the stories, when they listened to the impact on families and the older people. I think most, you know, if not all of the authorities realised that this was an issue that needed to be looked at. And obviously the Care Partner scheme emerged from those discussions.

Q. If we could then move on to care partners, and I'm going to refer back to the 8 October correspondence you sent to the Minister, if we could have that back up on screen please.

INQ000250250, and just at the bottom, then, of that page.

You say that:

"[Your] office has spent the last four weeks dealing with calls from families in distress and then angry, when care providers could not deliver the access to

their loved one which they believe the new guidance entitled them to."

And then also, that:

"Home providers are stating that they're not able to safely facilitate the visiting arrangements outlined in the most recent Guidance."

For the avoidance of doubt, this correspondence and these paragraphs, is that dealing with the care partner concept in particular?

A. Yes, that's correct, yeah.

Q. And in your statement you say that you observed tensions between family members who wished to have access, and care providers who were struggling to implement the concept. What, in your opinion, was the source or the cause of that tension?

A. This was a really big issue at the time. We were getting really mixed messages after the announcement of the Care Partner scheme. Some of the providers seemed to adapt well to it and put in measures that made it possible to introduce it. There was clearly some providers who wanted to do it but were saying that they had a lack of resources to implement it, and had some difficulties implementing parts of it.

And then at the other extreme we came across providers who just seemed to not adopt it at all, and we

had families come in to us who had said -- who had heard about the Care Partner scheme, had heard, you know, friends or relatives with people in other care homes getting access and yet the care home that their loved one was in wasn't providing this.

So there was a clear inconsistency of approach across the sector.

I think part of it was communication. It seemed to be that there was confusion from some of the providers that we dealt with directly who didn't seem to think that they had to introduce this scheme. And I'm not sure where that confusion came from, because they all should have received the guidance, the same guidance, but there definitely was a different approach from many of the homes. Some of it was about resource but some of it, I think, was about the understanding of what they were required to do.

Q. You talk about issues of confusion and we're trying to, perhaps, delve into where that arose. Do you think, whenever you look at the communications from the Department of Health to the providers and their families, do you think the concept itself was sufficiently defined?

A. I think it was confusing. It was a new concept, and it was something that, you know, had been brought together

quite quickly, in fairness, in relation to the response of families.

Again, it is probably an issue and a concept that, you know, probably needed a bit more time to be talked through on a practical level. I think most people were in favour of what the Care Partner scheme was designed to do, but again, some of the detail of it wasn't very clear and there was clearly some of the providers who struggled with introducing it more than others, and part of that was resource. Part of it was staff, you know, sickness. A lot of staff at this time were getting -- were contracting Covid, and there was a lot of issues around that. So there was extra work involved for the homes to implement the scheme and I think some of them were just more -- or had the ability to do that more quickly than others.

Q. In terms of talking this concept through, about a week or so before your correspondence, Ms Shepherd of the IHCP wrote to the Chief Nursing Officer flagging that there'd been no prior engagement with providers in the care partner concept. Do you understand that there had been no engagement with the IHCP on the care partner concept?

A. Well, I can't say for sure but I know that at that stage we had been in regular contact with Pauline Shepherd

right throughout this, and there was a frustration on our side, you know, that the lessons hadn't been learnt from the previous experience of developing guidance and consultation. So when we looked back on what happened in March, again, there was a feeling that there should have been, you know, a more collaborative approach to this, and again, that, in my view, led to the difficulties in implementing the new policy consistently across the sector.

Q. You used the word "our" frustrations there, so was the Commissioner for Older People consulted or engaged with prior to the announcement of the care partner concept?

A. There was, yes, there was -- there was consultation with us on it. Again, you know, we were aware it was being developed. I think it had -- from memory, it had come out of a lot of the meetings with the Public Health Agency, so we were aware that this concept was being worked on.

Again, from the commissioner's point of view, we probably weren't the experts in terms of, you know, identifying what was going to work and what wasn't, and that was probably something that did require more engagement with the sector as well, in terms of looking at the practical implication of this.

So whilst we would have had our views on it and

in -- and, you know, my view at the time was broadly supportive of the concept. I didn't think it was perfect, but it certainly -- it looked to me like a significant positive move by the department at the time.

Q. And does that continue to be your opinion today?

A. Yeah, I think it was a positive development, but I think it's something that if we were planning again for what we would do in a pandemic situation, I don't think that would be the perfect solution. I think it was quickly pulled together. It helped -- it certainly helped some families. It gained access for many families. But I think it's really important going forward that we look in the round. That it's not -- you know, I think a new policy needs to look not just at the sort of care partner type system but also just the wider general visiting as well in homes, as well as looking at GP access and inspections as well.

Q. I think there's a general acceptance that we're always going to fall short of the perfect solution for every scenario, but you're accepting that the care partner concept is a positive one, it perhaps just needs more work to work through the practical implications?

A. Yes.

Q. Robin Swann, former Health Minister, in his written

evidence to this module suggests that the concept should be placed on a statutory footing. What, if any, benefit do you think that would have?

A. Well, again, I think it could have benefit if it was a revised version of it. I think we would have -- part of that process, it should be reviewing how it actually worked in practice. Also any review of that would have to identify what resources would need to be put in place from a sector point of view to implement it. I think the idea is good. I think the idea that family members should have more of a say in the care of their relative is a very positive thing, and it should be facilitated as much as possible.

So, again, I wouldn't say that the care partner scheme that was introduced in 2020 would be just the scheme that you would put in in 2025, but it certainly would form the basis of reviewing what was needed, and I think it could be built on and made better.

Q. Thank you.

I'm going to turn briefly to RQIA inspections, and your position is set out pretty clearly in your witness statement at paragraphs 149 and 150. And you think a degree -- or inspections should have continued to a greater degree than they were.

If I could just ask you about the Services Support

Team, which was the reorganisation which took place to enable inspectors to support care providers during the early weeks and months of the pandemic in particular.

First of all, do you consider that that was a helpful step which was taken by RQIA, and secondly do you consider that it was in any way an adequate substitute for the oversight or assurance provided by inspections?

A. I think, again, this is quite a difficult one. I think at the time -- this decision was taken at the time when we were about reducing footfall in care home settings. So there was some rationale for stopping physical inspections, with that in mind.

However, reflecting back on it, you know, I had concerns at the time about that -- what that would actually mean. If there was no oversight of the services happening at a real critical period, you know, that -- that raised concerns with me.

Probably the bigger concern, based on my experience as commissioner in dealing with care homes and investigations, my biggest concern was probably the fact that, you know, without friends and family in visiting, I certainly felt that I'd lost my eyes and ears on the ground, because, to me, that was a more valuable source of information than RQIA inspections, that maybe only

happen once a year.

So whilst the inspections stopping I think maybe in the public's eye probably was a more worrying thing, I actually think, you know, that the bigger thing was the fact that families weren't allowed in, and I think that was a much more -- probably a much more damaging decision than the inspections.

I think the support services in theory, again, was a good thing, that RQIA would move to the sort of support mode for homes and I think that was a good thing. But I think also, with the reflection, I think it would have been, you know, better if we had -- if homes had the facility to bring in inspectors as well.

Maybe not from an inspection point of view but more, again, as a support point of view, because this was new ground for them as well, and I think if they had a bit more expertise on the ground that might have helped homes get up to speed more quickly.

Q. If I may just then move on to the issue of DNACPR notices. You made a series of statements during the course of the pandemic -- it's not necessary to call them up on the screen but it was 30 March 2020, 6 April 2020, and then, again, further even as late as November 2020.

Why did you think it was necessary to make

a statement even as late as November 2020 on this issue?

A. Again, this was an issue that kept raising its head every so often, you know, there was people who were -- had come to my office raising concerns about maybe their own family member. There was family members that were discovering that a DNACPR had been put in place without consultation with them, and worried that the resident didn't have capacity to agree to that.

So we were getting *ad hoc* examples like that. We also, at the time, I was working very closely with the Welsh Commissioner, and a series of organisations across the UK. We were having Friday meetings to discuss common issues, and this came up as a wider story across the UK where there was a number of stories that had broken where certain trusts and GP surgeries were writing out to people with underlying conditions and asking them to sign that, and it was seen as not good practice that there was this kind of blanket approach to people who might have been in that position.

Q. And in terms, then, of these statements you make, just to name a few, 30 March, 6 April, and then end of November, what, if any, response did you receive from the Department of Health to those statements?

A. From memory there was -- this came up in a few of the meetings we had with the Department of Health. We

raised it as an issue. We got assurances that this is something that they -- that shouldn't be in place. There was agreement that it shouldn't -- the process around DNACPRs shouldn't change.

So again, I think the outcome of that was really, again, communicating that. We were, you know, keen that it was being communicated out across the health service, whether it was at trust level or GP level. But as organisations, we felt it important to put it out there, because there was a genuine concern amongst older people at the time that they may not be admitted to hospital, as well, and this was, again, a concern for care home providers, as well, about whether they should ring an ambulance for somebody if they're in this position.

Q. And very briefly, are you satisfied that there was sufficient, then, communication from the Department of Health across the sector in order to deal with those concerns?

A. I think communication did go out, and -- but I think the fact that you've referenced, you know, some of those statements over a period of time reflects the fact that we were still hearing some cases where people were surprised to see this in place. So I think again, the communication got better, but there was still some experience where families were bringing to my office,

saying they were surprised to find out this was in place, because again, it would be something that should involve the family.

Q. And just in finishing, then, two final points: you create the impression that there wasn't sufficient learning from first to second waves of the pandemic. Is that a fair summary?

A. In terms of DNACPR?

Q. In terms of a whole heap of issues across -- affecting the adult social care sector?

A. Yeah, I think it could have been better. It could have been better. I think there was a lot of learning early on. I think I, you know, I went and gave evidence to the Health Committee who did a review of the response to the pandemic in, I think it was August 2020, August, September, and even at that stage, I felt there was learnings from the first few months. So I think by the time we were in the next wave, I felt we could have learnt more and be better prepared.

Q. And just very finally, then, your kind of global or ultimate recommendation coming out of all of your experiences is that future planning must be informed, if not created, by a group of experts, by experience, including private care home providers, their operational staff, and family members of care home residents.

Just in terms of practically, how would a group of that nature work and how would it have improved the response of the adult social care sector?

A. Well, again, as I said, I do believe there was a lot of commitment from a lot of organisations and members of the public who wanted to feed in to these very difficult discussions, and decisions. And I think, in the future, you would want to see more of a commitment from government to press the button on starting up a group like this, if we were faced with another pandemic, that this group would spring into action pretty quickly, working collaboratively with government. And I think if it did do that, you would probably get to the stage where you could get guidance, better guidance more quickly.

In terms of the practical implications, none of us have a crystal ball about when the next pandemic hits, so obviously just from a practical point of view, that would be something the government would need to keep updated on an ongoing basis to know. But I do think it would be valuable to have a group of experts because I was kind of -- I was surprised, even three or four months in, when I had some of my meetings with experts, about how little they had been called on from government, in terms of decisions. And I felt that was

a serious gap.

MR BEECH: Thank you very much, Mr Lynch.

Thank you, my Lady, I've no further questions.

LADY HALLETT: Thank you, Mr Beech.

Now it's Mr Wilcock who is just sitting there.

Questions from MR WILCOCK KC

MR WILCOCK: Good afternoon.

A. Good afternoon.

Q. I am asking you questions on behalf of the Northern Ireland Covid Bereaved Families for Justice, and I'm going to -- I've been given permission to ask you questions on four topics.

The first topic is the one you've just been dealing with, DNACPR, and I want to ask you about a question that the Minister of Health was asked by a fellow MLA in March 2021 about the application of DNACPRs in Northern Ireland. And the written question that he was asked was this: how many audits have been undertaken to monitor adherence to policies and guidance in relation to do not resuscitate orders in respect of people with, one, learning disabilities and, two, dementia, who have died with Covid-19?

And Mr Swann's answer, as he has explained to the Inquiry Module 3, was this: he wanted to make it clear that orders based on age or disability were

discriminatory and unethical, and he further asserted, in terms of the policy in Northern Ireland, media reports about the application of DNACPRs were ill founded.

But he was unaware, at this time, whether his department had ever considered or conducted an investigation into the concerns that were raised about inappropriate use of DNACPRs.

First question, did the Department of Health or any other agency in Northern Ireland proactively contact COPNI in an effort to understand the depth and breadth of concerns about the use of DNACPR in Northern Ireland?

A. I don't believe there was any specific requests for meetings to discuss that. I believe this issue came up in several meetings that I had throughout the course of the pandemic with officials, where that issue was one of a number of issues that we had raised with the department, but I don't recall any specific meetings being requested from the department to us.

Q. Thank you very much.

And presumably in those meetings you told them what you've told us, in your statement, et cetera?

A. Yes.

Q. Are you aware of any internal or independent audit that would have been sufficient, carried out by any agency,

to answer the MLA's questions, particularly with respect to those with learning disabilities or dementia in Northern Ireland?

A. No, I'm not aware of any audit.

Q. Did you have any sense that the department or any other agency was taking the concerns that you were mentioning in the meetings that you've told us about, that were being publicised in the media about DNACPRs in the year following -- between March 2020 and, let's say, March 2021, did you think the department were taking those concerns with the appropriate degree of seriousness?

A. I think, whilst these issues were raised in meetings with the department, I think it's fair to say that the majority of the time that I had to go out in the media and speak on these issues is because I wasn't convinced that they were all fully being taken on board. It certainly, with the DNACPR, when we did -- when I did the joint statement with other organisations across the UK, the feeling was, I suppose, we all were getting similar assurances, but we felt it was really important to raise that publicly, and put it out there in the public interest that this shouldn't be happening.

Just one other point that I would make. I was particularly concerned in Northern Ireland because we

were the only part of the UK and Ireland that still doesn't have age discrimination legislation in place, in relation to goods, facilities, and services. So I felt that we were even more at risk with some of this. So whilst there was concerns from me and others that there was maybe ageist elements to decisions being taken, I was conscious as well that we didn't have the legal protection that other jurisdictions had as well.

Q. Understood.

Second topic, which I can take relatively swiftly, RQIA. We know that in March 2020 a decision was taken to reduce the frequency of statutory inspections in care homes and to cease all non-statutory inspections.

Paragraph 149 of your statement, you indicate that there was no public announcement that physical inspections had in fact ceased. Do you think there should have been such an announcement? And if so, why?

A. Yeah, I think from transparency, I think it should have been publicly announced. As I say it was, I can't remember the exact time that I found out that they were completely stopped and then it's, you know, I had some discussions with the RQIA on that, but I think in these situations, it's, you know, public trust is really important, and I do believe when decisions like that are taken, that any public authority tells the public and

explains the reason and rationale behind the decision.

Q. And you've explained to us, when answering questions from Mr Beech, that in short, you feel that a consequence of this decision was that you, in particular, and every other agency looking at the care homes lost their eyes and ears as a result of this decision.

Now, in his evidence to Module M2C in Belfast, May last year, the Chief Medical Officer told the Inquiry that because RQIA staff were being, in his words, proactive in telephoning care providers to check in with them, then this by itself provided eyes and ears from the RQIA on the ground. Do you think that that did provide sufficient compensation for the loss that you've described?

A. Again, I don't think so. You know, I think the inspection regime stopping going in was one thing, but I think maybe a lot of the public would maybe not appreciate that that doesn't happen very often, and again, the biggest concern for me was probably family not getting access to the home.

I think certainly the support services were a welcome development, but I think, looking back, you would still have wanted some sort of physical presence for inspectors to go in in that circumstance,

particularly under the strain that the providers were under.

So yes, I think that was a -- that would have been a concern.

Q. Understood, thank you.

Third topic: the evolution of care partner guidance, again a topic that you have covered broadly already.

But in her statement in evidence to this Inquiry, Module 3, the Chief Nursing Officer of Northern Ireland, Charlotte McArdle told the Inquiry that "Northern Ireland led the way in ensuring that restrictions were applied in a person-centred way" and she pointed in particular to the evolution and implementation of the care partner guidance as an example.

Now, you showed us some of the correspondence you had had when dealing with the Care Partner scheme when answering questions from Mr Beech, and you told us about the tensions you had observed between families and care providers during that process.

Did you think that you were witnessing a world-leading example of person-centred care when your officers were receiving phone calls from anxious families and care homes about the implementation of this scheme?

A. Well, clearly the scheme was inconsistent, was operating

at many different levels across different care homes. Some care homes, the scheme worked well, but clearly there was a lot of care homes that were struggling with the implementation of it. And then at the other end of the spectrum, there was homes that just weren't implementing it.

So whilst it was progress on the issue, it was far from being a very effective option.

Q. Thank you.

Final topic, and this is about the role you played, and I want to give you an opportunity to comment on some of the concerns that families I represent have raised as to the role your office played during the pandemic. And to be frank, some families have expressed concern, and indeed criticism, that COPNI was not sufficiently effective in advocating for older people's needs and rights prior to and during the pandemic, and indeed since. They consider that there was a lack of visibility on the part of COPNI -- you've told us about the efforts you did take to get publicity -- and the slow pace of change, particularly in relation to adult safeguarding legislation, which you've spoken about as well, and the protections -- lack of protections against age discrimination.

Can you see why some people hold that view?

A. Well, I think in terms of our -- myself and my team during the pandemic, you know, looking back on it, I don't believe we could have worked any harder than we did on the issues. We were working very long days, and linking up with ministers and officials in a very difficult situation.

I think it's fair to say that we weren't experts on a pandemic, so we were learning, and having to learn very quickly of the issues we were dealing with. This was all new to us as well. But I can assure you that we were -- certainly with the resources we have -- you know, we are quite -- or COPNI is quite a small organisation -- that we were using all of our resources to try to influence where we could. But it was clearly a very difficult and challenging time. There's no doubt about that.

What I would say is, you know, post-pandemic as well, that there's been a lot of people who have raised personally with myself, older people saying that -- many older people who had actually campaigned for a commissioner many years ago were actually appreciative that there was a commissioner in place at that time, and it actually highlighted one of the reasons that they had campaigned for that. And I think what it proved to me, it was far from perfect, and the responses were far from

perfect, but I was able to get access to the likes of the Health Minister, on a regular basis to senior officials, and have some influence in there.

I would have liked to have seen things move a lot quicker, as I've given in my other evidence. I definitely think there's a lot of learning there for the future. And as I say, I hope that this Inquiry teases that out and actually puts in place real, strong recommendations that can actually bring about a situation that, if we face this awful situation again, that everyone will be in a better position to take action more quickly.

MR WILCOCK: And I have no doubt my clients agree with those sentiments. And I want to make sure, and I'm sure you've already noticed, I deliberately didn't say that the views I've given are universally held, but they are held by some.

Thank you.

A. Thank you.

LADY HALLETT: Thank you very much, Mr Wilcock.

Ms Jones is over there, just a couple more questions.

Questions from MS JONES

MS JONES: Mr Lynch, I ask questions on behalf of the John's Campaign, Care Rights UK and The Patients Association.

I want to start by asking you about the suspension of inspections by RQIA. The decision to suspend inspections arose, as you say, from a desire to reduce footfall in care settings and the risk that was thought to be associated with that. But in your experience did that decision take account of the risks on the opposite side at all, so the risks arising from suspending inspections such as an increased risk of abuse or neglect, or of a general deterioration in care, was that something that was taken into account before inspections were suspended?

A. As I've said, I think at the time the decision was taken, the focus was on protecting life and protecting the spread of the virus in the very early, early stages. But as I've said, I think that over the course of time in those opening months, it became increasingly clear about the negative side of not having access for family members into homes, as well.

So I think, for me, this is one of the key learnings in terms of what really would be done differently next time around if we were in this situation. I think it has illustrated just how important that family contact and social contact is with people living in those settings, and the damage as a result of removing those, you know, eyes and ears on the ground. As I said,

previously, as well, the removal of on-the-ground inspections, again, is something that I think the public probably would like to see in future continue, but for me, getting family members to be still able to access their loved ones face to face is probably the bigger issue here and giving reassurances to families, to the commissioner's office in future, and for other charities that represent older people.

Q. Thank you.

Just on the role of families, so not only in terms of the importance of access of family members for the wellbeing and care provided to people who live in care homes, but also in terms of the monitoring and oversight role that they play. Can I ask, do you think that was something that was properly recognised and taken into account when RQIA inspections were suspended?

A. I certainly think, in my experience, in the post as commissioner, the role and the intelligence from family members is absolutely critical in ensuring that the care home sector has the monitoring in place to ensure good quality care, and I think, based on my previous experience investigating a care home in Northern Ireland and the report that came out of that, the Home Truths report, it was really clear to me that that was probably the biggest single issue, that family members are so

important in ensuring that care is of a high quality, and that when they have concerns about that, that they're listened to and acted upon. And I think that is absolutely fundamental. And I think, going forward, certainly we need to restore public trust that authorities will take the appropriate action if we're faced with the circumstance again.

Q. I hear your recognition of how important those things are. In your experience during the pandemic, were they recognised to be important by decision makers?

A. Well, I think decision makers did recognise the importance of contacting family. I think -- I mean, and that was clearly in the conversation at the start. I don't think there was a -- people didn't see that as a big issue, but I think, as I said before, there was no right -- there was no good decision here.

At the time, we that deep concerns just about the scale and impact that Covid-19 would have in care home settings. There was -- it was frightening, some of the conversations that were being had at that stage. And I think, you know, everyone knew that there was consequences for restricted access, whether it was inspectors or family, but I think at that time the decision -- the primary thing was to save life and to take decisions to try to protect life, and that was

really the basis of it.

Q. Thank you. And then my final question is on a slightly different point.

At paragraph 178 of your witness statement, where you set out the recommendations that you would make, you say that:

"Future planning must be informed, if not created by, a group of experts by experience, including private care home providers, their operational staff and family members of care home residents."

You don't include in that list the care home residents themselves, and I just wonder if you think that work should include people who live in care homes and who can bring their own experiences to bear on what preparation and planning should be undertaken?

A. That's a good point, and I would, of course, include care home residents in that, and I would probably go further and say, you know, you'd probably want to include older people who aren't care home residents currently; because I think it's really important to get the views of people who may be future users of those services as well. We need to have a clear understanding of what people want, it's back to the point about care homes being people's homes, and that, we need to protect that, we need to protect the privacy, the family life,

and all of those wider things as well as their health and social care needs.

MS JONES: Thank you very much. Those are all my questions.

LADY HALLETT: Thank you, Ms Jones.

That completes the questions we have for you. Thank you very much indeed, Mr Lynch, for the help you've given to the Inquiry. Extremely grateful to you.

I think this is probably the last time we're going to call upon you, so the burden is over. I don't know if you still live in Northern Ireland, but if you do, safe journey home.

THE WITNESS: Thank you, my Lady.

LADY HALLETT: Thank you.

10.00 tomorrow.

(4.11 pm)

(The hearing adjourned until 10.00 am the following day)

INDEX