Written evidence submitted by Group 6 (Event 2) (EPW0086)

Transcript of roundtable event with patient representatives and patient support organisations held on Wednesday 11ᵗʰ May for the Health and Social Care Committee Workforce Expert Panel.

Group 6

Anita Charlesworth: … and so I thought it would be nice if we all introduced ourselves because we are now in a small group together. So, if it's OK, what I'm going to do is call out peoples' names based on where they sit on the screen because I haven't found a better way of doing this on [Microsoft] Teams. If you could just say who you are, either from an organisation or an individual, and what perspective you're bringing to this conversation? So, Participant A, could we start with you?

Participant A: Yes, of course. Participant A. I'm here representing people affected by dementia who draw on both health and social care.

Anita Charlesworth: Welcome. Participant B?

Participant B: Hi, my name is Participant B. I've got an extensive background working as a nurse specialist and nurse consultant with the NHS, and I'm obviously here to represent people affected by breast cancer.

Anita Charlesworth: Welcome. Thank you. Participant C?

Participant C: I've mostly focused on the cancer care workforce in my role. We had hoped to put a patient representative as well, but it was difficult to find someone.

Anita Charlesworth: Thank you very much for being here. Participant D?

Participant D: I'm Participant D, and I'm representing the Parkinson's community.

Anita Charlesworth: Lovely, thank you very much Participant D. Yohanna?

Yohanna Sallberg: Hi everyone. My name is Yohanna Sallberg, and I am the Second Clerk to the Health and Social Care Select Committee, and the Head of Secretariat to the panel, so I'll be here in the background trying to keep discussion to time.

Anita Charlesworth: Lovely, thank you very much. Participant E?

Participant E: Hi everyone. I'm Participant E, here representing the views of people affected by CVD.

Anita Charlesworth: Brilliant, thank you very much. And we've got somebody on hold, so…

Participant E: That's Participant F. He's a patient living with CVD, so I hope he does come back as I know he's quite keen to take part in this.

Anita Charlesworth: If it's not possible for Participant F with whatever's going on we can arrange for him to have a conversation with one of us if he'd like to do that. So, it isn't now or never... So, a couple of ground rules… We're thinking about the NHS and social care. I think with all your organizations, many of the people with those conditions will be using both, won't they? So, if I may, could I really encourage you to be very clear and think about both the NHS and social care? That's very important to this review. We've identified as the committee.... Oh, hello Participant F. Could I ask you to introduce yourself?

Participant F: Yeah, sorry I had a bit of a technical problem there. I'm Participant F. I live with CVD. I had a stroke as a teenager. I work primarily as a volunteer.

Anita Charlesworth: We're immensely grateful to you for joining us. So, we're just saying in terms of ground rules, we're thinking about both NHS and social care in this review, and then what we're looking at is some of the commitments. Now, commitments around workforce are either hyper-specific or incredibly vague, so what we've done is kind-of grouped them into three areas. You'll be pleased to know I'm not going to go through and ask you, 'do you think the NHS is on track to meet the 50,000 nurses target, you know, is it going to be 48,000 or 52,000?' I'm not going to ask you that. What I want, and in particular, because you represent people who use and rely on services, is firstly to explore the impact of both number of staff and the skill mix of the staff providing services on those who are using services. So, the first set of things that I'd like us to discuss is about the number of mixed staff. The second set of things is really then about... we're interested in some of the pledges around the training and development of staff. The second set of things I'd like us to talk about is the extent to which that commitment to support the training and upskilling and development of staff, how that impacts on those who need services. The third thing I'm going to ask you to think about is how the wellbeing of staff affects and impacts those who need services. So we'll take them in turn, and if it's alright – because it's so important that we hear all the voices – would you mind terribly if what we do in a fairly structured way is to take each of those questions in turn, and I go around and ask each of you for your reflections so that I make sure – because obviously you represent people with very different conditions, who may have very different experiences and it's really important I think to get that diversity of experience and perception here – so when we're going round could you think about both NHS and social care for your groups? I'll go around broadly in the same sequence that we did for the introductions, so you can mentally check when you're going to come. So, could we start, Participant A, with me asking you for your reflections on how the issues around the number and the mix staff is affecting the people that you work with in both the NHS and social care? Are you seeing, for example, the increases in numbers that are committed to mix the staff, and what impact is that having?

Participant A: It's always tricky going first, isn't it? The nature of dementia is that it does straddle both health and social care, and part of the reason for that is because there is no significant real pharmacological intervention for dementia. It is a health condition, but for that reason it's largely treated or supported via social care. From a medical perspective it's quite mixed as to where dementia sits, so it is often put under mental health, but it's not a mental health condition; it's a physical health condition. It is a brain disease. Again, that might be due to the fact – it probably is – due to the fact – that there is no significant medical intervention, and therefore it's more around treating the symptoms rather than treating the condition itself. But due to the fact that dementia is such a complex condition that doesn't have those significant interventions available, people with dementia will often, like I said, they do straddle health and social care, but they also straddle a whole host of different disciplines within those two areas as well. I can talk about the pathway in this group because… we all know what a pathway is. So, the usual process that people might go through, so for example, before they receive a diagnosis, when they receive a diagnosis, post diagnosis support and more advanced support, all the way through to end-of-life care. That's generally what we often mean when we talk about a pathway. People with dementia will encounter all sorts of different disciplines and professionals during that period. There is – and correct me if I'm going off on a random tangent here and not actually answering the question – but the nature of that means that they often have to retell their stories and what they've experienced, and obviously for people with dementia that's particularly difficult and disempowering as well. We certainly see a lot of examples, far too many examples, of people saying to a clinician or a social care professional who

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should know better, 'I have dementia', and therefore they proceed to spend the rest of the appointment directing everything the clinician wants to say or social professional at their partner instead of at the person. In terms of the number of staff that are out there, like I said, a lot of people with dementia rely on social care. I think that the shortages in social care staff are well known, and they were particularly bad pre-pandemic and they've gotten worse since. During the pandemic we've seen upwards of about 40,000 or 50,000 people, I think, leave their jobs in social care after the vaccination as a 'condition of deployment' rules were brought in and then subsequently removed; aka 'no jab, no job'. So, we're seeing significant shortages there, and then even amongst those who do work in the sector, the knowledge and awareness of dementia is quite scant. Amongst social care staff, only about 44% have had any kind of dementia training, and we know, for example, in residential care homes at least 70% of care home residents have dementia, and amongst those who draw on home care, at least 60% have dementia as well. We know that – and I'm going to shut up in a minute – we also know that a lot of people with dementia go into hospital for entirely avoidable reasons and often get stuck in hospital because they can't go home, because the support isn't there for them, and they often deteriorate whilst in hospital and things just get worse. I'll pause there and allow others to come in.

Anita Charlesworth: That's really helpful Participant A, thank you. Participant B?

Participant B: When I was looking at the prep, it was asking about experience of care, and the kind of words I wrote down that we hear are 'varied' and 'inequitable'. So obviously my organisation is very sub-specialized, and I guess predominantly within the NHS, then maybe some crossover into social care, which I think then someone will be accessing maybe in more generic services rather than the specialist services within the NHS. I'm just thinking of social work, what we are hearing from people that just haven't got any kind of family support or practical support, that kind of thing. I guess what we're hearing in terms of the workforce is that there's just – from both the workforce themselves and from the people within the services – that there's just not enough time. People sometimes can't actually access their clinical nurse specialist, and when they do have a concern, the inequity can be certainly towards much more support to people with primary breast cancer than those with secondary breast cancer. There are huge discrepancies and, you know, we try to support the NHS in recognizing that, but that's certainly something that comes through. **Anita Charlesworth**: Thank you, Participant B. Participant C?

Participant C: Thanks. I expect we're going to agree on a lot of the things that are said across the charities. The first thing to say, the cancer population is changing, and more people are living longer with cancer, so over time there will be a larger social care aspect to that. A lot of our asks at the moment aren't necessarily focused just on social care, but we do have a big focus on end-of-life care. Similar to what Participant B was saying, there just aren't enough numbers. I did some rudimentary analysis of one of our most recent surveys of patients, and 'time' and 'support' are the third and fourth most used words after 'treatment' and 'cancer', which are obviously going to be first and second. Such analysis is obviously very limited, but it nonetheless gives an idea of what patients are saying. We're hearing more and more that patients aren't really being given the time, but they can see for themselves that nurses are completely stretched and overworked- nurses don't have the time to give to patients, and they're finding that impact on their care. I have tried to pull out a couple of quotes because I thought it might be useful, but just a short one from one of the patients we surveyed: "more nurses and staff in general needed… I have no support, I have no idea how to deal emotionally with what I've gone through, I'm completely lost right now and relying on Facebook groups for support". Other patients surveyed have responded along similar lines to this. A lot of it is that they're looking for support-more cancer nurse specialists- but there is a wider issue and there is

a need to train more allied healthcare professionals as well that can then support cancer nurse specialists to free their time up and help support patients more to do some of the things that allied health care professionals can't do. The numbers of staff just aren't anywhere near where they need to be to support patients in the right way at the moment.

Anita Charlesworth: Thank you, Participant C. Participant E?

Participant E: As Participant C said, lots of common themes. I guess the most important thing to stress when it comes to the CVD workforce is that we actually don't know a lot about these people, including how many of them there are. We don't know how many specialist heart failure nurses we have, let alone how close they are to retiring. We've done a big audit of NHS HR databases and have found that it doesn't provide any more illumination either. So that's one of the big things around talking about workforce, is just, you know, we don't know who they are, we don't know where they're working, and that's before we get into the impact of the pandemic on how staff are feeling. One of the ways this impacts on patients… it's quite apparent in patients who phone up our helpline. About a third of them are talking about struggling with access to care and struggling with knowing who to go to for support. So that's the first thing I really wanted to just mention. We also don't know about the multidisciplinary heart team. It's being developed, it's at different stages, so different areas have a different concept of what that means. We've looked for one kind of consensus definition about what good looks like when it comes to that, the heart team of really the future, and nobody agrees on that. So that's another problem that we've identified. In terms of the skill mix of staff, the best analysis of that is from the GIRFT report into cardiology, and they found very variable levels of competencies amongst people in the heart team. [There is] great variation in the extent, for instance, of who's prescribing; that was one of the things they particularly highlighted. I'd also just want to call out the lack of diversity in cardiac leadership that translates directly, we think, into quality of care, and especially on the lack of diversity in academic cardiology, which impacts on clinical research and the care that we're able to develop for heart patients.

Anita Charlesworth: Thank you very much. Participant D?

Participant D: I thought I'd start with social care because I think that's probably what we know the least about in terms of the workforce and numbers and skill mix. I mean, we know the overall picture is pretty gloomy as Participant A mentioned for Alzheimer's. In terms of skill mix – and I might come on to this a bit more in terms of training – but we produced a report recently called 'Nobody Really Knows Us' which was looking at Parkinson's related dementia, and our survey of unpaid carers found that only around 25% felt that the home care staff understood dementia, and only 29% felt that they understood Parkinson's. So, there's a real need for specific training within the social care workforce, which we also feel would help in terms of enabling better career development and making social care a more attractive career choice. In terms of the overall picture, there's 145,000 people living with Parkinson's in the UK, and we expect this to rise by nearly a fifth to 168,582. There are over 40 symptoms associated with Parkinson's, so this requires an integrated kind of multidisciplinary approach to care, seeking expert input from a range of specialities. For example, this could include neurologists, geriatricians, Parkinson's nurses, physios, occupational therapists, speech and language therapists, mental health supports, and specialists such as neuropsychologists and neuropsychiatrists. So, it is clear that there's a lot of different inputs that are needed. However, we know that there are workforce shortages across these specialities and so people with Parkinson's, depending on where they live, aren't able to access vital aspects of their care or, if they can, there might be long delays and so they may not get the sort of physio or the mental health support they need. It's a progressive condition, so we know early intervention is key. We've looked at workforce data around these different specialities. For example, there was a survey by the European Academy

of Neurology in 2019 that ranked the UK 44 out of 45 European countries in terms of neurologists per head of the population, with only Ireland being worse. We found the Royal College of Physicians have in their survey found that 48% of consultants, geriatricians in England are set to retire in the next 10 years, which is rather concerning. In terms of Parkinson's nurses, the data is generally put together by ourselves, and NICE used to recommend a maximum of 300 patients per nurse, and on that basis there's 480 Parkinson's nurses in England in terms of headcounts at the end of December last year, and to meet that 300 caseload we'd need another 34 Parkinson's nurses. We are working on an analysis of working time equivalent and expect the actual number to be much higher. In terms of allied health professionals, the data is really poor in terms of what's publicly available. However, we know that access can range quite a lot. We have a patient reported experience measure questionnaire as part of our audit of Parkinson's services, with over 8,000 people with Parkinson's taking part, and for physiotherapy, for example, the overall UK figure is 66% had access to physio which obviously means 44% didn't. This ranges regionally in England between 43% and 77%. [What was] particularly bad was that for speech and language therapists, only 47.8% had access, and across the UK this ranged from 30.8% to 54.7%. So, as you can see, there's a real need for better workforce planning, increasing supply, looking at the pipeline of staff entering, retention etc. The impact on our community is longer wait times and worsening symptoms, because Parkinson's, as I mentioned, is a progressive condition. I think in our survey last year looking over the course of the pandemic, 8 in 10 people experienced worsening fatigue and 83% an increase in stiffness, and 88% an increase in slowness of movement. Maybe if I just end on a quote: one of the quotes from a survey participant was, "I feel abandoned by the NHS. I can't get to see my neuro-consultant for five months, and we have no dedicated specialist nurse to go for advice. My deterioration is very speedy now and it frightens me the worrying effects; the lack of sleep and the depression". That is not a particularly welcoming picture in terms of getting people with Parkinson's the support that they need.

Anita Charlesworth: Thank you for sharing, that's very powerful stuff. Participant F, would you like to offer your perspectives on whether there's enough staff, how that affects you, and also the mix of people that are that are that are involved in care?

Participant F: Can I just say that I do work in clinical research as PPI, as well as primarily with BHF, but also with people like National Institute for Health Research and NHS England. I do lots of service reviews, I do lots of funding applications et cetera, et cetera. So, I've got a pretty good knowledge across the board really. I know we only have a short time and I'm going to try and fit an awful lot in a very short space of time. So [in terms of] personal experience, I still can't get a GP appointment without having to make recalls and recalls and hanging on the telephone line to make an appointment to see a GP. I've had two exacerbations for a multiple condition that I live with, COPD, and I've had exacerbations and and not been hospitalized through my own self-management of my own conditions. I've had no referrals to any particular specific condition leads, etcetera. I have to have annual reviews, because of my stroke at a very young age of 17, and developing my abilities to live a life through my own initiatives really and support from being locked in, to living with basically left sided hemiplegia. I have never, ever had any social care, support, inquiry, or any contact with social services without being abruptly told to go away; politely, really. With regards to staff, we still don't have enough stroke units; we still don't have enough ambulances; we still don't have enough beds; we still don't have enough patient care, both in the community and in hospitals; we've got limited staff resources looking after beds, numbers that really are not safe in my opinion and do not provide a quality of care that we should be, you know, aiming to achieve. [On] the mix of skills, the pandemic… I know through lots of people that work in academia that they were reallocated into NHS services, and NHS services reallocated everywhere else. From the patient perspective, during that that period of the last three years nobody knows who they need to contact. We need clarification

around, 'do we phone 111? Do we phone 999? Do we speak to a GP?' That's one area. The other area is that not only are we dealing with the psychological effects of the pandemic, but we also have young kids waiting for heart operations, waiting for treatments, waiting for diagnostics. Their mental health must be a real major issue. So, we really need to address mental health in a big way. We also need to address the mental health… the support that the Medical Staff, clinical staff, are providing because I think that they've been under so much stress and pressure over the last three years. I think they have lots of underlying things that we need to bring out into the open to discuss and be very, you know, candid about what needs to be done. Let's be honest and truthful about what's needed. I think that the resources and funding that are being allocated to areas where perhaps it should be reviewed and looked at. We have not in any way, shape or form provided any EDI across anything around the pandemic. And please don't let us go back to pre-pandemic services, because that wasn't really any good either. We still have people with learning disabilities. We still have heart attacks; we still have strokes. We've got to think about the whole community, not just the fact that people might be of a different race, colour, or culture, you know. Working mothers are a group of people that aren't included. We need to get these people involved, improve health literacy levels and understanding about health conditions. We need to educate children in schools around managing health conditions, living with health conditions. COVID isn't going away. We've got other things to look forward to, unfortunately, but we need to be very positive about how we approach things. And predictive… I could talk for hours about prevention and the lack of prevention. Just prevention alone… How many people on this call know about CPR? How many can actually do CPR? Why aren't we learning that? Why aren't we understanding how we can save a person's life just by applying a bit of pressure to somebody's chest in the hope that the ambulance arrives in time? So there's lots of things we need to look at and a really do something about, take action around it, not sit and consult about it with middle class white people, you know, because the people who are dying, the people who are waiting, are the people from the lowest socioeconomic areas of our society who live in the worst housing conditions in the worst environments, and we've really need to get the message out to those people. Sorry, I would go on, but wellbeing of staff I think I've covered. Training and skills of staff: I'll give you a personal experience of going to see a consultant and neurologist who was Greek, who had no understanding of the interpretation of my conversation with him and the report that I received. He had no understanding about the fact that I can't have MRI scans because, in his presumption, I've got metal in my hip or in my knee, which I have, but it's not that. It's the fact that I was pre-titanium craniotomy, so I've got nuts and bolts in the top of my head, not titanium. So, it's that understanding and culture which isn't just about recruiting. I've known for the last 30 years, we've been recruiting nurses from across the world, but we need to understand that we have a different culture in this country that clinicians need to learn and understand, and that's through practice and meeting people. So, I think there's a whole load of areas, and that's before we start talking about research of course.

Anita Charlesworth: We'll hold off on research, as that's not the topic for today. But one of the things that we've not touched on so much, which is one of the things that we want to explore a little bit, partly linked with the training, is the impact of digital on both the workforce and then how that's playing through into patients. So, does anyone want to come in at all with any reflections on digital and technology in relation to that? Yes, Participant D?

Participant D: I had a quick think in preparation for this in terms of how people with Parkinson's experience digital technology and the use of that throughout the NHS. It's quite a broad topic, but I guess there were two things that I wanted to highlight. One is that there is kind of a smart watch called the Personal KinetiGraph, which is called a PKG, which monitors symptoms in terms of movements and processes them through an algorithm, and that data is sent to clinicians directly

which helps monitor the progression of the condition and the related management of it. So, it's quite an innovative approach. It's recently received £500,000 of extra funding from NHS England to look at further integrating that data into NHS systems at a Parkinson's service in Plymouth with the intention if it's successful to roll it out more broadly within the NHS. Then I guess the other big theme of the last couple of years is virtual consultations. I think there has been quite mixed views in in terms of how they are experienced by patients. I think there's a lot of work that needs to be done in terms of making sure it's safe and appropriate for the individual, that the individual retains the choice or right to the face-to-face appointment, if that's what they would prefer. In terms of some of the statistics from our survey of Lancaster University last year about COVID restrictions, 3 in 5 people with Parkinson's had a phone or online appointment with their Parkinson's nurse, and over a third had one with their consultants; only 40% said they were pleased with the outcome of their consultant appointments and just under half, 46%, of people with Parkinson's felt their doctor could understand them well, and fewer than a quarter felt that connection with their doctor was comparable to face to face; and only 1 in 10 would recommend online or phone appointments to other people with Parkinson's. That was in brief our community's experience of use of technology in the NHS.

Anita Charlesworth: That's really helpful, thank you. I'll go around because I think most people want to contribute. Participant A?

Participant A: If I may just briefly, inspired by what Participant D said in the in the previous answer as well…. Of course, the nature of dementia is that dementia is a catch-all term as well. It covers potentially more than 100 different conditions – we don't actually know – and each of those different conditions present in a slightly different way; they have slightly different symptoms and all of that. So how you support somebody with dementia is very different according to the dementia that they have, which we don't record as standard, and obviously it depends on the individuals themselves as well. But in terms of the question of digital… Generally digital isn't used especially well in social care. If you live in a care home you often have kind-of a 'this is me' book which is meant to be a guide about the residents, and obviously for people with dementia that can be a lifeline because it tells you about the person where the person is unable to tell you themselves. We know that [for] people with dementia it primarily affects their short-term memory. Their long-term memories are pretty good, and as soon as you start engaging them on what they might have done when they were younger or whatever they can really come alive. So being able to record information like that is incredibly helpful, but also being able to record some of that short term stuff is really helpful because the person themselves can't retain it, and obviously there's a significant turnover of staff, but also there's obviously different shift patterns. Generally, those 'this is me' books are used quite sparingly and not very effectively, I would suggest. Oftentimes it's just who is the usual person coming to visit you, and how you like your cup of tea. There's not something in there around, for example, 'Mary lost a child when she was very young and therefore this might be triggering for her', or 'she was a very established clinician', 'there's no sense of the person in there'. It's just, 'I might like this, and my son and daughter are going to come and visit me'. Also, we saw during the pandemic, and we unfortunately continue to still see, care homes not being very digitally up to date, for example when visits have been massively restricted. Digital visits aren't ideal for people with dementia but they're better than nothing, but very, very few care homes were set up to do that, and very few still are. More broadly in terms of social care – and of course with people with dementia it's not just about residential care or home care, but it's about support services and things like that as well – I think there's probably a bit of an assumption that because people with dementia are generally older people then they're not especially digitally literate; that's not true. As with everybody across society, there's a real mix. There's those who love digital and those who hate it. So, it's about

making sure that we recognize that mix. But also, in terms of things like assessments, whether that is a care needs assessment or a carer's assessment or similar, or even a memory assessment service to try and diagnose if you have dementia. Sometimes they can work well digitally and sometimes they can't; say for example if you require a memory assessment service, sometimes you might need to have a PET scan; sometimes it's helpful for the clinician to be able to see your gait as well; or just to see how you respond to the people around you and things like that- for all of these in-person assessments are necessary. Similarly in terms of carer's assessments as well, what we find with carer's assessments is that oftentimes the carers aren't necessarily looking for substantive intervention and substantive help, they're looking for somebody just to listen to them and hear their concerns and understand their concerns, and often just feeling as though you've been listened to can go a long way to making you feel better. If you've got somebody like that, who does that day in, day out, if they say to you, 'you're absolutely nailing this, you're doing brilliantly at this', then that's a real confidence booster. So that can have a big impact, but also in terms of kind of general assessments, whatever those might be, when we talk about digital I often think of a digital form for certain people with dementia. They often have comorbidities and so their form is too binary and too static. So, it's important to be able to have that discussion with people, but that doesn't necessarily mean, you know, jumping in a car and going somewhere. It could be a video call, for example. I think that's all what I was going to say so I'll stop there.

Anita Charlesworth: Brilliant. Participant B?

Participant B: There were just a couple of points that I wrote down in terms of workforce. I think the complexity of breast cancer treatments has to be reflected in the workforce and the sub-specialization, but again there's still not enough numbers. I agree with Participant E's point. I think we really don't know how many specialist nurses there are. Lots of NHS Trusts have lots of different models of how they run that. So, I think, yeah, that lack of understanding. I think succession planning and training and developing new nurses. In terms of digital, I completely agree that whilst it works for some people, we just have to be really aware... COVID showed us the Internet poverty issues. So, I think we just need to be really mindful that we don't isolate some of the population. W use digital/social media to communicate with people, but I'm really mindful of the people that we don't [reach], and that we just further compound kind of inequity of care really. But nursing staff and nurse specialists having an app to help you sit there and do a family history assessment can be really, really helpful. So, you know, it's for and against really.

Anita Charlesworth: Yeah, thanks very much. Participant C?

Participant C: Thanks. I'll just also agree on a few points from the workforce side as well. Not knowing exact numbers in the workforce is a key problem, which is why it was disappointing that the government didn't back the amendment to do the regular assessments of workforce numbers. That would have reassured a lot of people, I think. They've got the 50,000 more nurses' commitment, but I'd rather see a continuous, concerted effort to understand and address the problems rather than just putting out what can sometimes feel like arbitrary targets, and then we go back to trying to figure out what this might mean in practical terms for the workforce. I agree also that often the problem is a lack of support around the care plan, so patients are trying to get support on their mental health or their diet or lots of other things that cancer nurse specialists and others withing multidisciplinary teams can be really helpful with, but there's not always the capacity to do this for every patient. On the digital side, I'd again agree with the others. It can be genuinely great, and some patients do really like aspects of the digital stuff, but it has to be an option and not forced upon everyone because some people just don't like it. The other important point is that any digital or data solution isn't going to work as effectively if we don't have the numbers, because the staff

need to be trained, they need to be able to fully understand and explain these things to patients, and if the numbers aren't there, then they're always going to fall short of what the tech or digital solution could potentially be. I'm conscious of time, so I rattled through that quite quickly.

Anita Charlesworth: Thank you. Participant E?

Participant E: My point was really Participant C's last point actually, which is that the pandemic has really accelerated huge positive transformational change for certain areas of CVD interventions and especially cardiac rehabilitation, and now that's done in a hybrid way. But now I'm hearing from the cardiac rehab staff that we need to take into account the tech support as part of the core team. So, we've been mapping the team, they're like, 'we need the tech people', because the nurse like, 'why is the specialist nurse… 'So, the physio is spending all their time now trying to train people up on tech and train themselves up on tech. I think that was a kind of big revelation for us in talking about staffing. I think the other thing I'll just really quickly mention, because I'm also conscious of time, is that you detect high blood pressure opportunistically, so any intervention which takes people away from being in front of a health care professional does tend to worry us because that's one less opportunity to make every contact count and get somebody's blood pressure taken. So, in the first year of the pandemic, we know that there were hundreds of thousands fewer prescriptions for statins made, and if those patients aren't found and monitored to target, that will lead to thousands of additional heart attacks, and unfortunately, we see that bearing out now in heart attacks and strokes and in the ambulance waiting crisis. So, I'll stop there. But just to say there are definitely positives and there are also negatives to this agenda. I think that just needs to be fully understood, and we still actually don't fully understand that. So that's just another point.

Anita Charlesworth: Thank you. And Participant F?

Participant F: I'd echo what everybody's been saying, really. The only additional thing that I would say is that there is a mistrust, I think, within communities around the use of data, and I think it's important that things like the data guardians are used and their pillars are used in any use of data, and that organisations which use my data promote the good use of data across health and social care. Additionally, the MHRA, who provide the licensing of safe technology, it's used not just in self-management, but also in in clinical aspects as well. I think that patients need to know that things are safe that they're using. I mean, it's again around literacy levels. A lot of people still don't know how to take their own blood pressure. So, it's a learning process from that aspect as well, and obviously, as other people have said, we're missing out a whole load of communities there.

Anita Charlesworth: Thank you very much. So, two final things that I want to pick up on if it's, OK? We've talked a lot about specialist services, but if anyone's got any particular points, they wanted to make around primary care, as there are a lot of important commitments, particularly 6,000 extra GPs, 26,000 extra staff into general practice from pharmacy and physio, etcetera. So does anyone want to make any final points as well about how wellbeing of staff and the effect on patients and service users. We've just got a little bit [of time] left. If it's alright, I'll go around one more time and ask you particularly to reflect on some of those things which I think we haven't concerned so much yet. Participant A?

Participant A: In terms of workforce, not a huge amount on primary care except that there is a significant and growing backlog of… basically diagnosis rates of dementia have fallen through the floor, as they have for other conditions, but they've fallen through the floor from a fairly low level to begin with. We still experience some GPs, for example, saying, 'oh, I'm not going to put them forward for a dementia diagnosis because there's nothing that can be done to help them, so I'm

taking the decision that they're not going to be diagnosed'. In terms of the question about staff wellbeing – so again this will be predominantly for people affected by dementia, predominantly through social care – so [in] social care, morale is probably at its lowest level that I've ever known. We're having lots and lots of staff leaving because they're just fed up, and this is [not only] frontline staff but also very senior staff who I've spoken to who head up providers, big national providers, who are absolutely just fed up. If you work as a care assistant or similar, you could get a job in Tesco for far less stress, far more money, far better work life balance. That's entirely understandable them doing that, but it will obviously have a significant impact on those who draw on social care. For people with dementia, we know that they need time, and they need patience, and they need people who support them who know them, because sometimes they don't quite know themselves or they can't quite get out what it is they want to say. So having that inconsistency of staff is far from helpful and actually positively damaging. We do see deterioration that isn't necessary. But also, if staff are rushed off their feet and unable to support people then that has an impact as well. Just looking back during the pandemic, when we saw family and friends basically being taken out of care homes, or usual support services being withdrawn, that was essentially a massive withdrawal of the workforce. We saw during that time a massive increase in the number of very strong, very dangerous antipsychotic medicines being prescribed for people with dementia, and those have historically been used as what's known as a 'chemical cosh', so as a way of restraining people and sedating people. That is not what we should be doing. Obviously sometimes such medicines are necessary, but for the most part, where people have dementia, if you have the right care around them there's absolutely no reason for that to happen. And yet we saw a massive increase in the use of those drugs. So, I think that's a really strong example as to the impact that staff's ability to support and staff wellbeing has had on people affected by dementia.

Anita Charlesworth: Thank you, Participant A, that he's really powerful. Participant B?

Participant B: In terms of primary care, I guess from a breast point of view we are relying on GPs and allied professionals within primary care to refer patients with breast symptoms, and that's not just primary breast cancer. There are issues around people being referred with secondary breast cancer symptoms, and sometimes being investigated in multiple other specialities before a secondary breast cancer diagnosis is even thought about or found. So, it's about doing a lot of work, partnerships and collaborative work, with primary secondary care and us in the charity sector. In terms of… I've never known morale as low as it is at the moment and it's, you know, it's quite saddening. We support nurses in practice with education and training, NMC re-registration and what we are hearing is some nurses are paying for their own education. A lot of the time they're doing webinars at 7:00 o'clock in the evening because that's the only time. There is still that compassion and drive there to improve, but people are doing it in their own time, and education and training really needs to be valued.

Anita Charlesworth: Thank you, Participant B. Participant C?

Participant C: I agree with what Participant B just said there. Morale is very, very low. Even before the pandemic, 39% of nurses felt that the current workload was unmanageable, and 44% said that the current workload was negatively affecting their morale. That's got worse since the pandemic. On top of this, a lot of CNSs are now considering leaving the workforce, and that was the case before the pandemic as well. A survey conducted by the Royal College if Nursing in October 2021 found that 57% of nurses state that they are thinking about leaving their job or actively planning to leave. These issues are being seen across clinical roles within the NHS. This is linked to training and development. People don't feel that they've got the opportunities to train and develop, and that can push them out of wanting to continue in their roles, when they don't feel like they can progress, especially

when morale is so low. There's one more quote I'll just finish on, and this is from one of our CNSs: "I pride myself on the level of care I can provide to my patients. However, at times I leave work feeling deflated, knowing that if I had one less patient, or there was one more nurse on shift, those patients would have had an even better experience that day. There is only so much overwork, stress, and heartache we can endure before you reach breaking point". I think that is how a lot of CNSs feel at the moment.

Anita Charlesworth: Thank you very much. Participant D?

Participant D: In terms of primary care, there have been issues in terms of referrals. There's some research recently published, funded by AbbVie, the pharmaceutical company, that found there was a 20% drop in referrals to neurology compared to pre-pandemic levels. So yes, people are struggling to get access. I believe that they have picked up again more recently, but it all contributes to the backlog of care. Most of the Parkinson's care is managed in secondary care, however it is felt that there could be better links between primary and secondary care. In terms of staff wellbeing, and again we probably don't have figures to hand, but talking with health professionals on a regular basis, I would echo what others have said in terms of feeling burnt out and overloaded with work. A lot of Parkinson's nurses were redeployed to ITU during the pandemic, and I think a lot felt that they were torn, because they wanted to help out with the COVID effort but at the same time wanted to make sure that people with Parkinson's were getting the care that they need. One final point on training, with more general staff and condition specific, which continued to be an issue during the pandemic was getting Parkinson's medication on time in hospitals. If someone with Parkinson's doesn't get their medication on time, it can have devastating consequences on their health, leading to people not being able to walk or talk or swallow, in some cases. Around 63% of people from our 2019 survey didn't receive their medication on time every time in hospital, and from our Lancaster University survey during COVID last year, only 53% of those admitted received their medication on time every time. So, I think in terms of training there is a need to provide that very basic training. We recommend a 15-minute guided presentation on Parkinson's medication, and that's provided through the UK Parkinson's Excellence Network, which is free of charge. It's something that we want to see greater uptake of, so those simple things like just having your medication on time are considered. So, I think there is a lot to do on training, there's a lot to do on numbers, and we need a careful look at how technology is used to make sure it's all the maximum benefit to people with Parkinson's and others using NHS services.

Anita Charlesworth: Thank you. Participant E?

Participant E: Thanks. In terms of primary care, yeah, access to primary care is probably the single biggest issue for people at risk, with living with CVD, and that is routinely one of the most frequent issues that patients tell us when they phone our heart helpline, is access to their GP. We know that during the pandemic there were around 2,000,000 people whose hypertension management was disrupted, and that's largely because of the suspended QOF in primary care. So that's a huge priority for this year, is getting back to those hypertension targets, but how we are going to do that, you know, is another matter altogether. It's a hugely ambitious ask to go out and get these people back managed to target. That will lead to thousands of additional heart attacks and strokes, as I mentioned, if we don't find those people. But further to that, hypertension hugely correlates with health inequality. There is this huge focus on tackling hypertension in a targeted way, but that's just another challenge on top of getting back to the baseline of where we were, which was already not at a very good level. So that's probably the top thing when it comes to primary care. Then in terms of staff wellbeing, I don't have anything unique to cardiovascular to add to what everyone else has said.

Anita Charlesworth: Can I just ask you about the point you made about inequalities? Are you seeing any particular issues in relation to the geographical differences in access to things like primary care? So, there's obviously a target to increase staff, but actually one of the important questions is also [whether] that is reaching places where the need is greatest? Do you have any observations around that?

Yohanna Sallberg: We're out of time now, I'm afraid. So, it would have to be a very quick yes or no.

Participant E: Just to say, Anita, I certainly could get it for the committee in terms of geographical breakdown, but [I don't have it] to hand.

Anita Charlesworth: Thank you. Participant F? Very last word to you.

Participant F: I think from a patient's perspective that everything is very fragmented now, and whether it's accessing your GP or trying to get mental health sorted or trying to get counselling services, there's no clarity. We now have a new system being brought in with integrated care services, which nobody knows about really in the community. It's basically a very mixed bag of fragmented services that we have no clear way of accessing. I'd like to see health and social care under the same systems, supported by mental health throughout the whole of it.

Anita Charlesworth: Thank you very much. What an amazing group you've been. That has been quite a sobering hour to listen to what you have to say. Your contributions are incredibly valuable, very gratefully received.

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