**Moderator:**  
I'm so firstly, if everyone could introduce themselves just you know, your name, how you like to be called today and you know your role in people of Parkinson's. And I'll start with the order of my screen. So *(PD specialist 03)*, from wanted to go first.

**PD specialist 03:**  
Hi everyone. I'm *(name).* I'm a consultant geriatrician and I have an interest in Parkinson's. And I do two clinics at the moment of Parkinson's. One in *(town)* every week and one at the *(hospital)* every other week, which is covering a colleague.

**Moderator:**  
*(Physio01)* if you wanted to go next.

**Physio01:**  
Hi, I'm *(name)*. I'm one of the physios down at *(region)* independence team and recently pick up the PD link within the team.

**Moderator:**  
(OPMH01)

**OPMH01:**   
Hi everyone. I'm *(name)*. I'm a clinical academic in old age psychiatry and I run one clinic a week, for people with Lewy body dementia for (trust name).

**Moderator:**  
Great. So before I start our discussing, I'll just briefly summarize the main issues of treatment burden that people with Parkinson's and their caregivers experience and you might have read it in the summary that I sent to you and mainly these issues relate to attending appointments, getting access to healthcare professionals was a was a main issue, getting satisfactory levels of information and also managing prescriptions and medications. Another thing that they talked about was also you know the lifestyle changes. and you know what they had to do within their life to try and accommodate all of this as well as, you know, difficulties with exercise. And we say physical activity. So I just wanted to start, you know, we've got which is quite useful as well. There's three different aspects of the specialties here is one of the challenges they talked about was the lack of care coordination between GPs, primary care, secondary care, hospitals.

mm. And you know how they felt that sometimes there was a lack of communication between teams and they've themselves felt that they were, you know, the messenger between specialists. And I don't know what your thoughts are about, you know, how we can improve this and whether you've experienced this yourself and you know what works and what doesn't quite work.

**PD specialist 03:**  
Who wants to start? I’ll start shall I only as I'm quite fresh from my clinic yesterday.

Umm. I think you know you think of your Parkinson services as amazing place where you're going to be with a group of therapists, speech and language or PD nurse specialist. And then you end up sitting in a clinic on your own with the clinic nurse, which if that's in (town), that's amazing experience, and if you're in (hospital), it's an awful experience.

And you then have this clunky system how you communicate to the GP. And I think that really causes angst and problems with the patients and their relatives. I will write a letter, I will check it. Usually not bad timing, but you know, within the week that then gets sent electronically to the GP. Someone doesn't read it. The GP doesn't read, it will be someone who, you know, for action for GP: change in medication. Parkinson's medication always causes confusion, and I've had feedback from patients my last audit saying that's the bit they really struggled with. And obviously that's something I need to address. I keep trying to address, but often I'll say we'll add in a drug like ropinirole, and they think that they need to stop their Madopar for example and it causes all sorts of problems. And I've frequently get phone calls.

They always have my letter. And so I know. So they know the plan themselves, even if they possibly some of the few aren't that keen for the letter. But I do push it so that carers and other people can see what the plan is.

And the best communication is with my sister-in-law, where I WhatsApp her confidentially and we share a few patients we both know really well and then she'll say “*(name)* sorted. I've I've prescribed this drug on NHS Spine and there will be with them tomorrow”. I’m like yeah great well and that should be the case where everything shouldn't it.

Umm, but you know, I write to the therapist for example, and I think that's just awful. “Please see letter to GP. Please could you assess.” And actually my letter, I don't want to actually guide them too much, I want them to to see actually they think there are other problems that going to someone's home that I haven't picked up. So yeah, that's my views. I think there's loads of room for improvement for communication.

And electronically we’ll get there. I mean, why I can't prescribe to the pharmacist and make sure the GP knows my prescription is happened and I want them to continue the prescription. We always go through the GP because I know if we don't go through the GP, then my ropinirole I've started won't continue, you know if I go an FP 10 for example. Yeah. Anyway, over to you two to see what you were you think?

**Physio01:**  
I can try go next. Yes. On my side, I recently I went to the PD warrior training. So we trying to implement some of the exercises. But what we struggling the level of Parkinson's we see is around stage four and the PD warrior their exercises like balance they designed for only like idiopathic Parkinson's which in a community we might see with MSA or PSP. So it's not quite for that group and they already passed that stage three, most of them using walking aid support, so we kind of like implement like the cited ones as much as we can. But lately we've been struggling with low mood, apathy, blood pressure drop and like asking the GP to review and they were review like the blood pressure.

I spend a day with them, our specialist nurse (name), which she mentioned that sometimes they find the training is not, as you know, as facilitated. When she started, she didn't have much, you know, specific training to help her. So she was good with, like, bowel care and bladder but not you know, not as much. And with the medication. But then she did mention that the specialists like trying the antidepressant medication. They show good outcome from it with increasing the blood pressure.

And so and with yeah, when I get around, I'm just like a bit struggling with because you're trying to encourage them. And once we have, we were only temporary service. So up to like six weeks and then we'll like you know we can extend it depending on how we are. But if we don't see improvements and we don't see like much rehab potential, we'll you know we'll make the plan to give the chance to another person instead. And quite often we see we, we, you know, engagement with the exercises. Then we stop for a period of time, then then they do not carry on with what we've been doing. And then the GP will refer back. “Ohh. You know, they don't really well with you, can you please review them and it is a bit difficult…

**PD specialist 03:**  
There's a real subtype of patients with Parkinson's who do have this apathy, and they just don't want to engage. And you find that desperately the carers and relatives are trying to get them to see therapist. Oh, that would be really good. And you can see them for the GP's and for me, you're desperate to get into therapy because that's all you've got to offer. You've got nothing else to offer to improve these people's lives, which are just awful when they get to that stage. And we get to you far too late. You say the PD warrior that should be right from the start of diagnosis, shouldn't it?

**Physio01:**  
Yeah. And like I think with the Parkinson’s and what I’ve noticed is that they tend to be diagnosed a bit later on to the time that we can, yeah. And then the combination with the frailty and comorbidity, that's another thing which impacts on. Now going around with the specialist, I tried to spend a day in a clinic, it's been almost a year. I'm chasing (consultant) and I asking the them, his secretary, she even put a sign for him and yeah.

No luck for me, but I spoke at our clinical meeting with (doctor) and she said, you know what you can do just tell the admin and said please stick this patient that you’re struggling at the next clinical appointment and that actually worked. And I was like, oh, that's good. So yeah, the person actually is going to be seeing this Friday and it took like 2 weeks to come here is like, oh, this is great. I wish I would know that before but but.

**PD specialist 03:**  
Ohh, how to manage the doctors as much as the patients. That's awful. You you could tell (consultant) and (consultant) share an office, don't you?

**Physio01:**  
No, no.

**Moderator:**  
And this is this to jump. It is how you know, what do you find about the communication? You know, you probably get communication from the PD specialist and GP and you know, going back any issues you communicate back to the GP and the pretty specialist, how did you find how do you find that interface and and what can we improve? I'm sure it's not straightforward as you've already said.

**Physio01:**  
I What I got feedback from people as well will help with some more like education around what is PD. Most of them not quite understanding that and what like, it will help. Also I've seen people that were diagnosed and they just went to the cabinet and seeing all the other people that were like progressing they just got their mood down. And some of them just said I really needed to turn back because I couldn't face this seeing all those people and knowing that I'm going to end up like that.

So it might help doing like a single visit so then they don't get that overwhelmed. Cause you know, some people are at the beginning, but other people will be more progressive. Now, with um on the other side, with the medication, They seem be on board once they understood, you know the times and what they taking, and if they need the family support with or the carers will step in on helping with all the medications. They some of them, feel like the medications they slow down Parkinson's.

From the PD Warrior training and going into that we know that it actually helps with the symptoms but doesn't actually treat Parkinson's. And like to be honest, I was shocked like no one from my community knew that, or was told by the doctor that it will make such a difference from their understanding to know, you know, that it’s unfortunately a progressive condition, what it helps to keep yourself active and engage with, you know, with activities to keep, keep yourself active as much as you can.

And I spent I think the other week, a session just talking with the person, the relative. Cause the couple, the wife was, like, very active, like overly active and he very apathetic. And they did have a chat with the well-being supporters to say, what advice could be given but not feeling that was enough for them. And there’s no diagnosis of cognitive impairment or anything like that. So the mental health would just say, you know, we can't help because he's not, like mental health issue in that respect. So I'll probably help for me, as (name) is here, if you can advise me with some of support on when it goes higher than that. But I was just talking with them imagining like, you have, like, a grown up person and a very small person walking each other. The one person might go too fast and one might go too slow and actually, oh, you know, that makes sense. But to me, I was like that it’s not something major. But they get too overwhelmed with what they struggle with. And sometimes I think the pressure just creates a (…) sometimes. But yeah, we work on that and with the rehab programs. But at downsizes, we are temporary, they get better but then they don’t carry on with what we're doing so they need just goes yeah away quickly.

**Moderator:**  
I think education and like, you know, information for people with Parkinson's and cargoes expectation I think is quite important. But as (name) says it’s even educating you know, other physiotherapists about how this is important and Parkinson's.

And I don't know (name), whether you’ve had any thoughts about, you know?

**OPMH01:**  
Yeah, just to build on what *(Physio01)* said really about, I'm going off topic slightly and I won't get it for long, but they're definitely parallels with with dementia and the lack of education about how the disease progresses and what patients and caregivers would expect. So just, yeah, interesting to hear you talk about that (name) because I think we have similar experiences in our and our specialty.

But going back on topic now, so thinking about communication between different agencies. So it's quite nice to have people from different aspects so different perspectives of care. And so like, obviously I come from the perspective where people generally have non motor symptoms, but when they see me, particularly cognitive symptoms, sometimes neuropsychiatric symptoms.

And it does all feel very disjointed in terms of the care and the communication. So you've got psychiatrists looking after certain symptoms, you’ve got geriatricians or neurologists looking after certain symptoms. You've got the GP involved as well, and we all should be looking after the whole patient. And we all, I think, like to think that we do, but I don't really think that we actually do it very effectively. And I think a lot of it falls down on these communication. I'm much slower than *(name)* in my letters, so takes me a good two or three weeks for that letter to go out to the GP and copy it to the patient.

And yeah, it just feels like everything just takes much longer when you're waiting for letter. And it's a bit annoying because you're, well it’s more than a bit annoying. You know, you're writing to people that you know personally, and you know, there's gotta be a better way, better way of doing this.

**Moderator:**  
Any thoughts of the better way so far? From what works?

**OPMH01:**  
Yeah. So I know (consultant) and (PD specialist) have been involved in setting up a case discussion group between (hospital trust A) and (community trust), and, you know, key people. I guess I've missed a few. The ones I've been to, no one else has been there. So I think, you know, I think it would be nice if we had some sort of regular forum, if only just to familiarize ourselves with who we know who, who we are and what we do. And get started to get some informal general advice, if we can progress that to specific case discussions about challenging patients that will be fantastic. And I just think you know somehow maybe involving primary care in that as well. I don't know how we would do that. But yeah, just somehow making sure that we all know what we all do and how to access services. And maybe a bit about my bugbears about terminology as well and you know, we all use different terms I think for the same thing. And I think that can confuse patients and clinicians sometimes.

P**D specialist 03:**  
Yes, it's always difficult because GP's only often have two or three on their books, don't they?

**OPMH01:**  
Yeah.

**PD specialist 03:**  
Umm, but and I guess the virtual ward has got this really nice, for those really sort of sick in the community being managed in the Community and that sort of MDT approach. I mean it is really clunky.

**OPMH01:**  
How does that work? Just to interrupt in terms of the virtual award.

**OPMH01:**  
OK. Yeah.

**PD specialist 03:**  
(Physio01) would be much better person to probably talk to. So the community consultants, they have community sessions where they have maybe, I don't know how many are on their books, again (Physio01) will know better but, say 20 who are being actively managed in the community. Either because they're well known and hospital admission, it would be a disaster for them or just to actually avoid hospital admission. And they’re sort of actively discussed, bloods maybe taken, therapists going in, nurses going in, carers acutely going in to try and you know, so that’s the (community service). Umm, which is irritatingly very good if you're a (region) consultant and can't access (community). But for (city), it is a really good service I think.

But you know, you can imagine you've got, you know you often in your head you have three or four that Parkinson's patients who are really on the cusp and you know, you know, I saw a man yesterday who surprised me. He's got Parkinson's and Parkinson's dementia. And he's actually awful, but he's still able to cycle 14 miles with his best friend around the forest. Now, he does get lost. And there are lots of things that made me think, “Oh no, this is awful.”

But you know, actually, you know, I'm really proactive in my clinic because my numbers aren't as high as say the neurologists. So if someone who's sick or I'm changing their medicine, I think it's gonna be potentially go very wrong. I can see them in three or four months. But actually they need to have, you know we say phone me or or phone the Parkinson's nurse cause actually what you want to know is really in two weeks are they hallucinating awfully and we need to step back or do something different.

But yes, we've got offered attention to bit there, but I mean it's like everything that the biggest communication and support that all the patients say the Parkinson's nurses are absolutely crucial aren't there but we need about 20 times the number we've got, don't we? Yes, I think that's a real resource issue and capacity issue in the Community with that.

**PD specialist 03:**  
And also we've got practitioners that we're training up, usually from a nursing background. But actually I think to to train up a Parkinson's specialists nurse, I think takes… I think they come with so much experience over years of knowing you know the social aspects, getting blue badges and the social support you need versus the tinkering feeling comfortable tinkering with medication.

Their often the ones who sees them and then e-mails me, I hope you don't mind that I’m bothering you.”. Always have an e-mail that starts from the same way and it's like no, thank you, It's fine. But then typically I'll find (PDNS) has seen one of my patients a week before my clinic appointment. Because my clinic appointments are really clunky. I've said four months and it happens that (PDNS) has seen you know the week before by coincidence and you just think oh, that is rubbish, isn't it? Spacing it, yet.

**Moderator:**  
Yeah, yeah. So the spacing out of appointments between, yeah, I think we both mentioned that before here.

Yeah, I think the idea of a virtual ward MDT for people with Parkinson's sounds like a terrific, or at least this is (OPMH) saod, a forum where, you know, people who do look after these complex people, you know each other and know, you know, this other things that we expect when they reach, you know, more complex phase of PD, you know, physiotherapist you can access then OPMH, if you need to. PD specialist PD nurses. That's also the great idea of if we can implement that in in real life and obviously getting GPs on from board.

Now I suppose the other the other issue that we talked about you know is actually with current, you know, healthcare pressures. I'm sure you know people will talked about difficulties actually even getting access to healthcare professionals, you know GPs or long waiting times to see if physiotherapist and your psychologists or OPMH. I suppose it's a difficult, difficult question, but you know, from your experience, can we improve this despite, you know, with the current capacity that we have?

**PD specialist 03:**  
So we still have to work cleverer, isn't it? I always feel we're all sometimes on the cusp of being a bit cleverer how we give treatment, but we're still not there.

It's difficult, you know, some ways, you know, our services are still very much, doctor led. And to some extent therapist focused rather than patient focused, aren't they? It's convenient for me to see my patients and one afternoon on a Wednesday in (town). It's not really convenient for the patient, is it? And although it's, you know, you talked about the burden of getting to appointments, I'm always amazed at the incredibly frail patients who still come to my clinic because the carers and relatives are so desperate, will go to ridiculous lengths to still make sure they get to see me.

And you know, I do sort of reflect when they see me, how often I do actually anything that's useful, I think probably the most useful thing is chat and and almost sort of therapy of unloading the just awfulness of their lives for some people. But sadly don't have help or solutions. But you know they will go to all sorts of ends. So you know to be honest, you know, you'd much rather have… No, I I I am lucky that I (town) is so small and the service, you know I just reflect that actually when my receptionist goes or my nurse goes it'll totally be totally different. But you know I say to all the patients I think roughly I'll see you in nine months time I think you're quite stable but please phone up and change the appointment.

And although that can happen at (hospital) it's just such a bigger place it will gets lost in the, well you know there's no real… there's my secretary, but she's managing lots of other consultants, whereas, you know, they found up (receptionist), you know, things have really gone downhill. Couldn't can we see (doctor name) a bit earlier and they get, “Yeah. Let's see you next clinic”. Because I could often put people in. Umm. And that's where you really want to. Of course, the Parkinson's if someone deteriorated quickly, it's usually not their Parkinson's and something else. But that doesn't mean they don't need to see a doctor. They still need action. And it's not their fault. But it's actually not their Parkinson's that’s made them unwell, but they will be on the cusp of needing more help. I mean, I guess with (name) for you it would be maybe someone getting more confused very suddenly and needing help and support. So, sorry, yes, I didn't have great solutions, but.

**Moderator:**  
I didn't think people have. But I'll ask the question just in case. I don’t’ know if (Physio01) or (OPMH) have anything to add to that before we move on?

**Physio01:**  
No, said the only thing I would say, like in the Community, I'm not it I'm. I think the only one that I picked up with the Parkinson and I see not only Parkinson's I see everyone. So the caseload is variable. And our waiting is I think we have now waiting more than 100 on the list and he's about like, yeah, he goes a bit crazy and the rehab program. So until the rehab supporter starts now, they waiting, they just let us know in the meetings about two weeks to start.

Yeah. Umm. So yeah, we tried to do what you know with things around what I think personally helps, you see them in their own environment and you review their transfers and how they manage gives you more ideas and what can you know for support. The thing I struggle is like the psychological side of it would like personally with the people that are not diagnosed with dementia, but they're low mood and apathy. So I just wondering if *(OPMH01)* has any advice how you know the referral pathway to to them or how that goes around?

**OPMH01:**  
Absolutely, I do. Perhaps I'll catch up with you afterwards about more specific advice, but just in terms of generally. I think there are from my perspective in terms of your questions. I think people should be seen by the right person with the right qualifications or the right competence at the right time, and I don't think we do. We do very well at that, particularly in OPMH where triage is done by a community psychiatric nurse who are on duty and are basically firefighting and have a referral that might come in from a GP and then it's allocated to the next most convenient slot rather than it being someone with any level of appropriate experience or competence in people with Parkinson's.

And so, yeah, I think we need to do much better at that. But just thinking more widely and from what *(Physio01*) said about neuropsychiatric symptoms. I think we've got a real lack of understanding and awareness and our specialty about. How Parkinson is not just a motor syndrome and you know, I think that's a huge gap in our OPMH services in terms of the level of education and understanding about that.

And so I'm not particularly hopeful about, you know, telling you where people should be referred to (Physio01), because I think even if they get referred, they're not gonna necessarily see somebody who's going to understand fully what to do, but I'll happily have a chat to you afterwards though.

**Physio01:**  
Thank you.

**Moderator:**  
Education and awareness, you know, among healthcare professionals about PD and how complex it is and trying to pick out what is PD and what it is and that's tricky for everyone especially you know people get older and they have multimorbidity and that's gets even harder.

And so I suppose the other, the other main burden is really about information. We give them lots of information from different aspects. We give them information, I’m sure (PD specialist) gives them about medication symptoms, (Physio01) would give them about exercise and what to do. And (OPMH1) would simply give them the same information from your clinic. But I don't know, people find that sometimes it's too much, sometimes it's too little and sometimes they can't understand it.

I don't know what how we can improve them or what you found has helped help them retain the information and you know, actually take that on board because you know having information we know if they understand it and they can take that on board actually can manage to health better. And what ways can improve that to think or what have you found or what you think can improve that.

**Physio01:**  
I mean if, what I’ve from like as it progresses stage, and as it advances you lose that dual tasking ability. We know it's with the exercises and with the PD warrior, that's the more exercise you show, the more you make the person more confused. So you just say like, copy what I do. Umm. And until you can get with apraxia, yeah, it takes like I had someone like talk about 6 times just to practice with the sky reach to follow. He was like so confused like, “Ohh hich one I do?”. I said don't worry just copy what I do and then we'll go step by step.

Wait, yeah. And if the you know the because it is a combination of force and stretch and amplitude is not like when you get in. They need to look on the videos as well to help have a better understanding cause on the paper, it's really difficult to explain the movement. And then some of them will not be technologically keen for with that. And so that's why it's taking 2-3 exercises. I noticed that helps and with the group that I've seen, that's tends to be too much already for them. And then if you get you start giving too much then they start losing interest. And yeah, you're just tend to work on poor stability and transfers and yeah, and review but.

That's about where you talk about. Yeah. Leaflets. I do have one. Like for the posture that seems to help posture and strengthening like to prompt with that. And it let them know that, you know, if like poor posture impacts on the feeding and like the air, the breathing. So just to you know make them more aware with that and then they tend to be you know oh OK yeah. now I need to be mindful of that. But until you explain that they just think ohh you know I'm getting older that's alright just, you know, carry on with it. So like education, I think it does help, but not too much education, just gentle education to not to lose that engagement sometimes.

**PD specialist 03:**  
I.. It all sort of feels a bit too late. What I find really helpful did find helpful. I'm not sure. I think it's been stopped was the Parkinson's UK first steps and that, you know, I think was over a couple of days and it was really good because it was lots of people who'd all been diagnosed at the same. They're on the same place in their diagnosis. Newly diagnosed, now admitted some might be rather later in their diagnosis. But for them, this diagnosis was new. And then they'd have to sort of forum where they met and that sort of connection chatted and then had lots of people talk of for various things.

And then, you know, I frequently get told how wonderful the (local) Parkinson's group is. And I went to see them a few months ago and you know, I looked around all my patients. And you know actually, you know that is a forum that health professionals use to chat regularly about some item or some problem, because you know when you think I mean, I've been doing Parkinson's for about 10 years and I I know less and less about Parkinson’s as you go on. And I think the other problem is that they're all different, aren't they. Are they serotonergic subtype, are they adrenergic subtype? Are that, you know, you got some who are tremor dominant, non tremor, dominant they they are all different and their needs are different.

But it is so much information to give them. Too much information. And there's always a leaflet, but leaflet starts to be red and you know, I was amazed I refer. I do refer quite a few of my patients to sleep clinics, to (consultant), and that was amazed that he's got a leaflet on Parkinson's and sleep. I thought ohh my goodness. So that's when I'm next in that's my job to get the leaflets and see what the sleep clinic has to say about Parkinson's and sleep. I’ll be fascinated.

But you know you you write in your letter, and you try and explain things in a letter and I guess the letter is much more pertinent to someone than a leaflet is specific. But it's at the end of the day, you're giving them a huge amount of information that health professionals struggle with.

To unexpected patient and you know, in an ideal world, these patients need health input from someone at least every two to three months, be it the Parkinson's nurse with sensible tips therapists to actually say, “Right. You've been newly diagnosed. Right. These are the exercises you need to do every day for the rest of your life.” That's what we need to be saying, not when they've got such advanced dementia they can't follow what you're doing. I mean, you still give them benefit, but actually, if they were doing and already got ingrained in them that these Parkinson’s, PD warrior exercises you do from day one and do the rest of your life. That will make a huge impact.

And we always know the ones who do better are the ones that’ve got relatives and carers looking after them. I've got two patients, one who is very frail comes in with his wife and his wife died unexpectedly under my care a few weeks ago and I now know how much his whole world is particularly imploded. And again someone else. Well, yesterday wife has now had several TIA's and she looked really unwell and she's been holding him together for several years and that whole structure, you know. You know how much they're dependent on their partners.

Yeah, it's just very sad, isn't it? And you know, you always need the ones who do better are the ones you've got a carer coming in with them to at least two, two people listening as well as the letter. But, Parkinson's UK's great I think, but I think their website is still not brilliant for information to you know, I think it's all there. I think how you access it is still not straightforward as it could or should be.

**Moderator:**  
Do you write your letters to your patient?

**PD specialist 03:**  
No. I write them to the GP, copy to the patient and then copy to (PDNS) plus to any other health professionals who've been directly involved. And I try and explain all my terms in brackets. Some people write to the patient first and health professionals copied in, but sometimes I find those letters just really woolly to work out what's going on. And I think my letters still need a lot more work. You know, you try and write. Diagnosis for each one.

Ideally it’ll be lovely to say: diagnosed this year, driving not driving. Cause you always end up trying to fill up the DVLA forms. Motor symptoms, non motor symptoms. I try, but I'm not perfect always putting the list of medications. It's amazing how between me, my last clinic letter CHIE, the GP, there's a mismatch somewhere along the line.

And then you know, actions for GP, action for care, actions for patients. I do want to use medical language cause it we have medical language for a reason which is specific. Especially when you sort of, you know, visual-spatial dysfunction, so important to say, look, actually they can't get themselves through doorway because that's so typical of their Parkinson's. And I might then put brackets. That's why you're not you knock into doorways, those brackets, but it does make it also a clunky letter to read.

Uh, try putting bold what needs what's the most pertinent bit, because what you want, you know, is a sort of (consultant name) letter, isn't it? Where you've got absolute gold dust written on 3 or 4 pages, but also, you know, you haven't got time to read all those four pages necessarily in one go and highlighting what's good. that have been, I think (consultant name) wrote a really good letter for one of a patient I saw how she'd laid it out to make it easily accessible for the bit of information you need there and then versus the long way to dwell on and think about.

**Moderator:**  
But when it's helpful is to see if we put that information to patient then remembers what's been said. And there's a way of getting the information that you've told his GP what you've told him or her. And then that's a helpful reminder for them, or what was talked about in terms of information and yeah.

**PD specialist 03:**  
And and it also makes you be a bit honest as well. You know, actually if they if you think they've got dementia, you've gotta start putting that in letter. And if the consultations gone really badly I've just done their MOCA and it’s awful and you know I've started hinting that you know I think this is dementia. For some that they already know for most they already know and it's easy and it's fine, but for you I might leave it till the next letter but you know you know the MOCA tells the GP just what you're thinking. It’s all sort of process, isn't it?

And then the advanced care planning, and all that. Trying to get that into a letter. You know if someone has Parkinson’s dementia, you know that their prognosis is significantly worse and you really need to crack on and make sure you know what their wishes are.

And there's so many streams to Parkinson's of how much you've got to communicate. Umm, in an appointment that in a… I've just changed my appointment lengths to half an hour, 45 minutes for someone far too long, and then you know you 15 minutes for your follow-ups that you then spend 45 minutes seeing them when you're going through all their very difficult problems.

**Moderator:**  
(OPMH) I’m sure you've got some, you know, information that you're giving clinic and how people find that actually because obviously talking about dementia and PD dementia, that's a lot to cover in a in a clinic for patients and carers.

**OPMH01:**  
It is, although I’m lucky I have much longer appointments. So up to an hour and a half potentially for a new patient and I don't tend to see follow up. So I just do a kind of tertiary review and then they go back to their CMHT. So I've got a bit more time to explain things. I think people appreciate not being rushed in clinic and which I think is a positive thing.

In terms of information that I give, I know there's a move towards writing to the patient and copying the GP and I think our college has recommended that we do that. So I'm I, I don't do that. I write to the GP with a fair amount of technical language because I think that's what I feel like I need to do in terms of having, you know, a medical record of what's been said and what's been, you know, so people, so other collisions know what I'm saying.

And I do have a more of a lay summary, but at the end, which is sort of highlighted and maybe I can move that to the beginning and I like to think that that's a good way of doing it. And I always say to the patient, I will copy the letter to you. Is that OK? And if you have any questions, my numbers at the top give me a ring and no one's ever rung me. So I don't know how useful it is, how much they read it and you know how, how helpful it is.

I do occasionally use leaflets, probably should do that more, but again, do people read them? I don't know. I think what's worked best for dementia services, including people with Parkinson's, with dementia is the “Memory Matter Course” course sort of pre COVID sounds very similar to the Parkinson's UK Forum. You have, say, five or six sessions over a couple of months and where people with a new diagnosis of dementia, including people with PD dementia, would come together and have lots of talks and their carers would receive lots of talks as well and and yeah, more about understanding with diagnosis and preparing for the future essentially. And that's all unfortunately largely stopped because of COVID has gone online and it's gone to recorded sessions and I just don't think it it's particularly helpful. I haven't had any direct feedback as to say that, but I can't I think the most helpful thing is that peer support and you can't get that watching something back on teams.

**PD specialist 03:**  
I think that's why these Parkinson's groups are so helpful. That's sort of offers everything a bit of education, a bit of peer support, carer support.

**Moderator:**  
Yeah, absolutely. And one of the things that I've seen you we've mentioned already is that the carers take a lot of the burden for people with Parkinson. So not only you know if the activities of daily living, which they do, but they come to be appointments with them, they help do their medications with them. They're the ones saying, you know, you need to exercise, trying to get them through the exercises. So they also experience, you know, treatment burden, even though it's not for them. And I don't know, the study found actually 50% of caregivers at high treatment burden levels. So that's quite significant. And how can we improve the experiences for caregivers? You know, appointments are always for our patients and you know, they should always be the priority. But you know, I think there is some aspects of how we can improve the experiences for caregivers. What can be done? What can we do to try and get it better for them?

**PD specialist 03:**  
I know that they always value someone to be… when they've got a problem, someone to speak to. And you know, if you're up with someone who's really got very disturbed sleep in the middle of the night and you're now a night four, waiting for three months for your next outpatient appointment or whatever is not really an option. Umm, I have had feedback in the Parkinson's UK helpline has been very helpful for that for some of my patients.

Getting to clinic, you know, getting someone in and out of a wheelchair if they need that, you know, we do have patient transport, but that's always assumed if you can't, if you've got a carer who can drive and can get the wheelchair in now, it seemed or you weren't need patient transport and that's always clunky. I think it's always someone to be able to speak to and knowing what access you know. we know getting social care and support is very clunky, but at least making that smooth to be able to access when you need it and getting respite care when that happens and is organized, it could be it would be great.

I do say to my patients that always have a look around your local nursing homes or someone have now got open days. You know where you have a morning at a nursing home. And I quite like those homes because actually for carers they can have a bit of respite for one morning and then it's gonna hones then home from “I don't want to go into a nursing home and never want to go into a nursing home”, and then they need to go into a nursing home because their care is just too much. And then at least they know they've got that. I think you need a carer peer support and hub.

How you make you know, appointments just easier. And someone to phone who can actually be genuinely helpful. And that's where the PD again, PD nurse specialist come in and able to do those home visits that they value so much as well.

**Moderator:**  
Yeah. So knowing who to access, how to access getting help.

**PD specialist 03:**  
Yes. And I know (consultant) does home visits. But she comes in and says, you know, actually there's often nothing she can add as a doctor. Would it be the nurses who do add something practical and helpful. That's what you're looking for. The community rehab teams offer something that's helpful.

**Moderator:**  
Yeah. (Physio01) and (OPMH01). Don't know if you had anything to add to that.

**Physio01:**  
The only thing is like the Locus specific PD Warrior group is in (city B), but we don't seem to have (city A). As as as much as I'm aware of, to be honest. And then when, like people that are, let's say, you know, you know, specific one that I can attend like going all the way to (city B), it just puts them down.

**Moderator:**  
Yes, of services are not uniform. Even across Wessex. It sounds like some people can access it might be a depending on where you live, what what access you can get, which seems a shame. And based on your post code.

**OPMH01:**  
It's the same with them adult services, isn't it? You got slammed in city in (region) County Council and you know, trying to navigate that as a carer I think is challenging isn’t it. People are having to make multiple phone calls just to get to the right, right department and the right person to arrange a care assessment. And it's, yeah, it's not how it should be. It's making that process easier I think will be a real or more transparent with more information I think would be great.

**Moderator:**  
Yeah.

**OPMH01:**  
I think what we really perfect is have one provider though. That's never gonna happen. Is that?

**PD specialist 03:**  
It's not. And actually, I think the problem with that is that you know the care and provision of care is different and you know I think they tried out, I think that's where (region) actually went wrong, isn't it? They tried to provide one big care or a couple of care agencies and then didn't realize that all these little agencies were working quite well because they were for carers who could then serve a small area in somewhere very rural and didn't have to drive so far. And then they they amalgamated and all these small care agencies and small carers then ended up leaving work and going to work ALDI of whatever.

**PD specialist 03:**  
But yes, you're right. One phone line, single point of access, I think, yeah. Yeah. But it doesn't really work, does it as well as you’d like

**Moderator:**  
Well, I think it's currently in trial. It's, I don't think it's been implemented as yet single point of access, but it may work. I think the idea is that you can sign posts, people to who they need sign, post them to the information they need and then direct them to the right service because it's at the moment they're struggling to find out who, where and get given many different numbers to contact them self as a as a massive burden, yeah, I suppose.

**OPMH01:**  
I mean, we're struggling, aren't we, to contact each other and knowing which clinic to refer to. So yeah, trying to, yeah. Expecting a carer to go to navigate that is not really realistic, is it?

**Moderator:**  
Yeah, that's that's. Yeah. Then your suggestion of a, you know, actually within our local services having that connections and or forum or somewhere where everybody can access and say actually I think these are services that are available that we can refer to and also I think the difficulties between where they live from the referrals which team they go to is also tricky. I'm sure the PD specialists which locality they live in is which clinic and not everybody knows that’s another way to improve.

I haven't got any other questions but just tied it up. I don't know if you can think of anything else that we haven't discussed in terms of ways that we can improve things for people with Parkinson's and their caregivers in managing their health. You know we've talked about in the single point of access, we've talked about information and you're giving it the right information at the right time or trying to see the right patient, the right person at the right time based on your needs. And anything else that perhaps we have uncovered. That you think could work if implemented.

**OPMH01:**  
It's just thinking about follow up for people with Parkinson's and Parkinson's disease dementia and. It's a bit outside my remit in terms of I know I don't have a Parkinson disease clinic, but if it's anything like our MCI or dementia clinics, there's a … there are always discussions it within the service about how often we should follow people up and who should determine that. And actually I think having a having a more flexible approach. You probably do this already, but I think having a flexible approach where carers can or patients can call up and bring appointments forward if needed or delay appointments when not needed and I think would be really helpful. We don't do that very well in OPMH services? And it sounds like (PD specialist), you do that in your clinic and but I'm not sure if everyone does that.

**Moderator:**  
So I think they are. The NHS have recently also advocated for patient initiated follow up in some specialties especially in the hospital. Whether I don't how well that works with Parkinson's, but I think the idea is, you know, to give it patience there, the remit to say when they wanted to follow up.

**PD specialist 03:**  
I think that idea sounds lovely. I think my worry is always the wrong patients want to be asked asking for follow up and you've got the extra anxious one that you can't anything with and then the one who doesn't want to bother the doctor doesn't initiate the follow up. It's really hard, doesn't it?

**Moderator:**  
Absolutely. yeah.

**PD specialist 03:**  
Umm, I think is it a noble idea that like everything will be those who demand the most will get the most and those who are a bit more passive and have a greater need won't. But maybe I'm just too cynical.

**Moderator:**  
(Physio01) anything else you'd like to add that from your point of view in the community, from physios, about how we can improve things?

**Physio01:**  
As you know (OPMH01) said to get you know, to get more facility like in referring among us around if you notice that to be reviewed. Because at the moment, sometimes after is a bit of a battle.  
  
**Moderator:**  
Great. So you know it's nearly half one. So I've taken up with what's your time? I was like, no one else has anything else out. I just want to say thank you very much for your time. I know you're all. I'm very busy, so I really appreciate it.