**Moderator:**  
So firstly, if everyone could just introduce themselves. And it will start kind of by my screen. So if you *(P02)*, if you wanted to go first.

**P02:**  
OK. Yeah, fine. My name's *(P02)*. I live in the *(town).* I'm 73 years old. And I've got Parkinson's, which is a pain, a real pain cause I shake so much. And it's, I'm shaking now and it's terrible. I don't know what other things you want me to say, but.

**Moderator:**  
Yep. That's great. Just, yeah, your role would be and you know, role here is great and *(P03)* if you want it to go next.

**P03:**  
Hi everybody, my name's *(P03)*. I have Parkinson's. I was diagnosed in 2016. Although I think my problems started long before that and I live near *(town)* and recently moved back to England from living in Australia for 15 years.

I’ve in fact, just change my medication today. To see how it can improve my symptoms, which at the moment, are uncontrolled movements. I've been through this the shakes, the the pains, the, various other symptoms. It's the uncontrolled movement of the hands waving… and stalling and stopping for no reason when I'm walking. A brief overview of (me).

**Moderator:**  
Thanks *(P03)*. And *(Pharm01)*, if you wanted to go next?

**Pharm01:**   
Hi, my name's *(Pharm01)*. I'm a pharmacist and I work half my time in a GP practice or a PCN in *(city)*, which is the PCN I work for. And then I work half my time for the CCG, which is the clinical commissioning group. So that kind of overseas the overarching policies, et cetera, for practices. I work in the *(city)* area team of the CCG. In my practice role, I do a severe frailty clinic. So I look at patients that have severe frailty. I wouldn't have said I'm a Parkinson's expert by any means, but obviously I come across some Parkinson's patients within those severe frailty reviews that I do.

**Moderator:**  
Thanks *(Pharm01)* and *(Pharm02)*.

**Pharm02:**  
I thought I recognized *(Pharm01)* name. So I'm also a pharmacist. And thanks, *(P02)* and *(P03)*. Nice to meet you both. I worked in hospitals for 25 years up in the *(region)* and then moved into general practice about six years ago. So I have, I guess I would say I've seen and helped lots and lots of people with Parkinson's and have seen some of the difficulties that they have in relation to living with the disease and the unfortunate side effects of taking the drugs and how complicated it can be.  
So very used to seeing Parkinson's patients, both mild and very severe, from a hospital point of view.

But now that I've moved into primary care. Like *(Pharm01)*, I do clinics. So I run these things called structured medication reviews, which people like yourselves, probably by definition, by being on lots of medicines should probably be invited to on an annual basis. And if you're not, then that's something that perhaps we might wanna talk about. And that sort of fits into the new GP contract sort of. And I also do phone calls. So I'm part of the duty Doctor team. So if you phoned up to my surgery, by the way, I work in *(city)* and *(city)* primary care network. And so if you phoned up this morning and you had a question about your medicines, whether it be, I don't know, it was started last week by the clinic or you went to see the cardiologist and now you think that this new medication may have made your Parkinson's worse. Anything to do with your medicines and your Parkinson's, you probably end up on my list. So not a week goes by without me speaking to a Parkinson's patient.

**Moderator:**  
Great. Thanks, *(Pharm02)*. So, what I'll do is just briefly summarize the main issues of treatment burden. And I think hopefully you should all have received the one page summary. And you know the main issues that people have Parkinson's and their caregivers face mainly relate to appointments and trying to access healthcare professionals, getting information related to Parkinson's and also managing their prescriptions and medications which I'm sure you're all very used to.

So I think first thing I like to kind of start with is you know the national guidelines of Parkinson's at the moment recommends that appointments are held about every 6 to 12 months and some people find that actually that's probably not enough. And some people find that too much. You know, it's too frequent. I don't know what your thoughts are about how we can try and coordinate this and how we can improve the appointments or frequency of appointments that people with Parkinson's have.

**Pharm01:**  
Can I ask a quick question before you? Where's that appointment meant to be? Is that an appointment with a specialist or an appointment with?

**Moderator:**  
Yes, the Parkinson's specialist, yes.

**Pharm01:**  
OK.

**P02:**  
I would like it to be… Mine is every six months. I would like it to be sooner, actually every three months cause I'd like to know. What stage I am, where I am, because it's difficult for an individual to actually know exactly where you are, you know. I find walking very hard and things like that. The worst thing at the moment is the shakes.

**Moderator:**  
Yeah.

**P02:**  
The worst thing… The walking I can manage if I think about it, because its's definitely thinking about something that makes you do it better.

**P03:**  
Yep.

**P02:**  
So you know, I'd like it to be every three months if it could be.

**P03:**  
Yes, certainly, three, rather than six I’d fine better. I've yet… and I've tried to find or make contact with the Parkinson's nurse because, you know, we don't always want to see the consultant, but someone of the nursing paternity would be reassuring. But I haven't managed to make contact with one yet.

**Moderator:**  
Yeah, and certainly I think some of the issues that we found was trying to access healthcare professionals whether that's you know, in primary care to GPs or PD nurse specialist, even the PD specialist themself. And I'm sure you've all read the news about the access. And I don't know how we can try and improve this especially for people with Parkinson's who are quite complex. And what your thoughts are about who you know, how, how people can access healthcare professionals better.

**P03:**  
Well. I mean just using Microsoft Teams, the program we're talking on now, if that was... or something like it. So you don't have to see everyone face to face. But you know, I think we could make better use of technology, to you know… shorten the problems between healthcare professionals and patients.

**P02:**  
I think listening to *(P03)*, you know his symptoms, he's definitely more, miles ahead of me in… you know, his situation. So I think you know, someone like *(P03)* definitely needs a lot of help and that's what should be available to him. You know, so that he could… so he feels better. Because I say mine's the early stages. So at the moment all I've got is the shakes, and the walking. I can live with that. Well, yes I hope I can. But it does need I think some sort of agreement where we, you know, can get help much easier.

**Pharm01:**  
I thought all patients had access to the Parkinson's nurse.

**Pharm02:**  
So did I.

**Pharm02:**  
How long have you been here, *(P03)*?

**P03:**  
Well, two years.

**Pharm02:**  
OK.

**P03:**  
Since we last Australia. Where they, they Parkinson's nurse was part of the course out there.

**Pharm01:**  
I very much thought they were here as well, and if I've got any questions about Parkinson's patients, that's who my first point of contact at the hospital be is the Parkinson's nurse. And I never had them say that patients aren't under their care.

**Pharm02:**  
No, I agree. I think even just as a takeaway for yourself, *(P03)*, you should ask your practice or the neurology specialist centre that you're under, “Are you not expected to have at least an annual review with the Parkinson specialist nurse?”. Because that is, I would say that was the norm.

**P03:**  
Yeah.

**Pharm02:**  
Where? Where did you say your you live in the *(town)?*

**Pharm02:**  
Right. OK.

**P03:**  
*(town)*. Just that just that side, *(town).* Yeah, I'm getting. I'm getting 6 monthly face to face with a with a consultant. But you know, it's the time in between when you think, “Ohh you know I'd really like just someone to… “

Give an example, I I've just been changed my medication. Now some help and instruction on how to make the transition between madopar and stalevo. And I just well, I didn’t know what to do to transfer, transiting from one medication to another.

**Pharm02:**  
OK, so did the specialist neurology consultants, did they? I mean, it's possible that in your area, for whatever reason, they don't currently have a Parkinson's disease nurse specialist. I would think that's some, you know, it wouldn't be likely, but it's certainly possible. I know there's been difficulties even in *(region)* where I work. You know, they have been under strain as everyone has post pandemic. But there is some service and there's a telephone. For example, there's a 24 hour not 24 hour, but there's a telephone helpline where people are encouraged to phone, leave a message and then they will get back. They certainly won't come back the same day, but they expect to answer you within the week, shall we say. So you should check whether or not that is available.

**P03:**  
OK.

**Moderator:**  
Yeah, I think some of the issues that we found from the studies actually you know, you're right, everybody should have access to a Parkinson's nurse specialist. But obviously because of workforce shortages and capacity issues, that's not always been available to them. And that obviously helped increases their burden. I don't know, I suppose from your point of view *(Pharm01)* and *(Pharm02)* getting.

Yeah, you know, patients asking from help from the community related to Parkinson's, whether you know with medications issues, you know how how, how is that coordinated from in your area and you know how can that be improved for people with Parkinson's from your point of view, any medication changes, medication issues that you may come across.

**Pharm02:**  
*(Pharm01)* you want to go first.

**Pharm01:**  
OK. That's fine. I think it varies very much across the areas. So, I think both myself and *(Pharm02)* probably work in practices that have got a very forward-thinking pharmacy team who would like *(Pharm02)* was saying, they have like a duty pharmacist. We have a very similar thing in the practice that I work for. So, but that's not by any way the norm.

And I think what you will get from each practice across the country will vary considerably. Pharmacists in GP practices are very new for a lot areas. So and I think it is something that is upcoming and I think it will improve. But again, the people that are taking up these positions, some of them are quite junior. So, to deal with patients with Parkinson's would be way above what people that they're probably normally used to dealing with, and they probably be quite worried about talking to someone with a complex condition and all the complex medication, and I think they would probably refer back to secondary care quite a bit.

So I think probably both myself and *(Pharm02)* would be a bit more confident about helping and making those changes, but I don't think that would be something that happens widely across the country.

**Pharm02:**  
Yeah. Well, I would agree with what you've said there. I mean, I have to say that most primary care networks, which is a group for *(P02)* and *(P03)*, that's a group of practices that have sort of joined together probably about 30 to 50,000 patients. Most of them should have a pharmacist, probably a pharmacy technician as well. But as *(Pharm01)* said, it very much depends on your background. So I've just told you about my background. My background is quite extensive, I suppose would be the right word. So yes, I'm very comfortable to have those conversations like for you, for example, *(P03)*, in relation to answering any questions that you might have about transitioning.

But because it's such a specialist condition, that, as *(Pharm01)* said, and I'm, I'm interested to know from both of you actually whether or not you find almost find the same issue with your GP. Because what's happening now I think in, in, in general practice is that specialist areas people get deskilled a little bit, particularly if they don't have many patients who they come across. And particularly now with perhaps less face to face ,you know you only need to see a Parkinson's patient to see that you know, how the burden I think is well from my point of view as a health professional “burden” sounds like a good word. You might hate it.

**P03:**  
Yeah, yeah.

**Pharm02:**  
But I always think that, gosh, how burdensome it must be to live with Parkinson's, because I know all the things that you know that come with it. And I know all the problems of the drugs. So. But like *(Pharm01)* said, I'm probably at the other end of the spectrum perhaps. But I do wonder if you find the same thing with general practitioners and that they, they don't feel confident in the area. Is that true?

**P03:**  
That's what absolutely yes, definitely yes.

**Pharm02:**  
Yeah.

**Moderator:**  
Yeah, that's certainly been echoed in our study that you know people actually choose not to go to their primary care physicians because they feel that it know enough about Parkinson's and always refer back to secondary care and that maybe a lack of experience like education, about the complexity of Parkinson's, which is common. And I think the other issues obviously people have Parkinson's, not just have Parkinson's, they have other long-term conditions. And then it's tricky. Then determining which is which, who do I contact that relates to Parkinson's and not and suggestions to improve that. You know from your experiences you know would be helpful. How do we how do we change that? As you said, you know the specialists and primary care divide, even though it's not just Parkinson's that people have.

**P03:**  
Yeah, yeah.

**Pharm02:**  
Of course, yeah.

**P03:**  
Because this this is, this is after you've actually made contact with the doctor. You know, it's hard enough now to get a face-to-face consultation, which makes it sort of doubly difficult in every way.

**Pharm02:**  
My personal feeling, is that having worked in a hospital and took responsibility for some very big national pieces of work, one of them I'm thinking of was this, which really made a big difference and Parkinson's disease, Parkinson's UK really got behind this, which is this point about people with Parkinson's, if they don't get their medicines within an hour of when they would expect to take them, that is a real problem for them. And hospitals after that national alert came out, I bet it's probably 10 years ago now to be honest with you, lots of people, because it was repetitive messaging… People understood that actually *(P03)*, who's on Ward 4, you know who's got Parkinson's? He can't wait as long as John Smith, who's on the next ward. And I think that the messaging. I've come to learn in my 30 years career that the messaging is absolutely key. And it needs to be messaging for the public, but it also needs to be messaging for the health professionals.

And I do wonder if the access problem in community would be helped by… and you guys, I’d be interested to know in your views. Because I know sometimes people don't wanna be “badged” as “I've got Parkinson's.”. But I think that when it happened in the hospital and everybody knew that oh, actually yeah, they can’t afford to wait for a delay in their medicines because they've got Parkinson's, that if you had some kind of “badge”, almost that would get you in from an access point of view. I wonder if that's something that I don't know if that's come up on any of the other groups, but I'm beginning to wonder whether or not, and not just Parkinson's. But Parkinson's being a really good example where people need to get a certain “badge” to almost move up the queue in relation to access.

**Moderator:**  
Yeah, that's interesting. That hasn't come up in, in the groups, but I don't know what the, yeah. There's a *(Pharm02)* said what your views are *(P02)* and *(P03)*, I don't know, *(P02)*, what your thoughts are.

**P02:**  
I think it would be nice to have that badge really so that you get a priority. Because I've found that when I've contacted the GP well, it's been by phone, but it's always been someone new. I've never had the same person. So, it's difficult. Because you go through the situation again. And you know, the practice in *(town)* seems to be very poor on that. I don't know who my doctor is, you know, and that sort of thing. So it's hard. So yes, I think it'd be nice to have that badge. I would be happy to have that that on my shirt, you know. So they know who I am. And yes, *(P02)* is needs help or whatever.

**Moderator:**  
Yeah.

**P03:**  
That's interesting. Having just spent three days in a National Health hospital, which was a bit scary.  
Certainly, m medication was way down the list of priorities in being an issue. I have an alarm on my phone that goes off every four hours. I have missed taking them, but generally… where was I going with this conversation?

I think it’s linked. In Australia, I used to wear a watch, a smart watch which triggered off every four hours. Well, in fact it didn’t. It actually measured the amount of dopamine I had at any one time and I could tell when my low point was and when my high point was, through this device. I don't think I haven't heard of them here. But, there has to be a place for technology, I feel.

**Pharm02:**  
Sure.

**P03:**  
I mean, that's fine to remind me. But some, as I say, if you know if you're in hospital or out somewhere, other people need to know that it's time for my medication, in many cases. Does that make sense?

**Pharm02:**  
Yeah, it’s disappointing to hear that you had that experience, *(P03)*. And as I said, I've left hospital six years ago and I worked up in the *(region)*, but I can definitely tell you that it did make a difference for many, many years. Now of course, in the post pandemic years, however, I suppose my question to you would be, when you were admitted to hospital, they obviously, you told them that you had Parkinson's. But did anybody at any point whilst you were there, for example, say to you, “ohh I know because you've got Parkinson's when we need to sort of treat not treat is the wrong word but to consider your needs slightly different.” Did anybody do that for you?

**P03:**  
Emphatically no.

**Pharm02:**  
OK. Well, that that's very disappointing to hear, because that's kind of what you need, isn't it? You just want to, you don't wanna be special, OK, but you need your needs to be thought of differently to the person who in the next bed might have very different needs. And it might be more urgent than yours. If they don't get there, they might, you know, die within the next 5 minutes. That isn't gonna happen to you. But, for you personally, compared to the average patient who doesn't, you know, doesn't need something in five minutes and it doesn't really matter if it's two hours late. There needs to be a sliding scale in relation to complexity, is my personal feeling.

**Pharm01:**  
Yeah, yeah. I was going to say I think that's really disappointing as well. Because my background is also hospital, so I've only been in GP practice about three years and before that I worked at (city). And I know that they've done a lot of work on trying to prioritize Parkinson's patients and using their electronic systems to flag that medication when patients are in. And so they're prioritized as a priority. So yeah, that's very disappointing to hear, *(P03)*, that, that wasn't, that didn't happen.

**Moderator:**  
Yeah. Yes. Yeah. And I think you're right, *(Pharm02).* The messaging of medications over the last years about Parkinson's, you know certainly you know was very clear about getting medications in time, but perhaps not translated pandemic years and change.

**P03:**Especially the I'm sorry for jumping , but whilst I think of it, I mean especially compared with the rest of the care I got the National Health hospital. You know, I could not fault it. You know, it was it. People knock the NHS. But really, I can't. I can't see how they can justify... I had fantastic service. It's just one little thing like this, well whatever spoils it.

**Pharm02:**  
Yeah, sure. And I think going back to the discussion that we were having is, is that just to try and help, I suppose *(P02)* and *(P03).* In that the way that we try to think about things, and certainly I do is that we need to think about proactive care, and we need to think about reactive care. So the proactive care for people like you guys should be your, you know, your once a year minimum, whether it's with a specialist nurse or within a neurologist, OK. And then the ability to go back to them via some kind of reactive need.

OK. So that whether that's a phone line or whatever or indeed via the practices where you are but going back to our point about, but you can only… the practice can only help if they've got somebody within the practice who is competent and experienced enough to be able to deal with it. And so, I think that's the issue, and it may well be that even if practices started to think about well, because this happens for lots of other conditions, we'll say, right, well “Hang on a minute.” We know we've got this person because they're really good at skin complaints, and this person does a lot of women's health and so maybe primary care networks need to identify a clinician… OK, that might be a GP, that might be a that might be a nurse, an advanced nurse practitioner it might be a clinical pharmacist, it might be a paramedic practitioner. We've got some really good paramedic practitioners who are very used to dealing with Parkinson's patients who go and see them when they're at their worst. Almost, you know, when they've rung for an ambulance.

I do wonder whether or not a possible solution, is to try to get a named person who deals with and is the port of call for Parkinson's patients. Even if that wasn't a health professional in the first place and it was a dedicated reception person who had an expertise. Because I think they all have got different bits of expertise. No, I just think that might be the future.

**Pharm01:**  
Yeah.

**Moderator:**  
You know, that's a great suggestion. Sorry, *(Pharm01)*.

**Pharm01:**  
I think for some of our long-term conditions, we're kind of moving that way as well. With the advent of the primary care networks in that some of the specialist services are kind of coming out of hospital into community. I guess with Parkinson, it might be a bit more difficult in that there's very limited resources within the hospital and actually they might be stretched across quite a wide area. But I don't think it's something that should stop us thinking actually, from what *(P03)* and *(P02)* were saying, I think perhaps there is some great things about working together and maybe some group work. And even if a Parkinson's nurse can't see everyone individually, perhaps some group sessions within a PCN, not necessarily on a frequent basis, so.

Like I don't know how you guys would think about that, whether that would be something that you think might be beneficial if there was some kind of group team sessions that you were able to attend that were kind of based in your like local area. Or I mean they’d be virtual. So actually whether they even need to be based in the local area, that could be it could be more wider.

**Moderator:**  
Yes, good suggestion here about kind of virtual appointments. I suppose there's a troubleshooting appointment for, you know, for reactive needs or questions in between.

**Pharm01:**  
Yeah. And I mean, I think something to be said about learning from each other as well. Like *(P02)* was saying that *(P03)*s clearly further down the pathway. And so actually learning from… patients learning together is also of massive benefit.

**P02:**  
Yeah, I agree there. I think I said earlier that, Umm, it's everybody you speak to, it's someone they know that’s got it. And that doesn't help you at all because you know, they say, well, they live for 15 years and haven't had a problem with it, you know. But that's not really answer you want. You want to know from someone who has the same situation as you how they overcome certain things.

**P03:**  
Yeah. Yeah, there's a lot in that. I've got a younger brother who's just been diagnosed. And I see myself now as a, not a mentor, but someone that he can go, he can go to. I didn't have that pleasure with my father, who also had Parkinson’s. But I’m sure I couldn’t learnt a lot from him.

**Pharm02:**  
Sure. Yeah.

**Pharm01:**  
Yeah.

**Moderator:**  
Yeah.

**P03:**  
Yeah, like I think you all you all we all play part.

**Pharm02:**  
Yeah. And I think lots of, I think lots of different areas are beginning to realize that it needs to be, you know, some of the terminology you know, is very NHS speak. But I was listening to something this very week actually, which was the national NHS meeting. And I watched it on YouTube because I'm a bit sad. And they talked about needing to need to “take down the walls” as the new terminology. And so we used to call it seamless. But essentially this idea and I quite like the taking down the walls idea.

So, it doesn't matter who you are and where you are. It doesn't really matter whether you're in the hospital or whether you're at home, or whether you're at the, you know, the Community Trust or the GP, and that you, you are that same person. And we all need to communicate better, including like we've just discussed with yourselves and having the potential of doing stuff as a group because that's, you've all got lived experience. We've got learned experience and you've got lived experience. So this is very much a thing that's being done in mental health for a long time.

And then we've got dementia care, for example. So the way that it, the way that the care looks for dementia is very different to Parkinson's care. And I know we've got a lot more dementia patients, but I can't… I'm gonna go back to my same thing again. If, and I don't realize whether why this hasn't been considered before, but having something that that, like, it's a badge. OK. I know they've got the “forget me not” for dementia care, but it has really opened doors, I think, because it doesn't matter whether you're the receptionist or whoever you are in the practice. If they know that that person's got dementia, they know that they need to think slightly differently. And I'm wondering if that's, I don't understand why Parkinson's UK and Parkinson's speaking for nationally are not talking about that as a way to improve access and thus, better you know, well-being and hopefully better care.

**P03:**  
Yep. Hmm, it's interesting. Yeah.

**Moderator:**  
I think some of the issues as well is that you know is making breaking down the walls and certainly a communication between different health services, you know, GP's and pharmacists and medications, you know, changing your medications, you know from clinic. It, it doesn't go seamlessly from one from your secondary care to the GP to the pharmacist and I know lots of work has been done in that area. But I don't know how we can improve that because people have, you know talked about you know we take the prescription to the GP and then there's an error and they spend time running between the pharmacists and the GP trying to correct any errors in their prescriptions. And, you know, Parkinson's medications are so important for patients. And how can we change that for them? Change their experiences.

I don’t *(P02)* and *(P03)*, what your experiences of your medication changes have been. And it's traditionally the specialist writes your GP and presumably you you wait for the prescription changes and and have that.

**P03:**  
Yes. And that and then the help stops. Though in my experience, that's when the greatest need is. You got this, you got this new unfamiliar tablets. Do I start all in one go or do I migrate slowly off the old ones to the new ones? Yeah. So. Right. Yeah.

**Pharm02:**  
Do does part does Parkinson's UK not have a similar? So look at asthma UK for example. You can actually go online, and you can speak to a nurse who works for asthma new UK online. You know, like you you do when you go on and whatever you go on to these days it's sometimes a bot, but this is actual people and somebody is paid to sit there and answer public patient faced questions about their conditions. I mean, does that exist for Parkinson's UK?

**P03:**  
OK. Uh, if it does, I'm not aware of it, but then that's not unusual.

**P02:**  
Yes, I haven’t got a clue now this. So I haven't looked, to be honest.

**Pharm02:**  
OK. But I'm just thinking laterally about the way that I see other conditions. I'm a very positive person. So I looking for the things that I think have done well that, that, that different areas, different conditions have seemed to you know worked well and trying to provide better care for patients who've got those conditions.

**P03:**  
Plus, but certainly worth. Looking up, *(Pharm02)* to see what is available on that on that side.

**Pharm02:**  
Yeah.

**P03:**  
No.

**Moderator:**  
Yeah, I don’t think it is available on Parkinson’s UK actually.

**Pharm02:**  
Do you think it is? No.

**Moderator:**  
No, I don't think it is. No, it's not. Yeah.

**P03:**  
OK.

**Moderator:**  
So that's an interesting. Suggestion, yeah.

**P03: P03:**  
I’m not gonna find it then.

**Pharm02:**  
No, but I'm guessing the whole point of these kind of focus groups and the research is that Parkinson's UK hopefully will see the results. And then if that's one of the things that we talk about, then you know, I absolutely am sure that somebody's probably mentioned it before. But it requires, it require things to be continually messaged and reiterated for for them to finally go, “Well, maybe that is something we now need to do”. Because access is getting worse. Let's be honest. Access through primary care is getting worse. And yet, how are we going to help people? And as I said, they've got there's a more limited number of Parkinson's patients than there are say dementia patients for a PCN. But if you ramp that up across England, that's still a lot of people with Parkinson's who perhaps could benefit from that.

**Moderator:**  
Yeah.

**P03:**  
Yeah.

**P02:**  
Going back to *(P03)* and his brother, now been diagnosed, should I worry about my son having Parkinson's?

**P03:**  
Well, it's an interesting question. Alright.

**Moderator:**  
But I suspect there's probably slightly outside the remit of this focus group, if you don't mind.

**P02:**  
Alright, OK, alright. I just, I just wondered that was all. Yeah.

**Moderator:**  
Of course. Yeah. I'm happy to have a chat after if you wanted to give you some basic information. But I quite like to just slightly move on and quickly to the next aspect of treatment burden which is about information regarding Parkinson's. And you know, I'm sure *(P02)* and *(P03)* have experienced trying to get information on your own. And that can be confusing and I'm sure you can *(Pharm02)* and *(Pharm01,)* giving you know people with Parkinson always have questions and where you know where how can we improve their experiences of getting the right information at the right time. I think people are diagnosed and given sometimes a lot of information at the beginning saying here's Parkinson's, you know, read this and that can sometimes be distressing. How can we try and mitigate those challenges with information?

**Pharm02:**  
Just to interject before you answer that. I just looked up Parkinson's UK and this is what it says on the website around helplines for Parkinson's. I thought it might be strange that there was nothing. It's a Monday to Friday nine till six, but you might wanna test the system *(P03)*.

**P03:**  
OK.

**Moderator:**  
Yeah.

**P02:**  
Here.

**P03:**  
Yes.

**Moderator:**  
Yes, send me a number to call, but not quite a bot like the Asthma one. I need to have a look on the small one that sounds.

**Pharm02:**  
Yeah, well, the Asthma one, it says to you this will be a WhatsApp group and you immediately go into a WhatsApp group.

**Moderator:**  
Umm.

**P03:**  
OK, well, that's something. Yeah

**Pharm01:**  
I also think, *(P03)*, you could you could ring the Parkinson's nurse at the hospital and they would speak to you. I don't think you have to be under their service. I think if you rang the hospital and just said I want to speak to the Parkinson's nurse that they wouldn't say no.

**P03:**  
I have tried that I have tried that *(Pharm01)*, it's well. I've just been unlucky that I've just not been able to make that contact.

**Pharm01:**  
Yeah, I'm really surprised at that.

**Moderator:**  
Yeah, yeah.

**Pharm02:**   
I just put some more stuff in there for you, *(P03)*. Sorry. Will you go on?

**Pharm01:**  
This is, but this is also about resources and information, isn't it?

So yeah, I think probably using… everyone using Parkinson's UK as a kind of national resource. It's good to have kind of central point so that everybody is using the same information. And I don't know what our specialist services provide from an information perspective. Because for a lot of our other specialist services out in primary care, we know where to go for other conditions that we can log on to a portal and know exactly where a suite of resources are. I wouldn't know how to do that for Parkinson's. I probably would go to Parkinson's UK or some of our kind of more national ones, but actually, is there something to be said about having a local resource set of information?

**Moderator:**  
Yeah, yeah.Yeah. having something available and you knowing that knowing it's there and knowing how you can sign posts, people to the right place.

**Pharm01:**  
And and that you're giving people the right information and we're not, we're not all directing people at different resources that say different things.

**Moderator:**  
Yeah.

**Pharm02:**  
Yeah, but just going back to finally, to *(P03)*'s point, you know the point about, “how do I transition from one medication to another?”. That would be an incredibly common question. And I would be very surprised if when you ring that number, somebody can't give you even the basic about normally it would be done like this.

**P03:**  
OK, I'd like.

**Pharm02:**  
I'd be. I'd be very surprised.

**P03:**  
I'd like to think you're right, yes.

**Pharm02:**  
I would like to think I'm right as well, but I'm happy to be proven wrong because you've already shown me. You've already told me about the hospital experience, but yeah, I think I that is exactly the sort of thing I would expect them to at least know where to direct you or give you some basic information.

**P03:**  
I will certainly follow up, *(Pharm02)*. Thank you. That's for raising that.

**Pharm01:**  
I would have expected your specialist also to give you more information.

**Pharm02:**  
Of course, yeah.

**P03:**  
Yeah, I mean that.

**Moderator:**  
Yeah. I was about to say that. Yeah, perhaps something actually awareness from the specialist itself, that this is probably where people struggle the most with medication changes and emphasizing that a bit more and doing the appointments rather than saying I think we should change your medications. But actually, you know, writing out how to do that specifically, whether that would be helpful.

**Pharm02:**  
Yeah.

**Pharm01:**  
Yeah.

**P03:**  
There is almost a case of information overload. I mean, it's not just about formation, it's the right information for that particular issue or person. The internet is full of information on the subject, I mean it covers it from top to toe. But it’s getting to the point that you want to get the answers that you want, you know.So specifically.

**Pharm02:**  
I think that goes back to the point about messaging. Sorry, *(P02)* Yeah.

**P02:**  
They're not just to say I think if you go online and look, I think it's quite frightening to read everything they say about it. So I think it's best not to do that.

**P03:**  
Yeah.

**Pharm01:**  
Yeah.

**Pharm02:**  
Yeah. Yeah. One thing. I think that's very honest of you to say that. But I think that that's why the key bit. So even if you did know though that, you know, try here first, right that number, then that would be useful, wouldn't it? And that's the problem that we have in healthcare now is there is so much information that we can't see the wood for the trees. And that's both for us as as we've just discussed as as *(Pharm01)* just said, we don't sometimes know where to turn, but it's even more so for people who've actually got the condition. And so it's the messaging bit that's absolutely critical and it's a modern problem, I'm afraid it's a worse problem than it's ever been. And then probably we need it more than we ever did.

**Moderator:**  
Yeah. Yeah, of course.

**Pharm02:**  
I'm really sorry, because I'm gonna have to go. I've gotta go to a partner's meeting. So, I hope in some way that was helpful. And thank you very much for, for being honest about *(P03)* and *(P02)*.

**P02:**  
Yes, nice. Nice to see you anyway.

**P03:**  
Thank you, *(Pharm02)*. Thank you good too.

**Moderator:**  
Thank you. Thanks for your time.

**Moderator:**  
OK. Yeah. So I think you know some of the things we talked about comes from policy and messaging and a lot you know that that we can do from our end to try and help not just medications, appointments and information all that, all of which are very closely interlinked.

**Pharm01:**  
Can I ask a quick question, *(P03)*, when you're when you're medication was changed over, were you given a clinic letter from the specialist with the information on how to switch over?

**P03:**  
No.

**Pharm01:**  
No. See, that's that's kind of the minimum that I would expect. And actually what in an ideal world, what I would then like to happen is obviously when that clinic letter is read in a GP practice is that somebody will then contact you again to reiterate the same information. And that is what we're trying to work towards. And that would probably happen in my practice because most of the clinic letters are seen by the pharmacy team. Admittedly, we're quite far behind because of workloads, so that wouldn't have happened instantaneously. And we're much further behind than we'd like to be. So we probably wouldn't contact patients until about four weeks and we're hoping to kind of improve that.

But yeah, I think actually, that kind of like you said, being overloaded with information at that specialist appointment, we would then expect that specialist to write a more detailed letter to primary care and then actually in an ideal world then primary care can give you exactly the same message again. Which has come from the specialist, because I think actually otherwise probably primary care would struggle with that message. A lot of people in primary care I think would struggle with that complex medication switch. But there is nothing to say that we couldn't reiterate the same message that a specialist had already provided. And I think we should be doing that.

**Moderator:**Yeah, it's interesting *(Pharm01)* that I think that's a great thing to have it at at your practice and having someone reiterate that, I don't think it's it is available, but how do you?

**Pharm01:**  
We don't do it for all our clinic letters, but we would do it for something that was complicated. Yeah.

**Moderator:**  
Yeah. So actually, again, that badge, actually this is a Parkinson's medication and that might highlight things. Yeah.

**Pharm01:**  
Yeah. I mean, it's like another common one is like antiepileptics, any antiepileptics switching regime, we'd make sure we rung the patient to say, actually we've received this letter and this is I mean, to be honest, we do try and prioritize some of the letters within our system. So actually, I'd like to hope that Parkinson's patients, medications, switches with get prioritized as more urgent. So it wouldn't take quite that long.

**Moderator:**  
Yeah, that, that's that's great. So that having that foreverybody, I'm sure we will help them. Any Parkinson's medication changes having that help. And that resource whether that kind of resource come from that is that I don't think glance and *(P03)* would have that at their practice. And how is that organized when a PCNs?

**Pharm01:**  
Ohh every I'm a PCN level, all practices are now eligible to have pharmacists, so it's part of NHS England funding, so pharmacists and pharmacy technicians. Obviously, how each area has, I mean the funding kind of applies equally to kind of paramedics, like some of the nurse practitioners. So each PCN is allowed to make their own decision about what they spend that money on, although I don't think there's any PCNs in *(city)* now that haven't spent that money on a pharmacist.

Because they've realised the value and the input that we can have. But there isn't enough pharmacist to go round. That is the problem now. So although so it will be an emerging, it is an emerging resource and there's certainly probably is at least one pharmacist per PCB, but that just touches the surface of what needs to be done. So yeah, so I think it will. Yeah. And what each pharmacist does within a practice, there is guidance from NHS England on what that should be. So actually, like doing a clinic letter might not come into that priority, but we've kind of taken that upon ourselves that in our practice that that is one of our priorities. So, it does vary considerably.

**Moderator:**  
Yes, don't know. What do you think there should be a better way about how we communicate. You know, whether there is delays in clinic letters because of how long it takes to be typed and then sent. And I don't know obviously *(P02)* and *(P03)*, you've experienced it from your end and obviously from *(Pharm01)*, from, from the other side whether you found that's led to delays in your medications when you know you found that your symptoms have deteriorated waiting for them and how that can change? If there's been any changes in your medications and that you've experienced.

**P02:**  
On my side, it's very early days for me, so I I haven't really had any problems with that. I just sort of I do query things. “You know where it says you should do this. You should do that.” So, but that's all. And so I’d have to say it's very early days for me.

**Pharm01:**  
I mean, I would, I would openly admit there is delays in our practice for sorting out patients’ medication requests that come from hospitals. So and part of that is, yeah, like the letter might not even been written. So patients come, have their clinical appointment, don't understand that actually it's gonna take a little bit of time for that clinic letter to be written initially. So there is an initial delay and then obviously it takes a bit of time for that information to be sent to us at the practice. And then as an even further delay without going through the practice system and then getting to the right people that need it. So the whole thing is not a quick process.

**Moderator:**  
Yeah, yeah. I don't know whether electronic prescriptions have been suggested or you know of changing that before. And I know you in the focus group, some specialist talked about, you know, FP10s, so *(P02)* and *(P03)* might not know that it's a script that patient can take straight to the pharmacy to get their prescriptions rather than go through their GP to get it.

**Pharm01:**  
So I know that's been happening in our local area, in not necessarily that way. The actual outpatients department at the hospital have been doing some of the initial prescriptions because they were quite aware of that delay of on initiation. So that has been happening. But that's actually been met with some concern from GPs, because actually they feel that the hospital specialist doesn't that necessarily have access to all of the rest of the information for that patient. So they merrily start a medication, but don't think about the other conditions. So they might change your Parkinson's meds and not realize the rest of the medication that you're on.

And actually, we've come across quite a few situations where things have interacted, the whole pictures not being thought about, and we've had to go back to the specialist and say, “Woah, woah woah, go back a minute. Yeah. You haven't considered the whole the whole picture.”

**Moderator:**  
Yeah, that’s absolutely true. And I think that's your part of it, from a specialist point of view, sometimes we can't actually get access to see what patients medications are on. And in some patients, if they don't remember, if there are lots of different medications and what they take. And that, you know, communication between that different services can be can be challenging.

**Pharm01:**  
Now I know there is a much bigger national project going on at the moment to try and electronically resolve those issues, but that's gonna be a long time in the coming so.

**Moderator:**  
Yes, exactly. Great. So I think just a couple more things I don't know, about really is about kind of lifestyle changes that you've been advised to do. So you know, exercise, diet interactions with medications and diet with Parkinson's. Some people find that, some people don't and I don't know how easy or difficult you’ve found completing you know the recommendations of lifestyle changes that you've read or been been heard about, and and you know how we can help those changes. That was one of the issues that that people have Parkinson's talked about. And so, you know, they tell us to exercise, but it's difficult with tremor, with the shaking, with the freezing and how to overcome that or, you know, taking medications around meal times, recommendations to take it before meals or after meals and challenges around that. Coordinating that, obviously, other medications as well.

**P03:**  
Yeah, I mean. I tried to keep my life on the same even on the same even keel that I've always lived.  
Not to let Parkinson's take a priority role. Now I may have Parkinson's, but Parkinsons hasn't got me. Yes, I probably do a bit more exercise now than I have done in the past. But I also, well won’t let get Parkinson’s get in my way of what I want to do. And that’s a battle.It gets harder and harder to do things like walking and stuff like that. But yeah, I don't know how to give you a, you know, a good answer.

**Moderator:**  
Having a the right mindset sounds like, and persistence I think.

**P03:**  
Yes, absolutely it is. Mindset plays a big part in it. Yes.

**Moderator:**  
Do you think that there are things that healthcare professionals can do to help that side of things?

**P03:**  
People that want to help themselves will help themselves. It's, you know, I guess there's within the community those people that would help would follow whatever help they're given. Other people just, I’m probably in that category that I’m just going to get on with my life. I'm putting that category that. I'm just going to get on the bus. This horrible disease is, you know pushed in the background. I never thought I was a fighter, but I'm fighting this well.

**P02:**  
Good.

**Moderator:**Yeah, absolutely. I don't know whether you've experienced any of that *(P02)*. You know, you're quite early on.

**P02:**  
No, it's just it's just doing the things. I think the same as *(P02)*. I'm sort of saying to myself, you know, “I've gotta win”. This hasn't, but it is hard. This is a trouble. I find, you know, even at this stage, I find walking really hard. And I walk, you know, my wife says it looks like you're drunk, love, you know.

**P03:**  
That's it, yeah.

**P02:**  
It's, you know, because I can't. I've never been out of walking a straight line anyway, and now it's even worse so. But I don't know you know how to overcome that really except by doing more. That's all I've been doing is trying more a bit so.

**P03:**  
Yes.

**P03:**  
I don't know how you find it *(P03)*, but I find every day you have to relearn. Things like the steps to walk.

**P02:**  
Yes, yes.

**P03:**  
Because somewhere overnight, that ability is gone.

**P02:**  
Yes.

**P03:**  
So every day to relearn and hopefully you get. You know you. Yeah. You learn to laugh to lead a good life through every day.

**P02:**  
Yeah, I find I find my right side is my stiffest side and I don't know if that's related to Parkinson's or related to my stroke. Well, I find hand movements, my right hand, I've stopped doing. I don't. You know, I realized that now I shave with my left hand. Which. You know lots of things I do and I think I never did that before, but now I'm doing it in my left hand and I don't know if that's related to the stroke. Or Parkinson's.

**Moderator:**  
Yeah.

**P02:**  
So, you know, in a way, it'd be nice to know. I think it's the stroke actually.

**P03:**  
Right.

**P03:**  
Yes.

**P02:**  
I think that's effective it because I find it. I'm now seem to be more flat footed on my right foot. You know, that seems to drag. Sometimes when I'm, because I still drive at the moment because I can. I find that sometimes my foot stays on the accelerator where it shouldn't. But that's only if I'm changing gear or something like that. Going down, I realize I, you know, I realized I'm doing it and I pull away from it, but. But as I don't know what that is, if it's stroke or Parkinson.

**Moderator:**  
And it's just, I don't know what the having, you know, access to more exercise classes or, you know support to help with, you know things would help or whether they're variability as you said it's a day by day thing every day it's you know you're teaching yourself because your body reacts differently to the Parkinson’s medications as well as what people always say. One day is not the same to the other sometimes, and how that consistency you know, can be helped. And it's not just with movement, but I suppose with diet, or if you have noticed any of that. Not really. Yeah.

**P02:**  
Not for me.

**Pharm01:**  
I think for other conditions we kind of know sort of healthcare professional wise where we can refer people to for sort of exercise type classes, but I wouldn't know that for Parkinson's and like whether there's anywhere that would specialize in providing kind of good sessions I don't know. And I guess the patient numbers are small, so it would need to be it, it would probably be difficult for people to access if there was such a thing, I guess is is the problem. Whereas like for our other conditions that the patient numbers are bigger, so actually there's an advantage to having kind of things. In I feel like actually if we were to set something like that up that actually it would probably be too far for quite a lot of the Parkinson's patients to be able to come.

**Moderator:**  
Yeah, yeah, yeah. Travelling. Travelling somewhere central is not always easy and I think doing it online technology.

**P03:**  
Yes.

**Moderator:**  
Would work.

**Pharm01:**  
When exercise. Yeah, for an exercise class, I don’t feel like that's the right thing.

**Moderator:**  
Yeah. No, it's exactly, yeah.

**P03:**  
Change can I? Can I? But in the my bladder is not gonna hold out much longer. Can I leave this meeting?

**Moderator:**  
Yeah, no, of course, because I think we're just about to finish up anyway. And unless anyone's got any final thoughts. That's been a great discussion and thank you very much for your time. If we haven't talked about anything obviously *(P03)*, if you need to go, but if you know, *(Pharm01)*, *(P02)*, if there's any final thoughts about how we can help improve?  
  
**Pharm01:**  
Yeah. I mean, I think there's a lot to learn and I think there's a lot to learn for everybody. So I, yeah, I will openly admit that I think there's a lot that healthcare professionals can learn, like we've already discussed. Even if I went to my GP's for support, I think I would get the same the same information, no, please contact the specialist. So I think we do really need to get that information out from the specialists more into primary care settings. So and I do think there something to be said for kind of like sort of local, yeah, even online groups now. So I think that that was something would be really easy to set up going forward.

**Moderator:**  
Yeah, absolutely. Something to explore and, you know, help with the capacity and workforce issues. So trying to make more group things in online things.

**Pharm01:**  
Let's see why the Parkinson's nurse couldn't organise a yeah, a group session and across the whole local area and yeah.

**P02:**  
Thank you.

**Moderator:**  
Yeah, yeah, absolutely. And something to look into. I don't think we do it. So definitely a a good suggestion there. Yeah. So thank you very much both for you. Again, for your time. I won't keep you any longer. It's been an hour.

**Pharm01:**  
Thank you. It's been really interesting.

**P02:**  
Yeah. Thank you.

**Moderator:**  
Yes, thank thanks. Any questions you've got my e-mail if anything pops up. But thank you once again.