Interview 2

Interviewer:

Thank you again for your time and participation. The purpose of the discussion today is to help us gain a better understanding of your views about and experiences of remote patient public involvement and engagement (PPIE) working. We are also interested in your thoughts on how we can facilitate and improve doing PPIE remotely, working with people without face-to-face contact, in health and social care research. This information will help us improve practice in remote working in PPIE and help make PPIE activities more accessible.

So the interview is basically divided in two parts; first I would ask you to kindly share some information about your PPI work before COVID-19 and lastly, I would like to ask some questions regarding the current situation of COVID-19 and your involvement with remote PPI. Thank you!

Could I start first by asking you to tell me about any PPIE work you were involved in prior to covid-19, what PPI you were doing before COVID-19?

Interviewee:

so about five years ago, I started as a patient reviewer for, I think is how you say it. So I would get grant applications to look at, and then sort of give my opinion on things that were in my area of expertise as a patient, which unfortunately, is chronic pain issues and emergency surgery. So that's things that I've that I've gone through. And in one of the one of the newsletters that came through, was an invitation to apply to sit on committees. And started last year, working for the research for xxx panel. So I see it. So I sit on that panel there. And I think in theory, I would also do the other remote reviews, but I haven't had any. I haven't had any this year. So but but I'm sort of able to do those.

Interviewer:

Thank you very much. That's really important, So how did you do the PPI before? Was it face to face or teleconference anything similar if you could share please?

Interviewee

Yeah. So So originally, I would, I would do it remotely. So I would just get the application. And I'd fill out a form with with my, my views. But once I started to work for the xxx, I had a face to face interview, and started on the committee in a room with people in January 2020. And that was my first full meeting. But I didn't participate. I was just there as an observer. So when I actually started on the committee, it was all via zoom. So since then, and there's four, there's four a year, so I've done four now.

Interviewer 03:36

Okay, zoom, zoom committee meetings. Oh, yeah. He attended PPI via Zoom. Was it? Was there any reason that you prefer zoom during that time? Or was it far away the meeting venue or?

Interviewee 03:53

Yeah, so the interview was in K, which is about 30 miles away. And then the first committee meeting was in C, which was about 50 miles away. So I chose the xxx. So because I had seen other interviews in the world, the spaces that I could have gone for, but I wanted the xxxx ones to be to be more local, so I had less travel. Because of my own health, I thought it would be easier to do that. So

Interviewer 04:26

How do you feel about your PPI contribution over the last few years, if you could share, please?

Interviewee 04:35

I can understand how it's really important. I've had some really rubbish health experiences, and it feels that I'm putting that to good use. So if they're not wasted experiences, this sort of rubbish doesn't make doesn't make what I went through any better. But it just, I just feel more useful. And I think having gone through those things, if I can help them People have a bit better time or a bit better outcome, then then that's, that's really, really important to me. So,

Interviewer 05:09

If there was an opportunity to do the face to face so would you do face to face? Or? I mean, if it was near to house or area would you prefer face to face meeting?

Interviewee 05:25

Yeah, I think it sort of depends on timing. I mean, if something came up tomorrow, I wouldn't want to do it because I'd be quite nervous about you know, being in a room full of people but i think i think sort of come the summer I'd be I'd be happy to do it. My next meeting is in xx. Which I guess you know, if you're looking ahead to me now, it could be either and I think I would feel comfortable with it with being in a room with with people then and but I did struggle surprised I was quite surprised because on the the only meeting that I've been to, which wasn't very far away, I really struggled physically with with pain, having driven during rush hour, and then sat for eight hours. I did I did struggle with with the pain and wondered whether I could carry on with the meetings because of how physically they were hard for me to do. So in that way, zoom is much is much better. I you know, I know. I know I can sit for eight hours but sitting for eight hours and having to drive through rush hour either side was a bit much.

Interviewer 06:37

Okay. Anything in particular that supported your involvement/engagement at that time, before COVID introduced measures?

Interviewee 07:02

I think I'm self employed. Okay, so so it's so it's easy for me to do that, you know, I can tell I can take a day off I don't have to, to get permission to have a day off I can work around it. And I'm a I'm self employed. So it's dependent on the work and it's dependent on my health but i'm not i'm not full time. I would be if the circumstances were right, but but it is very easy for me to do that I have I have a lifestyle that makes it easy for me to to read all the documents and get involved whenever the meetings are

Interviewer 07:40

Anything difficult/challenging about face-to-face working (such as financial issues, carer responsibilities, travel, time, etc.)? So

Interviewee 08:08

it was the travel really, I really struggled with the travel. Because of the of the xx region of the it can either be at C, K, or B (cities/counties). B is very easy for me to get to untrain and K not to K l not so much. X University was rather C is okay. And so I think I was going to have to experiment with how I got there because driving was too much challenge. So the physical demands for me with my condition were were tough. But I mean only did one meeting I would have had to play with with public transport and see if that helps. But obviously now, if we were to have a meeting face to face, I absolutely wouldn't go on public transport. We know if it was in the next 12 months, I wouldn't I wouldn't go on public transport. So that would be that would be a demand that I'd have to weigh up whether I could do that.

Interviewer 09:07

Thank you! So we'll move to the current situation now. So perhaps now I could ask you to tell me about the PPIE work you are currently involved and/or engaged in: What PPIE are you taking part in at the moment after Covid-19 (organisation, research grants, project)

Interviewee

So the regional committee at xxxx.

Interviewer

So same PPI as you’ve been doing previously?

Interviewee

Yes. Yeah. So that's so I've done for in the last in the last year. Okay.

Interviewer

Okay. Well, What is different/changed about PPIE now? (limited face-to-face working, remote working)

Interviewee 10:03

Well, I only did one pre COVID. And that was as, as an observer. So I didn't, I didn't join in now this way you have, you have one meeting where you observe, and then you and then you start to participate. And of course, in that first meeting, there's loads of information to take in as loads of faces, you get, you know, and, and I think it slowed me down. It's been a hindrance to getting into the meeting. So working out how to manage the information myself. So you know, you have a lot to read beforehand, and then you can and then you talk. And it's and I find zoom meetings, when there's a big group of people, it's really hard to pick up on visual clues from people. So you can't read the room, you, you reading out what you've written down already. And so I think that's that slowed me down in learning, the best way of doing it and making me feel comfortable and confident doing it. I think if I'd have been in a meeting, if I'd have been in a room with people, I'd have got into the swing of it much, much more quickly than I have done. So I found that a real it's not a barrier because you do it. And I think the meetings have got better. So the time is managed better. But I think by by how strictly the time is managed, you're only getting the key thing said people don't necessarily talk around a subject as much. So I think it's I think it's been harder to learn how to the best way I can be, you know, I can I can input and be a committee member.

Interviewer 11:41

At the moment everything virtually, but you have been doing it virtually before COVID-19. So was it not that difficult before?

Interviewee 11:50

And I didn't do I didn't do many? I didn't do I didn't do any zoom meetings. So previously, the PPI work that I'd done, and they would send me something to read, and I'd fill out a form and send it back. Whereas this has actually been taking part in meetings. And I think it's been quite hard. Doing that over zoom.

Interviewer 12:12

So now how they're sending you documents via email?

Interviewee 12:18

Umm And well, that sort of strands that the majority of stuff that I was doing before COVID. I haven't I haven't had that was piecemeal. So it just came as and when there was a xxx with my that that aligned with my knowledge as a patient. And so I haven't had anything but I think, had I had something, it would just that would be exactly the same. For me. It's the it's the meetings that have changed. Yes, I have some add some knowledge of zoom meetings and interviews, but not but not very much. I'd certainly never hadn't done like a big committee meeting on zoom before the pandemic.

Interviewer 12:59

So this is something new for you?

Interviewee

Yes it is

Interviewer 12:59

Any impact on that, on involvement or engagement for PPIE? For for this new learning, is it just needed to go through lots of reading any other impact you had?

Interviewee 13:21

I think I missed the I think there would be a social aspect. And there would be sort of a peer, better peer support, and better sort of peer to peer learning. So I would have chatted, and I did the one meeting I went to I chatted with the other PPI reps, I got a feel for it. And I think that's what you miss over zoom. So I still have the opportunity. I have the email of the other PPI representative. And I can email her and ask any questions. But that's not the same as just being able to have lunch with somebody and say, Well, why did you say that? why did why did you? I didn't think that why did you think that? And and if you can't really, I don't think you can do that over email. You can't have those little asides and chats. And I and I missed that. I think that would have helped me enormously. Get into the swing of it much, much quicker.

Interviewer 14:21

So you could do them all the way to having tea you could have?

Interviewee 14:27

Yeah, because it's immediate. So it's the you lose the immediacy. And you lose the ability to have like little conversations, because as soon as you put them down in writing, if I was to say to somebody, why did you say that? That's a completely different completely different conversations that that's and you just you just can't do that and you and I missed that. Thank you.

Interviewer 14:51

Now I would like to ask you some question about the access to resources for doing people at PPI remotely and can you please share what access of resources do you have?

Interviewee 15:16

Yeah, so I've got access to a desktop or laptop, a smart phone and borrow. And also, because I work from home, and I'm completely set up for these things, you know that that hasn't been an issue for me at all? Yes. And you? And I also have, yeah, I also have somewhere which is for having someone with chronic pain, I also have somewhere where I am, I can sit for eight hours at a desk. And I think for someone who was involved in PPI who if that that was someone in the same position, I think you'll find the bone difficult to set, you know, on a chair at the moment, because this is half an hour, but I would love to sit on the dining room chair for eight hours. Though it's not only the technology for me, it's also that the environment that I've been able to create to a working environment has made it much easier to do zoom meetings.

Interviewer 16:15

Thank you. Oh, of course, I think you use Wi Fi as well.

Interviewee 16:20

And Wi Fi Yes, of course. Yeah. Yeah. And Wi Fi. That's fast enough.

Interviewer 16:29

Did you require any help and support to do your PPI work remotely?

Interviewee 16:42

I have, it's through setting up my working environment, I actually got an Grant 10 years ago. So this isn't directly for ppi. But again, that's that's helped me. So I've got a proper chair, I've got a I've got a desk that moves up and down. And I got that through a grant when I started working for myself, so that financial support, which I know if you were just doing PPI you wouldn't be able to get is helps enormously through through everything, but obviously helps with with the PPI work as well.

Interviewer 17:18

That’ great, thank you! Regarding PPI work any organization, you were working? Did you ask for any support from them?

Interviewee 17:37

Not, Not, only only advice, so I have been able to so so the last meeting was in January. And I you know and I've been able and felt able to send an email saying how am I getting on? Can I have a few pointers? So they've given me that sort of support? Which has been really really good

Interviewer 17:58

Support from family friends any support from them?

Interviewee 18:01

Oh, yes. Right. Yeah, my family of yes supportive. And we know we know when the meetings are going to be which is really good. Which means that we can plan it we can plan around around those, those meeting dates so I know that you know the next I know for the rest of the year and I'm able to keep those dates free

Interviewer 18:23

Thank you! Was there anything in particular that helped you involvement engagement during COVID-19?

Interviewee 18:35

i think i think it was the fact that I was already set up work to work from home that that you know that's that's been that that's the big thing so that's made it much much easier

Interviewer 18:51

That’s great that you got desktop and laptop so you got all the support you need all the resources and how would you say your computer literacy and access to resources using technology I will say?

Interviewee 19:13

I'm not too bad but my partner is very good. So I'm okay I'm okay until I get stuck and then I don't know why I've got stuck but I'd say it compared to compared to people in general i'm not i'm not too bad at all and I'm very lucky that I can I got you know personal IT support as well live in live in IT support.

Interviewer 19:40

Okay, so if you Yeah, if you stuck then you can ask your partner Oh,

Interviewee 19:43

Yes, yeah.

Interviewer 19:40

Good. Any particular support you might require in digital in relation to specific challenges for example, you know, reduced physical or any mental health issues any Do you think we're doing the COVID-19? While you are working remotely? Any support challenges you face?

Interviewee 20:09

Um, no, it's I mean, physically. It's easier. I don't know whether I prefer it. I'm really torn, whether it's better. But physically, physically, it's much less demanding. So I do I do prefer prefer that. So I feel that I need less support. So happy to have a zoom meeting.

Interviewer 20:40

Okay, thank you most of the thing, because you're quite familiar with working from home, even before COVID-19. So is it didn't didn't make a lot of it, seems it didn't make a lot of difference to your working environment, because you have been doing it same way before COVID-19. It's not that you, you know, the situation made you to do this, isn't it? I made it something. Because that's why something is quite familiar. You are doing what you're doing?

Interviewee 21:10

Yes. Yeah. Yeah. I mean, I haven't either worked in quite the same way. But it's pretty, it's very similar. I've got all the all the infrastructures there to just sort of get to get going.

Interviewer 21:19

Okay. anything about home environment, privacy or space time, issues..

Interviewee 21:47

Yeah, I mean, again, I've got the you know, I've got a room set up to work from an office at home. So. So that makes things easier that I don't have, you know, and I don't have any, any noise around or worried that people are going to come, oh, kids are going to come in? Because you do see kids wandering behind people. And when you're on meeting, so yes, I will all set up. So it's it's you know, that absolutely fine, and very, very easy for me.

Interviewer 22:19

Thank you! Is that anything that was difficult to manage, hasn't worked well, what has not work or worked less well doing PPIE remotely?

Interviewee 22:29

Yeah. I mean, it's just that interaction with people, it becomes over a zoom meeting. And you know, in a meeting that's very heavily managed for time, which it needs to be because they're big, long meetings, you just lose that interaction, I think it becomes quite quite staged, and you sort of lose, you lose the subtleties of of, of conversation and an interaction. There was there was a question about whether it would be better to do the meeting instead of one long. Eight hours, there was talk about whether it would be whether they do it in two half days. And but I think that was never going to happen with conditions because that would be much harder for people to get the time off. But I wanted to try that because I thought you could, you could have a little bit more freedom with time. So every meeting is going to run over a little bit. So I thought if you had two meetings that both went over a little bit, it would just give that more flexibility with time. But that didn't happen. So so we are sticking to one, one day meeting.

Interviewer 23:50

Do you normally attend that long hours meeting such as go for eight hours long meeting?

Interviewee 23:54

Yeah, so yeah, not well, slightly less, seven, seven hours. So what so I think it's been the nine the 915 to start for the 915 to login for 930 start, and then they go on to about four 430. And you have a break in the morning. Lunch break and an afternoon break as well. But you're still on you still is still quite intense. You still it's only sort of 10 minute breaks, and maybe.

Interviewer 24:26

So how did you want it when you said he wanted to break it down into parts? So how many how many parts if I say like this?

Interviewee 24:34

Just to do two half days, I wondered whether that would work quite nicely and give people a bit more freedom and time. But it's really hard for people to take. I'm not but you know, that's because I've got all the flexibility I want with time, but for people who are working you I appreciate you can't do that. But that was something that I think I would have liked to have tried.

Interviewer 24:57

That’s brilliant. So did you have you felt this during this time, or you felt this even before COVID-19?

Interviewee 25:03

I just just during this this time,

Interviewer 25:05

Okay this time, thank you! So what about before COVID-19 was that okay?

Interviewee 25:10

Well, before, before COVID, I only ever had very short, short meetings, so they were more conversational. And I was I was sort of doing remote meetings before, comfortable using a platform like this, and we'd be doing it over the phone. So I think the technology's moved on enormously than having three groups of people are all on speaker phones, which was horrible to try and listen, listening to everybody.

Interviewer 25:44

So do you prefer zoom than phone?

Interviewee 25:47

Oh, absolutely. Yes. Yeah.

Interviewer 25:50

Okay, thank you. Is there anything that you think could have been done differently? So that it would be better?

Interviewee 26:04

I think I think under the circumstances, they've, they've done it brilliantly. I don't, I don't think they could do it better. They're really sort of they worked out what works and what doesn't. So as long as there aren't a lot of new people in the meeting, we don't do that round the table, you know, the round the table, introduce yourself, because I don't think anyone listens. It's just really hard to take that team. And it becomes something that, you know, if you saw me and I introduce myself, you'd remember you'd at least remember that a bit. Whereas if it's just a voice, rather than the lady who's sitting three from the left, and you write that down, they're just disembodied voices and faces, and it becomes a bit meaningless. And so that so that bits been taken out instead of trying to replicate a face to face meeting things like that have now gone. And of course, it improves, it improves, it improves the time, and I think they've done it absolutely, brilliantly. And there are there are things that I prefer face to face. And there are things that I missed, but I don't think they could have done it any better under the circumstances.

Interviewer 27:11

Thank you. Is there any limitation doing PPI do you think? Limitations placed on PPIE through working remotely?

Interviewee 27:28

I think it's it's the Yeah, it's that it's learning from each other. And I'm probably the networking aspect would be more important to the clinicians, or the or the researchers who are in the meeting. Because I mean, that that networking aspect, I guess would be more important for their career. But But you still have that as PPI, it's still you still doing it to to learn something to give something. And of course, we all say you want to learn something from the from the process, and you want to talk to people and you want that social aspect of it. And so that and that, and that's, that's lost, and I think that's it, that's a real, that's a real shame. That's something that I miss.

Interviewer 28:17

Thank you. Just thinking about the time isn't nearly a half an hour, 30 minutes already. is there anything that I have not asked about that you would like to add/ that would be helpful?

Interviewee 28:32

Well, yeah, I'll just when I, when I received the email about taking part of this, this was already something I was really thinking about. And I had, so January 2020, I Sat as an observer. I took part and it was my first meeting. So it was a bit it was all new to everybody. That meeting was the first time I felt that I really could get involved and sort of participate fully. So this was this question of actually has, has zoom helped has, you know, has this remote working helped me or hindered me was something that I was I was thinking about anyway. And I'm still undecided having thought about it and having spoken to you I think there are there are good ways of working like this. But there's also huge disadvantages as well. I mean, I think that if if you look forward to what would happen in the in the near future, I think I would be quite happy to do it half remote meetings and half face to face that would that would be sort of the ideal for me.

Interviewer 29:57

Brilliant, thank you!” It's very useful to know that's pretty useful because as they this situation this COVID-19 we said it will, it will create somehow a new norm for everybody. Yeah. So you would prefer zoom meeting even once the lockdown is over, you still would prefer them. But..

Interviewee 30:19

Yeah, a combination, I think would look. Yeah, yeah, but I but I wouldn't want to get rid of it completely. But then of course, having worked having worked at home, I'm very used to working by myself, for myself by myself. And so it isn't it isn't that alien to me, even though the zoom platform is relatively new to just been sort of 15 months. And remote meetings are relatively new, like in this format. I'm used to the working by myself. And I think that's when I talk to people. I don't know anybody else who does PPI don't talk to anyone else who does PPI, but people who are working from home, it is that remote working that people struggle with being by themselves. I'm fine, I'm fine. We're fine with that. And so it hasn't been that big a change. But I think it would be really useful if it was introduced as an element of the whole?

Interviewer 31:20

Or would you? Would you like to see a choice or an option given to the PPI member to take part in PPI work in the future, I mean after the Covid-19? For example, in a group, if there are eight people, maybe five people who would go face to face? And would you like to see there is an option that some people could, for example, in a room some people are sitting, physically attending and there is a big screen where they can meet others who are attending remotely?

Interviewee 31:47

yeah, yeah. I mean, not yes. I think that I think given the choice, I would rather be in the room. I'd rather be there in person. Yeah, I hadn't really thought about it like that. I'd thought about it in terms of two meetings, the zoom meetings, two meetings, or face to face. But yeah, you could you could split up one meeting with some people in the room and some people over zoom. Yeah, I think that yes, that would work. But I think I would weigh in you too. I think I'd be I choose to be in the room.

Interviewer 32:15

That’s great. Thank you very much. That's very helpful, your opinion, extra value, anything else you you'd like?

Interviewee 32:24

I think through through talking to you, I hadn't really appreciated how important it's been to me to have that to the environment to be to be set up. Just the comfort of being able to sit somewhere. And I think if I hadn't worked from home, before hadn't been set up to work from home, I think I've really struggled with where I could sit comfortably. Because you can't get up and walk around. So that alleviates the pain. Obviously, I can't take painkillers, God will be able to concentrate on everything. But yeah, that's I hadn't appreciated how much how important that is. If you're somebody and I think if you're in PPI, you're likely to be somebody who probably has a condition that's, that's brought you to to ppi. And oh, yeah, but I don't appreciate it How, how important that is to have that place. It's comfortable to sit?

Interviewer 33:24

Yes, of course, I mean, it's very important to see it and as you said, you have the access to have all the resources working remotely

Interviewee 33:34

For me, that that is the only thing that hasn't been as important as the computer because you can do to tool without the computer. But I think that's that that comes set, you know, second after the technology to be able to do it somewhere and environments where you can sit comfortably. Because as soon as you're in pain, you don't participate. As soon as you're in pain, half of your brain is just thinking about not being in pain. And it's very hard to engage fully in any in any discussion or or anything really if you're in pain. So that that's that's very important.

Interviewer 34:18

Of course, yes, comfortable. And you got enough space and privacy, as a public contributor you can all make positive contribution.

Interviewer 35:22

Thank you very much. So I will I will stop the recording here on the on the PC so that we finish because it's done already and I will I will stop it now.