Interview 6

Interviewer 00:00

Thank you again for talking to me today. 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 01:28

Before COVID-19 hmm quite a lot. I am on the part of the research network forxxxx. So I get involved in various studies. With researchers for so I'm a public contributor for the xxxx West Midlands ARC.

Interviewer 02:04

Yes, I am.

Interviewee 02:05

Yeah. And also on public contributor for the quality and I forgot, forgot what they called the xx. In that it's an amalgamation of various universities looking at social and health care

Interviewer 02:26

That’s great. So you have been you have a very wide roads you have been doing it for how long? Have you been doing this for a long time?

Interviewee 02:33

About six or seven years now.

Interviewer 02:59

Thank you very much. Thank you. So you, you have a quite a diverse role in various universities and organizations. So

Interviewee 03:07

Yeah,

Interviewer 03:08

Thank you very much for doing this. So how did you do PPI before COVID-19, please?

Interviewee 03:15

I used to go physically attend meetings. Some in some in L, mainly in L and the X.

Interviewer 03:35

So you used to travel there?

Interviewee 03:43

I drive. Yeah. You know, going into the place in xxx, you don't want to take a car.

Interviewer 03:53

Okay, so how do you feel about how did you feel your contribution towards PPI?

Interviewee 04:12

What I've continued to do it really keeps on saying that I provide valuable insights and I made a difference in you know, two or three important areas. Yeah, good. Keep doing it. Get in it.

Interviewer 04:35

Yeah. Of course, you make a difference of course. So what did you enjoy the most about face to face working, please?

Interviewee 04:47

I like going out about you know, also meeting different people. meetings. You know, very, very good to You know, if you if you've got a whole series of meetings, you get to know people very well, and you chat about social things and you work a bit better when you know people. When you don't know people just just out on the screen, sometimes you don't connect as well. I feel that anyway.

Interviewer 05:28

Thank you. Did you did you travel far outside England for doing PPI?

Interviewee 05:36

I haven’t, no. Oh, so the representative, the patient representative from the xxx. There wasn't, there was a couple of sort of a, but I decided to join remotely cannot because it was quite a long journey. My wife, and I just got a couple of long term health conditions. So I don’t want to go..

Interviewer 06:22

Thank you. Anything in particular that supported your involvement at the time before COVID-19?

Interviewee 06:33

Sorry, could you repeat

Interviewer 06:35

Anything, any, anything in particular, which helped you to be a PPI contributor before COVID-19, please?

Interviewee 06:48

Anything could help me? Well, I've had a couple of long-term health conditions, I've got xxx at the moment, and I've always been interested in health research, you know, it's helped me enormously, I would come and deal with my long term health conditions. So I'm really interested in contributing to health research, especially in xxxx because it helps. gonna help me in the future, hopefully

Interviewer 07:30

It's great, So you, you were thinking about other people who would go through the same journey, so that will help them from your point of view?

Interviewee 07:41

Yeah, I’ve always been a umm, my, basically, I've always been interested in helping people and being a bit of a role model.

Interviewer 08:32

That's great. Thank you very much. Thank you. That’s brilliant. Did you find anything difficult about face to face working, anything challenging can you remember, think of?

Interviewee 08:45

I'm a bit of an introvert. If I'm meeting somebody, you know, in a new meeting new people, it takes me half off this session to get you know, to get comfortable with people need a bit of time to settle down?

Interviewer 09:10

That’s ok, that’s fine

Interviewee 09:12

Yeah, being an introvert versus Well, you know, if you're in a grave situation, you don't tend to talk very much. Usually in meetings, you know, two or three people hardly at all, you know, meeting together word in edgewise sometimes. So as you become more comfortable with people, especially face to face, you know, you can you can feel more comfortable to be able to talk and say what you want to say, huh?

Interviewer 09:51

And you also mentioned about the challenges about traveling, go outside UK and is That one.

Interviewee 10:01

Yeah, it was a bit challenging their job and the meeting was in xxx, but I joined by joined by phone and that was before COVID. And we weren't into zoom with a big way like we are now.

Interviewer 10:21

Yes, now we'll move to the current situation. Could you please tell me about the PPIE work you are currently involved and/or engaged in?

Interviewee 10:43

After COVID-19? Well, it's been a year of zoom meetings. Well, it started off with Cisco WebEx. Now we moved to zoom. With thexxx, we've had about 20 odd meetings that it has been quite difficult.

Interviewer 11:33

That was xx.

Interviewer 11:35

Yeah, there's 26 people leading the meeting at any one time. To me, it's quite hard to follow sometimes, because some of the accents you know, you English is not their first language. Yes, majority of people. And

Interviewee 11:57

That's been very enjoyable. I've been involved in xxx, a number of various meetings. And xxx has been doing some meetings. The recent meeting in the last couple of weeks was with the xxx company here. Looking to do some research the UK.

Interviewer 12:32

Okay, so it's quite a few national and international involvements

Interviewee 12:39

And last week, xxx University, I'm on their expert patient group.

Interviewer 12:47

That’s great, was it was it from last week when you joined them?

Interviewee 12:53

Now it's been going on for about four years now.

Interviewer 13:05

Thank you very much. Thank you. So you're quite busy with you PPI involvement? You’ve got national and international involvements. You feel busy with those work?

Interviewee 13:15

Yeah, I'm retired and had quite a few meetings this year already. Hmm.

Interviewer 13:27

Thank you. Yeah. What is different/changed about PPIE now? Now, if you compare before COVID-19 and after COVID-19 if you please share something. How it feels different, please?

Interviewee 13:42

Yeah, we used to have two or three hours meeting and we used to have lunch breaks. You know, they used to provide lunches for us. Now we don’t have any or give any lunches?

Interviewer 13:53

Yeah, that's a good point, even for the conference as well.

Interviewee 13:56

Yeah, and you don’t have any opportunity to talk to people before or the during the conference and after the conference.

Interviewer 14:12

Right, anything else you can think about? Any differences you can add on that?

Interviewee 14:18

Yeah. It's, it's not. It's not as easy. You know, all kinds of things are going on. You know, so some of the people out there were children in the background. Picking up the the, the one the host for that has got a nine month old baby in the background. And a bit surreal, some time what's going on in the doctors and physiotherapists and neurology is often breaking off, stay patient and coming back. As it is, it's so different in some respects.

Interviewer 15:24

Hmm you’ve got to have a lot of patience, I guess. Anything, anything new for you any impact on involvement for you?

Interviewee 15:43

Yeah it seem to be getting more involved in things. Yeah. You know, face to face meetings probably have double the amount of meetings on zoom now that I used to have with face-to-face meetings. Perhaps is that cheaper to learn?

Interviewer 16:13

So you got even more work to do before COVID-19? You work has become double now?

Interviewee 16:22

Yeah, it has there's more work now

Interviewer 16:28

Why do you think that is the reason if I may ask?

Interviewee 16:32

Well, it's because me, myself, I've got involved in lots of different things. And the more you become involved in one area, they will point you in another area. And yeah, she could do other things. Perhaps some of us would probably useful to a lot of people and, you know, getting lots of opportunities to do other things.

Interviewer 17:06

Was it like? Is it because everything is online? Now? Is it easy to get access or easy to communicate to you or anything? Yeah, of course, you your your expertise important in it. So when did he do contact you before? COVID-19? Was it the communication problem? Or?

Interviewee 17:31

Uhh no, I think it's it's just that nationally, I get more face to face meetings without COVID… it’s just..er. The points of where I am at the moment is that, you know, I'm getting more opportunity. face to face. I'm probably getting a few more because of the COVID.

Interviewer 17:57

Thank you very much. Now, can I ask you to tell me a bit about the resources you have available at home please. While that support you to do work remotely? PPI work remotely?

Interviewee 18:14

Yeah.

Interviewer 18:23

Oh, it's great.

Interviewee 18:25

So I've gotten laptops, tablets, and smartphones.

Interviewee 18:31

Brilliant, so you are an IT expert?

Interviewer 18:33

Yeah. Well, I wouldn't say an expert. You can always be tripped up on things.

Interviewer 18:40

Yeah, I could. I could feel that from your zoom screen. It looks very clear and very neat. That says all about your IT experience.

Interviewee 19:51

yeah. Can I give you some idea of the sort of things that I've done in the past? No.

Interviewer 19:57

Yes. Yes. Amazing. You done a long time ago, the remotely remote work and so they're they're the participants from all over the world they joined there.

Interviewer 20:33

So I presume presumably, but still I'm asking this question Did you need any support to for your resources at home? Are you are you are capable of doing this? If you needed any support it support any

Interviewee 20:55

Help in doing it support for you know, So yeah. You know, on the walk in support for myself. Pretty good. And if I don't know anything, cuz didn't find another way to look.

Interviewer 21:27

Yes. Great. Thank you.

Interviewee 21:29

That's one of the thing is about the, you know, this online stuff I know exactly. You know, I can find the information very, very quickly. I'm very good at researching things and finding information. Not just about IT, but everything.

Interviewer 21:50

That's great. So you can fix your problem and by yourself, if any problem you know, you know where to go for help.

Interviewee 21:58

Yeah, it's many, many problems. I mean, I do word processing. I've got a scanner.

Interviewer 22:12

Scanner. So you can use scan print from home as well.

Interviewee 22:17

Yeah. can now modified PDF, so I've got a camera, they can take pictures of things. Record things with zoom.

Interviewer 22:32

Oh, it's great.

Interviewee 22:35

Yeah.

Interviewer 22:37

Thank you very much. That's great to know, was there anything in particular that helped your involvement and engagement work during covid-19 current introduced measures, please?

Interviewee 23:18

Yeah. Well, I've helped with a number of COVID related research projects, very quick projects. You know, to disseminate things and Yeah, probably the COVID has changed my attitude to you know, get or getting a bit more involved in the dissemination of things, you know, putting the word out about things because we're all in this together my aren’t they? two to support each other.

Interviewer 24:10

Did you have to go shielding yourself or anything during this time?

Interviewee 24:27

Yeah. I'm helping to shield my wife. You know, we're getting everything delivered. On Monday going out for a walk. You know, don't go anywhere since the COVID-19,went to the hospital for my COVID jab or the pharmacy. Also, I volunteer to two days a week. and that's been furloughed here. Because of COVID is two days every week

Interviewer 25:10

Yeah, so its two days every week, great? Good sort of things to do. So do you do it from home? That volunteer work?

Interviewee 25:22

No. Face to face meeting? It's a very vulnerable clients so.

Interviewer 25:33

So I think it's disrupted at the moment this face to face meeting. How do organisations/groups you are involved with communicate with you at the current time?

Interviewee 26:06

By email.

Interviewer 26:09

So emails, do the ring sometime or just an email is it?

Interviewee 26:21

They well, very, very rarely did people ring me to just email email, okay.

Interviewer 26:32

So you have got so many emails to reply every day, I think? [yeah] Thank you. Any support you might require in relation to specific challenges you may be facing, for example, physical or mental support, mental abilities, capabilities. Any support regarding the IT support, not the computer, but for you. any physical or mentors have to support me?

Interviewee 27:09

I don't need any at the moment. My xxxx at the moment is playing up a bit because I'm a bit cold, you know, the house hasn't warmed up yet. Properly, just sharing a little bit.

Interviewer 27:27

Are you a caring for your wife? Can I ask?

Interviewee 27:35

Well, we care for each other in that respect. But no, I’m not a real carer. She's still managing. Thank you. She's she's got xxx. So she catches the COVID. And she’s scared she’d die, so she's very scared.

Interviewer 28:10

Thank you! Some of the questions keep coming, but we have already covered you have already shared, but if you please, you know, just share what you'd like to share, because some of the questions was quite, quite repetitive. And so again, it's asking it, was there anything in particular that made it more difficult to be involved in PPI work during COVID-19? Is there anything in this current situation make you difficult any negative experience you have during this time? To continue work?

Interviewee 28:49

Well, I mean, it's, yeah, I mean, it does have a bit of a mental toll on everybody this COVID and again, you know, not being able to see people face to face. And I just get a bit depressing sometimes and you do feel a bit lost to carry on.

Interviewer 29:18

You’ve mentioned your work has been increased to double. And you still feel that face to face was better. I mean, although you're more busy looks like you're more busier than before because work become double. [Yeah]. Anything positive experience during this time that COVID-19 feel as positive, any positive experience you can share.

Interviewee 29:53

You can still meet lots of some of the research projects I've been doing. I've been going on for some time. So, you know, at least it gives me the opportunity that I've gone see people face to face, you know, physically train them on, you know, online is, you know, battery courts, it is good. You know, it's still nice to see people until they interact, even though you know, when you've got a bit of rapport with people seeing them physically. You know, it's, it's nice to be able to still continue to see them.

Yeah, it's so been remotely this, this is one of the things from the hip, the whole thing would not have been done any other way. Yeah, so it was remotely we can get people from all over the world. You know, experts in that field. I'm no expert on the just the public. face.

Interviewer 31:27

Yes. So anything you can think of that could have been done differently could have been done better?

Interviewee 31:37

Yeah, the meats in it, you know, people are still getting used to being organized the meetings and you know, some of the best meetings with either, you know, if you join a bit earlier, five or 10 minutes earlier, you can have a bit of a chat with the people that have come early, like you did face to face meeting. So you can talk about, you know, things other than the meeting and get to know people better. Also, you know, it's hard for me has been an introvert to get a word in edgewise. Sometimes. I am, you know, some people know me they, by show that I get a chance to say what I want to say because I know that you know, might say something insightful or you know, really important.

Interviewer 32:43

Thank you. Now, I think this would be the last question. So, what if any, do you think? Are there any limitations placed on PPI through working remotely?

Interviewee 33:15

Well, we start with social animals and we need to do not this isn't me we need face to face You know, in all the meetings that I attend, everybody sits beside saying that they need to face to face contact. They'll be glad when you go fishing with them. You know, they can beat it. Everybody can meet up again. Yes. So cell interaction This is a bit of a limitation in this room and I'm sure we will continue to have some of these meetings we have a mixture of face to face and they need to be the future.

Interviewer 34:12

Once people are back to their normal routine and not staying at home, would remote working still be practical? Would you still like to work remotely? or not?

Interviewee 34:28

I'd like to go back to I've been a normal in a bit of I think I'd look forward to going back to a bit of face to face and a bit of zoom as well.

Interviewer 34:45

Great, so you want see a balance between face to face and zoom?

Interviewee 34:50

Yeah, balance basically the other thing about I've got colleagues that haven't got IT equipment You know, one particular colleague I've known for years has to dial in by phone. That's a bit of a limitation. And now we're like one or two meetings where people are dialing, xxx ones, their broadband in some countries are not very good. So sometimes you can't see their faces. They just speaking, you know, there's no face contact, and sometimes that the dial in and sometimes they go off and, you know, very intimidating and sometimes sometimes the, you know, the movement, the face movement and movements is not a real time. That's a bit of a off putting, you know, when you start people start children. Yes. You know, visually, yes,

Interviewer 36:09

yes. Yeah. So, yeah, I understand that when you when we talk if some screen are black, we feel like you are seeing me, but I cannot see whether I see you we cannot see me, is quite a bit of uncomfortable you know, the communication made inconvenient for some. Thank you very much for your thoughts. And just before we finish, is there anything that I have not asked about? Would you like to add anything that I have not asked in this interview?

Interviewee 36:44

Yeah, um, the one thing about the zoom thing, you have to be a bit more prepared, you have to do a bit more research. You have to be more prepared than you do. You know, face to face meetings. Obviously, when your journey, you can pick the bad things, and you're striking. Yeah.

Interviewer 37:19

That’s great. Thank you! We are at the end of the interview now, but thanks a lot.

Interviewer 37:46

Thank you. So once you finish this interview, I will email you again. I will. I will. cc our the finance lady will, she will contact you for for to say thank you for your contribution. Yeah, just a small Thank you, we can give you for your big, big contribution. So we'll email you again. And I don't

Interviewee 38:14

I don't do any of this for the money.

Interviewer 38:17

It said just our research formalities. Would you like to see the report once this project is, you know, ready to publish or?

Interviewee 38:28

Yeah.

Interviewer 38:30

Yeah. We will keep in touch and we'll email you. So you are communicating through email. So once the report is ready, we'll email them. Yeah. Thank you very much. So you take care

Interviewee 38:47

To me it was very lovely to talk to you. Thank you for your time. Thank you.

Interviewer 38:51

Yeah. Nice to talk to you.

Interviewee 38:53

Thank you. You take care. Bye bye.

Interviewee 38:55

Bye bye.