Interview 19

**Interviewer** 00:00

Please give me permission, this should be fine. Thank you. Okay, So this interview shouldn't take more than 30 to 40 minutes, it's up to you what you would like to share. So basically, so I think you have read the participant information sheet [yes]. So I don't need to go more details about it because you want to read it. So we're we're actually interested in your thoughts on how we can facilitate and improve doing PPI remotely. And this information will help us to improve practice in working remotely. The interview is divided into two parts. So first part, we'll talk about your experience before COVID-19. And the second part, we'll talk about the current situation since COVID-19. Thank you. So first of all, could I start by asking you to tell me about any PPI work you're involved in prior to COVID-19, please?

Interviewee 01:06

Right, I sit on xxx. And that's been during lockdown. So before that it was a xx committee. I also work for xxxx. I threw that I have before worked with xxx. I've been a public contributor on the xxxx Project. I'm not expect there's been some more stuff. But that's what comes to mind as really

**Interviewer** 02:04

That’s brilliant as you’ve been involved in so many projects.

Interviewee 02:10

It's been very, very, very varied. And that's over about sort of, I think probably it started xx.

**Interviewer** 02:25

You started to work as a public contributor?

Interviewee 02:32

That's frightening. Yes. Yeah. A bit less than that. I think it's probably about that eight. Yeah.

**Interviewer** 02:37

Thank you very much. So how did you do PPI? Normally, before COVID-19? Was all face to face?

Interviewee 02:49

Yes. I might just with the, if I couldn't get there, for one reason or another. I know that I think that that's one thing I did was when you have the machine in the middle of the table, and they you know, you you tap in microphone wise. But yeah, so telephone. teleconference dialing. Yeah, that's it. That's that's the only time and that was really, when the chips were really down, and you couldn't get there.

**Interviewer** 03:27

As part of your contribution. Did you do? I'm sure you had to do a lot of reviewing papers for Yeah, so so. So those kinds of work. You didn't need to travel or you could do it from home.

Interviewee 03:44

I did the work at home. But then I'm for the reviewing of papers. I had to go to xxx three times a year, for a couple of days. Sometimes it was one day, sometimes it was two days.

**Interviewer** 03:57

All right. Okay. So that in it was not like that they could send you by the toe pose to your home address with lots of documents, and they could do it from home. It was not like that.

Interviewee 04:08

No before No. But partly because I think that's what they stand for. It's the debating and the consensus that was you know, was I mean, they they're quite they are beacons for good practice, I think and so, some of that what you know, the face to face really benefited from that, but yes,

**Interviewer** 04:29

okay. Thank you. Now, could you please share the how do you feel about your PPI contribution?

Interviewee 04:36

And I feel lots of mixed mixed emotions. I feel very humble. Because at my age, doors usually close and, and they open and some of it has been, I volunteer or put myself forward when I know there is something that I've got lived experience so that I feel I cannot She contributes something I have been caring for my mum and lately for my partner. But that's the other thing I've been doing as well as xxx. So it's it's, I feel. So I feel humbled for having the opportunity, because it's totally I'm not a scientist, I haven't had an interest in medicine or anything like that. Quite squeamish, really. But, so there's that, then it's also helped me to develop which I, you know, they have invested in me along the way. So I've been given training, and I have increased my experience my understanding, so that I am now working outside my previous experience. I wasn't expecting well being. But there is there is. It's also the challenge. So it's just a whole, it's a combination. And what I do hope, I mean, feedback is, is encouraging that I'm, I'm helping to make a difference. But always you feel very much appreciated with whatever you do. It's really quite an eye opener, what you don't hear about on the outside of, you know, as a normal patient, you don't hear about any of this, it's going on behind the scenes.

**Interviewer** 06:16

Thank you very much. We're, of course, although you mentioned that you're not a scientist or academic. Everybody, but but but the scientist and the medical team academic, they rely on relying on you now. I mean, that's your contribution. Yes, because it's been becoming increasingly important. Very, very important to get your views as a public contributor.

Interviewee 06:40

Yeah. And that's always been that's always been underlying, they want the raw view, they don't want, you know, anything that is to schools or whatever, you know, they just, they really want that. And they make that really plain, they want honest, open opinions.

**Interviewer** 06:56

Thank you. So what did you enjoy the most about face to face working place?

Interviewee 07:08

I didn't realize it at the time. But it is the sub port. And the underlying, it creates the site, the safe, it's the interaction, and maybe the little chats beforehand, and tea time, coffee time, whatever. It creates the feeling of a safe environment to be not outspoken, but to speak, what you say what you've got to say, without fear. I mean, for me, it's not that that's not fear of censure. But it's the Have I said something stupid, but in that in that sort of face to face, you very much get the personal feeling that no question is too stupid, that it's safe to challenge. And the feeling of debate is more. it because it's more sensitive, because you're reading the body language, and you're reading the, you know, the visual signs more. So yeah, so I think that's, that was the main thing about the face to face. It was the it created that safe environment for somebody like me, who often will feel it's the imposter syndrome is, you know, should I be here? Should I be doing this? Am I up to it? So they people help to put you at your ease. That's what I think is what's most noticeable.

**Interviewer** 08:29

Thank you. Could I please ask? When you first joined ppi. Is there anything particularly that supported your involvement? Anything influenced you to join PPI? When you joined?

Interviewee 08:44

Yes. And I had an issue with my both my partner and my mother were being taken to task by the trust for appointments that they hadn't attended, but they'd actually not received the appointments in the first place. So the system wasn't working. And I didn't want to I'm not a complaining type person. So I raised the issue with him and said, Look, in my former life, if I if you people don't tell me what's going wrong, I can't do anything about it. I'm just telling you, there must be something wrong with your system and not receiving the appointments. And then things that they wrote to the wrong person or wrote about about the wrong person about my mom. And I just said, Look, can I see somebody's face to face? So they set up a meeting with somebody from pals, somebody from patient experience, and the Chief of nursing. And from that they acknowledged what the problems were helped to put me in the picture at the end of that, I said, Look, I've got spare time. Can you use me? Can I help in any way? And they said, Yes. So they asked what my skills might be. And I said, probably monitoring. And they said, what they did was they Put me on two wards to monitor the care for patients who don't normally have a voice. And so I was held to them to develop a tool for monitoring those patients. And that, then from that, they asked me if I would interview carers of patients with dementia. So that started it. While I was working with them, they put in front of me the opportunity to apply for a post with xxx. And from that, everything else spun off that gear. So yeah, so they like you said they want to get involved? Yes. To get it. I mean, it's the trust that they trusted me. And that was that was great to be involved. And that's still ongoing. I still have contacts there.

**Interviewer** 10:56

Thank you. Could you please share some of the challenges about face to face working place? We need, we have been doing it for a long time, anything difficult challenge for?

Interviewee 11:11

Yeah, to be honest, I can see it now, which is what's going to come in the next part of the conversation is it's the traveling, because most of my work has been in xxx. I didn't appreciate that, then what I do now.

**Interviewer** 11:49

Anything regarding your career or responsibilities? Or any financial issues? Anything? any challenges on that?

Interviewee 12:01

No, no, I mean, when I was nursing my partner, then obviously there were issues then.

So it's been, it's been a tough old, I didn't think it was tough at the time, I thought I was coping. But actually, I've gone from, you know, from bereavement to lockdown. So I'm now confined to the house.

**Interviewer** 12:51

It must have must have been a very difficult time for you.

Interviewee 12:55

Yeah, I am a survivor. But it's it's been quite a it. And that's what we're probably going to impinge on what we say is actually it's taught me different things about myself, which I wasn't expecting. But that's enough for me, personally.

**Interviewer** 13:13

Thank you very much. Thank you. So we'll move to current ppi. And yes, and we could talk about how PPI helped you we know my system. So what kind of ppi you are involved at the moment? Or was it from the same same PPI you've been doing?

Interviewee 13:34

It's the same, that's as I say, xxx, which is has got much more a bigger workload. And we do stage two proposals as well as stage one, so that there's a lot more work on that. And then with the the xx work has changed, I'd had only just think I'd only just started that at the around the time of lockdown. And that has, that's I'm now working on xxx, which is a whole new field for me. Others other things have taken a have gone quiet because of COVID. And working with the xxx that they had gone quiet and they're just picking up a bit now but there's been change of staff and all sorts of things. So those are the main changes.

**Interviewer** 14:42

Thank you! So what is what is different and change fo PPI Now, can you share please

Interviewee 14:50

It's the technology. It's the and the getting used to the different ways because of those new things. You're meeting new people But as we've said, not face to face on screen. But so that's the biggest difference for me. The actual work? I don't think I would say has changed. Is that sort of thing that you're asking?

**Interviewer** 15:16

Yes. Yeah, you’ve already mentioned it that you have been doing PPI for a long time. So what would be new for your doing PPI now. So eventually the technology is technology.

Interviewee 15:31

Yeah, technology that's the single biggest difference. And I am I will say now, I was perhaps not quite as much but a dinosaur. So it was the sort of thing in my past life, I would have resisted, I would rather have got there face to face than done things remotely. And even I have converted.

**Interviewer** 15:53

So how do you feel now about you about remote working?

Interviewee 15:57

okay? Okay. And I can see, from a personal point of view, it could be a way forward. And because I'm not going to want to go on public transport for some time. Was that what it that's what it meant, it's not cost effective for the organization's to, if I were to avoid, I mean, they, they don't ask you to go in travel in a particular way. And I always try to get the cheapest deal. So for example, for me, if I were going to xxx, which is where most of the work has been, it would cost me overall, I can do it for about 10 pounds return. If I drove, it would be in excess of 55 pounds, so I go by train. But to do that, it takes me a lot longer, I'm happy to do that, I was happy to do that, I'm not going to be as mobile. So to get the best out of things then then remote working is for me, I can see that it would be quite helpful. It doesn't mean to say I would be against traveling. But sometimes I was going down to xxx, three times a week, which is quite time consuming. If as I told you for the amount of time it would take me to get there. And then there would be outlying things, or some meetings, we're in both. And so this is an it's a big patch to cover. So it's, it's useful for them to have the geographical current coverage. And then for them, it's just the cost effectiveness of working from home, I can see that in the future. There won't be quite so many meetings. I think that's just my prediction. And I can see that it sort of makes sense that we have to find a new balance.

**Interviewer** 18:09

Great, we'll talk about this. Thank you very much. So how PPI has helped you during this period? Since COVID-19, is started all the work you’ve already mentioned? It's been very difficult time for you, is there any way PPI helped you? For example? In terms of your mental health or connection during isolation?

Interviewee 18:33

Definitely, absolutely, definitely. It's been. It's a bit dramatic, but it's been quite a lifesaver. And my family have noticed it because my family don't live close by. So for me, it's been Yes, the mental challenge. It's a sense of self worth. It's bigger horizons when you can't physically get out there and do things, you know, because of the coverage, for example, with the research papers, is just massive, you know, that the sorts of things that I'm dealing with, and and so it's absorbing, I, you know, I have absolutely almost treasured what it's been, because it's given me a sense of shape. So when, for example, the research papers come in, I am quite disciplined, and I will set aside so many hours per day to work on it. And I actually look forward to the order of it. And my self imposed post discipline, but the result of this was it's the rhythm of it. So yes, it has been really great. And I've really values it. That's, that's that particular type of work with the others. I'm doing things like planning a workshop, and, and I know those people very well, and we're helping to deliver a workshop. So this the planning for that and the exchange, which has been the social side of it, because I know them well from having develop, deliver those before. So yes, very, very positive.

**Interviewer** 19:57

Thank you very much. Although you mentioned that the technology is the new thing, so could you please share this? Is there anything any limitation placed on PPI? Because it was based going to remote? Because of the remote working? any limitation?

Interviewee 20:15

Well, there are limitations on what we would normally be doing, what we would have done doing sort of follows because we moved from face to face to remote work.

**Interviewer** 20:26

So is there any limitation? Because we're doing remotely? That thing we could do before now, we couldn't do anything anything, do you think? Or any other way?

Interviewee 20:41

Probably not. From my point of view, because I'm still learning. I mean, there have been things that haven't worked quite as well. But that's largely once you're on, it's okay. It's the, it's this. I've worked on three different three different systems, platforms, whatever. And, and they have worked to differing degrees. And then I've observed with other people as well, but then some of that is all of us getting to know how to work it. So there is still the learning curve. And I've, I've even taken part in a conference with breakout rooms and delivered at that conference. But we did that in a manageable way. We did it so that it wasn't a case of delivering us beach. It we did it in a conversation with. So one is the professor that we work with down at ue he, we set it up so that he would interview but the conference people that were watching, and so that was it was the lesson in how you can make it work. So that, you know, I feel quite privileged that we've, I've had that range of experiences.

**Interviewer** 22:08

Thank you. So how do you do review papers now? Before since COVID?

Interviewer 22:22

We do it by its team teams? I think it is it's just coming up. So I can't remember which platform is. So we did we we do it via teams, there was one round where we did it all on screens, put everything in on on screens, and then people added to it, that did not work for me as well. Because then if you're leading on a paper, you put your comments in, then other people could comment. So in terms of one of the questions you've already asked me, yes, this remote, right. So this wasn't easy. And so people would comment on that, and you could get back to them. But it covered more than one screen. So to find your way around, it was quite difficult. It was quite challenging, and not very satisfying, I have to say because you hadn't got that instant dialog. And also, but you see it was it was in COVID conditions as well. So the clinicians were really challenged, some couldn't get onto it at all, because they just didn't have the time it was very, it was really when the chips were really down. So it was it's quite an unfair comparison, but that didn't work as well. So, yeah, Does that help?

**Interviewer** 23:34

Yeah, of course, of course. Thank you very much. That was great to hear your experiences, you know, it's well all adding up for our analyses. So to do so normally do is is it like live living papers, for example, in a meet in a group live, okay,

Interviewer 23:54

Right. So what happens is after we pre score them from from home, and then they sort them up until now into an A list in a basement. This is what stage one proposal so that they sort them into an A and B list. And you are allocated the public contributors that the professional people are given an allocation to lead. And second, and they have a couple of papers each, the public contributors are given the whole lot split between them. So we have quite a lot more but obviously not in as much depth we're asked to focus on the plain English summary, and the public patient and public involvement. And then and also anything else that we feel, you know, like how it might be viewed as that what it would be a priority for the public. So you when the two professional people have led on that they then asked the public contributors to give their view of the paper. So that's done. And that's all done face to face. And then we have this is open for debate and discussion. And then it's a show of hands as to whether it goes school or not. So that has changed now. Virtually. That's that's the face to face procedure.

**Interviewer** 25:11

Thank you. Thank you know, could I ask you something that had access to resources for pbit woodworking you have at home the resource that you have for working remotely, please.

Interviewer 25:23

In terms of technology, it's the laptop, I did buy a tablet, which I take to xxx, because it's less to carry. I haven't found that very useful or helpful. And then the rest is just my records. You know, I keep a journal of what I do. Which is we're now basing things on pre evaluations. But in terms of other resources, it's just the phone, the laptop. That's it.

**Interviewer** 25:54

Okay, thank you. So, when you work on your laptop or via zoom, or do you find it? Is there the information and knowledge to guidance? Or is it the IT? Are you? Are you okay with them everything? In

Interviewer 26:14

I am now I've needed nursing in the early stages. But there's always always been ready, whichever organization I'm working with, there's always somebody who's there. And I'm very, very quick responses as well. And that includes now during the meetings, if there's a problem, there's always something set up that you can access somebody else, either by email or by your phone, whatever. And they because there have been problems, usually, as I say, with access to the, to the platform, and that, you know, it's it works. But as I said, some have worked better than others.

**Interviewer** 26:53

Thank you very much. So did you if you need any IT support? Did you ask anyone for any IT support as since you've been using it?

Interviewer 27:04

Yes, yeah. And as I say, it's usually to do with access, I haven't been able to get out it's been particularly with teams, that there's been a problem and that and when you're due to speak at a certain time, and you can't still can't get on. And so that they said that was down to probably an update. And and quite a few people have had a problem. The one that didn't work well at all was called remote. And I can't remember who was we use that with, but many of the clinicians couldn't get on because the NHS blocked the the back their computers blocked this unknown saw so that you know what there we were all doing this. I think that was the conference see type one. And and people couldn't get up. And it was, it was really, really, it was a bit of a mess, actually. But we got through it. And but yes, it's usually the access once we're on. It's only euro. It's only the things of you know, you're on mute. And you know, all of those usual things.

**Interviewer** 28:10

Thank you. Previously, we talked about challenges about phase two is working. You mentioned you mentioned some of the challenges when being face to face, for example, body language or other thing, you know, so could you please share any challenges you feel? doing the work remotely? Why do I meet you on zoom or teams? You're meeting 1020 people?

Interviewer 28:35

Yeah. I think one is not having those casual conversations just to put you at ease. So that's the first thing, just that little cap there, just the the little chitchat around the edges to make it at that safe environment. And reading, reading the signs when you're if you're saying something, it's just that those very light touch reading the body languages, which I particularly taking. And the other thing is, I think you don't get generally the same. It's not the end of the world, but it's the fact that it's the protocols of getting to speak. Sometimes it's you know, the person at the other end is either watching for hands waving or watching for the electronic sign. And so you don't get that and you can't, it's 26 of you, you can't have the spontaneous type. You've got to go through the chair and all the rest of it. I just think that's it's more of a challenge. So as for me, you I weigh up much more carefully whether my contribution is going to be valuable appropriate because you know, there might be loads of other people waiting to speak his mind. Really, it just put you put in another check level, which you might not do if you were face to face.

**Interviewer** 30:13

So do you think, to giving everyone a voice?

Interviewer 30:26

I think that's crucial. And there are some who are really good. I mean, it depends on the nature of it. And it depends on the work you're doing as to whether it's appropriate or not. But yes, I mean, everybody who's doing it has their own. They've got their own protocols. But also there are some who will go around and say, right, has it now give you the opportunity. That's not so easy with 26 of you, but but they will just check that anybody, but you can't do that at every single stage. But I would say that, on the whole, the standard of chairing is extremely high, under the circumstances, and as people are learning as well. And they are saying themselves, that they're finding things harder, they're missing the face to face that that comes across with all of them. But you know, in the night that we have no choice at the moment, but now I would say that the chairing is is good. And as a public contributor, I am encouraged to speak it's it's just probably it's me thinking, you know, do I really, is that really what I want? Is this the point to say is it really important, because you know that it's got to involve the procedure of them spotting and so you, you know, it I think it lessens spontaneity.

**Interviewer** 31:43

Thank you very much. That's very interesting. Thank you. So what has worked well doing PPI remotely you think

Interviewer 31:53

it's, it's probably, for me, personally, I have developed new skills for which I'm extremely whereas I was resisting with my family, and other people doing zoom calls, because that's the dad I want to do that I do not make it very gently forced me to open up my my horizons and my my set in my ways, ideas for PPI as a whole, I think what the big thing that it will do is open up doors for people who can't get to meetings for one reason or another. I mean, one of the organization's we've got a meeting tonight, from five till 630. For people who are working during the day, so that they can attend a meeting. If it was five to 630, I wouldn't be going because I do I wouldn't be getting back to late at night. And there is you know, I've got transport problems because of living out in the sticks, the buses stop, I have a stipend. So I think it's really good because it's enablers for inclusivity, it's going to make such a big difference. And again, with the xxx they have a really, really strong young people's group, the young people persons advisory group, and they are flying because the young people can fit it in from their universities or their homes in around their lives. And I think I think it will potentially open up the doors to make things more inclusive. And maybe that will suit people not to be face to face where some meetings can be quite daunting. You know, the board meeting type stuff for some people is is scary, which I can you know, I can understand it was for me to start with. So I think I think it's really good that it's gonna it's gonna open up doors for a bigger range of people.

**Interviewer** 33:45

Thank you very much. Now Could you please tell me what has not worked? Well? Just the opposite now.

Interviewer 33:52

Right if for me it was just when it's the panic when you can't get on so it's getting onto the platform. So it was that really the remote one was was ghastly. And I was I was beside myself because I was due to be delivering and couldn't couldn't get on. It's happened with teams several times. But we seem to have nailed that now. I don't think surprisingly for the dinosaur I don't think I can say that. There are things not working only what I said was that you know, it's just I just missed that. The the casual chat around it, but sometimes we log on early and, you know, if it's somebody that I know, but you you're not doing that so much. When you're not knowing the people you don't need it's just putting people at their ease. I think that's a little bit harder. But that's that's all.

**Interviewer** 34:43

Thank you very much. So we are nearly to the end of the interview. So a couple of more questions now.

Interviewer 34:48

Okay.

**Interviewer** 34:48

So once people are back to their normal routine and not staying at home, would remote working still we practically think sorry, which would Remote working? still be practical? Do anything online? Yes,

Interviewer 35:05

I do think so. Yeah. I'm quite ashamed of myself that I would have been dead against it. But in the past, and that's, that's down to me having closed, you know, closed mind?

**Interviewer** 35:20

Do you think it would work the remote working? It would be more it would work?

Interviewer 35:25

I think so I think probably from what I hear from the, the teams and the professionals, they would like a balance, I select a bunch of balances, think about about a balance. And there are things I mean, the workshop that we're doing on evaluation has always been face to face, we're going to we're running that now, virtually. And I'm going to about to do my first one. So that will be quite, that will be quite an interesting experience to see how that works. Because I haven't done a virtual one. So it's making this adaptive. But I still think there's a you know, I think a balance.

**Interviewer** 36:04

Thank you. You mentioned some of the training or something about technological thing. So anything that could have been done differently, could have been done better you think?

Interviewer 36:16

No, not under the circumstances. And because even when I had got a problem, the the admin support, they set me up on a, you know, a zoom meeting, or whatever, whatever platform it was set me up to test it before a meeting to make sure that it was going to work so that I wouldn't, you know, to take up valuable time from from clinicians if I couldn't get on or if it wasn't working. So people have gone out of their way to set up one the helpline, but also to actually give me the time to test it. So that everything worked smoothly on the day. So that you know,

**Interviewer** 36:59

Thank you very much. Thank you. So just before we finish, is there anything that I have not asked you, we have not discussed? Would you like to add something? which is which has no

Interviewer 37:08

No, I don't think so I've really welcomed the occasion the opportunity to reflect myself because I have I have grown with the the the remote. And I'm really appreciate that. So I wouldn't say perhaps was their one of their toughest challenges. But I'm really quite surprised at what's happened.

**Interviewer** 37:35

Thank you. Your contribution is much appreciated. And and you think you're doing great you technology using zoom, your screen is very bright, you're using your background, everything is quiet look like a professional user.

Interviewee 39:47

Okay. Thank you very much, and thank you. Thanks for giving me the opportunity to talk. Thank you. Take care.

**Interviewer** 39:53

Bye bye.