Interview 16

Interviewer 00:00

Thank you very much. Okay. That’s great you have read the participant information sheet. Actually we are interested in your thoughts, how we can facilitate and improve doing PPI remotely working without, with or without face to face contact in health care. We are interested in how we want to see these things going on forward. So first of all, could I fast start by asking you a few, please tell me the PPI work you have been doing before COVID-19?

Interviewee 00:50

So, I've been a member of a PPI group, and we had approximately two to three meetings a year face to face meetings, where we would discuss different things. And usually the meetings were two to three hours. I would commute by car, and I was reimbursed for expenses, parking costs free of charge. There were refreshments provided. That was more I said, I've also taken part in different focus groups and workshops. I think all of them were in xxx. And again, I would travel by car, I was reimbursed for mileage, and parking. There were refreshments. And those meetings usually will take between two and three hours.

Interviewer 02:09

So the PPI you're doing what are they organization or a research or projects err?

Interviewee 02:16

In so in the group that I a member of I'm actually a member of few groups now with with different studies, but the one that I've been the longest with is the xxx. I am also a member of other groups and I've also been a member of groups that have concluded because they were related to particular projects for instance, there was a project about problem xxx so, I had some experience in that I must have at the moment a member of patient advisory group for a study that is supposed to produce diagnostic tests for xxx.

Interviewer 03:29

So, most of the PPI you used to join them by face to face meeting

Interviewee 03:40

Yes, they were face to face meetings. Yes.

Interviewer 03:43

So as part of your PPI work, do you have to do any paper reviews?

Interviewee 03:51

Yes, yes. So different things. So, usually we are asked to review some patient facing documents like consent forms, questionnaires, lay summaries, and we are asked to improve them. For that group involved in xx research, I've also written I believe, three text dissemination texts. So one was about my experience of being a member of that group. The other was about was my xxx. And the third one was, was a kind of an article that I that I've covered and with another member, and it was about xxx.

Interviewer 04:51

Thank you. So yeah, so you have been, you've been involved with quite a few different things at the moment.

Interviewee 04:56

I'm also a co applicant on Three studies. So my role at the moment is to develop PPI plans to improve lay summaries. And also think of dissemination strategy. So I'll be I imagine I've been involved in writing different dissemination texts. I personally enjoyed writing different texts.

Interviewer 05:27

Brilliant. So you are the You are a co applicant for for a grant application, is it?

Interviewee 05:32

Yes, that's right.

Interviewer 05:34

That was great. So but yes, you believe so many I mean, organization and so many, you know, groups. So how do you feel about your PPI contribution so far,

Interviewee 05:46

I think I've learned a lot because I've started with simple things like review, reviewing and improving lay some. Because I wanted to learn, and through that group, in xxx, I've been exposed to a number of opportunities. And I am keen to learn other things to progress to more advanced roles. So I am also I'm hoping to be involved in CO writing a manuscript. Because that is something that interests me. I once wanted to be a journalist.

Interviewer 06:31

That's great. So it's brilliant. Yes, it's a learning part. And so how do you feel from your, you know, PPI meetings, and in the papers? How do you think the people who work with you, for the organization you work for how do you think they are benefited from your work? Do you think they are benefited from your work?

Interviewee 06:48

I think so. Because Because I, I'm for a number of long term diseases, and I have a lived experience of dealing with a particular disease. I'm also using the NHS extensively, because I go to a lot of appointments, I have different tests. I can't remember now, but I think I've been to seven or nine different hospitals. So I can share that, of course, I have some some ideas on on about what the healthcare should look like, in the future. And I tried to try to stay in the loop by reading different research papers, different articles, and also participating in different words, or conferences. So I look for opportunities on the people in research.org. And if there's something that that is related to my interest, or something that I can contribute to, I usually volunteer.

Interviewer 07:59

That's great. Thank you very much for your work. So how do you feel about face-to-face working… What did you most enjoy about face to face working?

Interviewee 08:10

I would say that the atmosphere to that being able to so to say rub shoulders with like minded individuals who have an interest in advancing medical research, that the opportunity to learn from, from other people. So when I started in that PPI group, it was it was even difficult to follow a meeting because there were so many different acronyms, abbreviations, and different technical aspects that I didn't know about. But they did some training and then I started to research some things on my own. So I think now I'm enough pretty good position to understand almost everything.

Interviewer 08:59

Okay, thank you. So did you enjoy meeting people when you did?

Interviewee 09:04

Yes, I do. Because when you when you participate in a meeting, you are exposed to different views. And you might hear something that will make you perceive phenomenon from a new perspective, something you haven't considered before because each person have their own has their own unique story, experiences, etc. And so people, people come from different backgrounds. So there are people who used to be researchers are former nurses, etc. So you learn from from people.

Interviewer 09:44

So you think that the learning part was very influential for you?

Interviewee 09:52

For me, yes, because I enjoy learning things. I thrive on the accomplishments so

Interviewer 10:00

Yes, we learn every day and all of us. That's true.

Interviewee 10:08

Yes, and it's also it also, the good part is the flexibility, because it's up to you how much evolves you want to be whether you want to progress or stay where you are. And all of these tasks are not mandatory. So if there's a task to do, you're under no obligation to do it unless you want or you have time.

Interviewer 10:35

Thank you. So anything, anything in particular, that supported your involvement? Do you think anything that was helpful for your involvement in in PPI work?

Interviewee 10:51

I've had some training, but there are still a lot of things that I don't understand. And I asked for, for additional training. But also try to read books on my own are different.

Interviewer 11:08

That’s great. So You got you, you got training from home? Can I ask…

Interviewee 11:12

Yes, from from that from that group that I am involved in. So they've organized like induction for new members. So like introduction to PPI, and I think it fall of the it had a lot of content from the NIHR. So yes,

Interviewer 11:31

so the training was helpful for you to

Interviewee 11:34

Yes, to some extent. Because there are other things that are, let's say, more complicated. And you'd have, you'd have to have some kind of bespoke training. But my background is xxx. And some time ago, I've read a book about research methods, and some of these methods apply to social sciences.

Interviewer 12:15

That’s brilliant.

Interviewee 12:15

Yes, thank you. But I think it's, it's being exposed to different opportunities, that gives you a chance to learn to ask people questions.

Interviewer 12:27

Thank you. Anything challenging about face to face work? Did you find anything challenging?

Interviewee 12:33

Not for me, because, for instance, I don't have any mobility issues. Live not far away from xxx. I can imagine that for people who are seriously ill coming to every meeting is challenging. So they prefer to do it online.

Interviewer 12:59

Anything that was any challenges regarding financial issues or care or responsibilities, do you think?

Interviewee 13:06

No, no, no, not for me. That's not applicable to my situation. But we've discussed such things in our meetings that we have to go an extra mile to involve some people like for instance, single mothers, that we have to organize care for their children or let's say adjusting hours of our meetings, so that most people can attend them. Thank you very much. No problem.

Interviewer 13:40

So, now we what do you do we talk about some some questions about the current situation since COVID-19. Started Please tell me about the PPI work you are currently involved in COVID-19.

Interviewee 13:57

So everything has moved to online meetings, tech conferences. So I have regular teleconferences with with different people. I believe tomorrow we have Yes, I have the meeting of our xxx group. Last week, I had a meeting with with the principal investigator and some other people that are involved in the study, in which I am a co applicant. So we were discussing the strategy to go forward. And I do a lot of things at home because at the moment I am shielding until the end of March. So I have time to write different texts etc to communicate with people via email. I am also a reviewer for the NIHR, so whenever they send me an invitation to do a review, I accept and I review different research proposals.

Interviewer 15:01

Thank you very much. So since COVID-19 started err…if we compare your current PPI war with your pre-covid PPI work what would be the difference? What difference and change you feel?

Interviewee 15:18

So everything has moved online. Previously, I would say that like 90% of meetings were face to face. And now 80 to 100% online meeting, so different different teleconferences,

Interviewer 15:38

Anything anything new for you, anything new or unfamiliar?

Interviewee 15:44

I believe at this point I've used I think every major teleconferencing platform, so zoom, Microsoft Teams, WebEx, Skype for Business, etc. I've used some interesting tools like like virtual whiteboards, or something like that. I'm not an expert when it comes to it. But I feel pretty comfortable using new technology. So there were no issues for me, I just, I would rather have face to face and he thinks I miss I miss socializing with people and miss a small stock.

Interviewer 16:33

Thank you. So how do you feel about being involved and your contribution on remote working? When you do everything is virtual now? I mean, if you just compare, how do you feel about your contribution at the moment?

Interviewee 16:55

I think it depends on on the meeting, because in meetings where, let's say 30 or 40 people, not everyone has a chance to speak. And because these meetings are usually not longer than two hours, usually 90 minutes. So I would say that it's it's harder to, to put your point across, so not everyone has a chance to speak unless there is a really good moderator that controls the discussion.

Interviewer 17:33

So it's the good moderator who, who tried to get involved,

Interviewee 17:38

Yes, involve everyone's to to make sure that everyone speak so everyone has a chance to say at least one thing on, on on each question.

Interviewer 17:49

So did you did you use to get get a chance to talk before COVID-19? When you did face to face?

Interviewee 18:00

It's, it's my goal is to speak because if I'm invited, then I feel an obligation to contribute. So I have to say something valuable that will make a difference.

Interviewer 18:14

So do you think more people are attending remote meetings than face-to-face meetings?

Interviewee 18:32

Yes. And also our group has grown so many more members. And there are so called Virtual members. So people who don't attend face to face meetings, but still do some work, contribute to the group and now moving online has given them an opportunity to to participate in group meetings.

Interviewer 19:00

So it's very interesting point. So So you're saying that the since COVID-19, everything has moved to remote work? Oh, PPI group members increased?

Interviewee 19:12

Yes, I would say so. Because some people couldn't meet with Yeah, couldn't couldn't participate in because because of the distance they would have to commute or because of their illnesses or difficulty finding a babysitter or whatever. Yes. So at the same time, a lot of people work from home now. So like it's part of the job now to participate in a lot of teleconferences.

Interviewer 19:45

Yes. So say something like this one positive thing is group members increased and the negative thing would be not everyone getting a chance to talk?

Interviewee 19:56

I think so because I think that some meet Things are dominated by some members, even though they they don't they they don't have anything valuable to say that they I don't know. I think they just like to hear their own voice.

Interviewer 20:13

And, and again, errr.. It depends on the moderator responsibilities. On the logistics, I think you need to have a very good agenda. And if meetings that involve a lot of people, you need to divide them into breakout rooms. have discussions in smaller groups, and that works.

Interviewer 20:39

Thank you. So if I would ask you limitation placed on PPI through remote working? Could you please although you mentioned about a limitation already the moderator role, any other limitation, you can think of remote work?

Interviewee 20:54

So it's a double edged sword. Because the people who are not very comfortable using technologies or even don't have access to the internet or don't have smart devices. So that that is something that may not work for them. And the same way not, not everyone knows how to, let's say track changes in the world.

Interviewer 21:27

Thank you very much. So yes, we'll talk about that in a moment as well. Now, if we so you mentioned that you have been doing so do you think your active reviewing papers has been increased, since COVID-19?

Interviewee 21:49

Or something special calls, there was a rapid response COVID scheme. And recently, I think that was put on hold. Even though I reviewed, I think three proposals, there was a call for vaccine efficacy, I believe something like that. Yeah, so that there's been a lot more research into COVID. Now we know that it's such a complicated disease that it might have long term effects on people.

Interviewer 22:31

So do you do any, any community work as part of your PPI work?

Interviewee 22:38

No, not really. No.

Interviewer 22:40

Could I please ask you to tell me a bit about the resources you have available at home please?

Interviewee 22:55

So I believe so I have all the basic so I have Wi Fi. I have a laptop with Office Suite. I think at the beginning of the year, I bought this headset. So it's really useful, because it has improved the quality of of sound. I have a tablet, smartphone, I have a printer scanner. So I think I've got everything. Yes.

Interviewer 23:29

That's great. Thank you very much. So what you mentioned earlier, there's I just want to know, I would like to share the information and knowledge to guidance on how to get involved remotely or PPI opportunities. Are you aware of this information and guidance?

Interviewee 23:48

Usually, when whenever there's a meeting or I'm joining a new project, there's a mention that? I think with with with the new technology, there's someone available to guide you. You just have to ask for it.

Interviewer 24:09

So did you ever ask anyone to get in this?

Interviewee 24:11

No, not not really. I think one of the forums is quite different. I think WebEx is EC is is different. But we've discussed some features in the meeting, because other people had questions as well. But zoom is pretty straightforward. Skype for Business, Microsoft Teams, Google Hangout or something else is out there. It's also straightforward.

Interviewer 24:38

So normally what platform do you use for remote working?

Interviewee 24:43

It varies, but usually it's either zoom or Microsoft Teams. And in some groups, it's WebEx, WebEx,

Interviewer 24:55

so which one do you prefer most?

Interviewee 25:00

The only slight differences between them, for instance. So is doesn't have an option to raise your hand. Okay. Yeah, so that is something that I miss. But otherwise, I think I had some problems with WebEx. So it wouldn't work the first time, I think I had to reinstall it or do something else. But other than that, they're pretty much similar, I think, more or less the same features.

Interviewer 25:39

Okay, thank you very much. So since COVID-19, started, we're asking the same question again.

Interviewee 25:44

Yeah, that's fine.

Interviewer 25:45

So as you mentioned that you are shielding as well, yes. And since COVID-19, started. So there's, so what at the moment, what influenced you to continue with your work?

Interviewee 26:03

So I have a lot of time on my hands, because I don't work. And it was my plan all the time to be involved. I didn't want to do it short time. And, as I mentioned earlier, I would I want to progress to more advanced roles, perhaps one day to become a researcher myself. So I am learning different aspects. And one day, I will come come up with an idea for my own research.

Interviewer 26:37

So yeah, so you would like to do research on what he says?

Interviewee 26:42

Yes. And the skills that I'm learning also, I think they have application to, to realize that I will, I can possibly use them in looking for a new job, etc. So as I mentioned, I've, I volunteer, because I enjoy writing. So I'm building my own portfolio.

Interviewer 27:14

Okay, that's great. Thank you very much.

Interviewee 27:19

And, also, I haven't said that yet, but my my first motivation to, to join to become a public contributor was because because I am grateful for the health care that I'm receiving from the hospital. So I was involved in that group, because I saw an ad in the hospital newspaper, and I replied to that ad. So you could say that they progress from being a patient, then study participant because I've I've taken part in, in different studies to public contributor, expert. Thank you!

Interviewer 28:08

So you have been receiving support service? I mean, from NHS and hospital leave said, Is this a? So you're trying to give them something back?

Interviewee 28:23

Yes, exactly. Because Because I am grateful. I think healthcare in England is exceptional. that very few countries in the world, when you have this level of, of, of support, and the fact that every everything is free.

Interviewer 28:43

Thank you very much. Thank you. So doing the remote work. So the support you require, and the very thing you're sufficiently received all the support you require. work remotely. Any kind of support any I mean, you can overcome any challenges.

Interviewee 29:07

As I said, I really didn't need any help with with technology, because I've used Skype before and other things. I'm also learning new technologies all the time. So I don't think I had any challenges.

Interviewer 29:29

Okay, thank you very much. So is this is this is there anything that you feel that worked well, PPI remotely. Anything worked really well?

Interviewee 29:49

I think that the fact that now more people can be involved. is a is a benefit. It's also the It's much easier to schedule a meeting. You just have to, you can do that or do a doodle poll and see with which dates and times are most acceptable to most people.

Interviewer 30:16

So it's it's because because everyone is working from home, same thing this time is flexible.

Interviewee 30:24

Yes, I think so. Yes. And obviously savings for organizations because you don't have to reimburse people for for expenses. You don't have to provide refreshments. You don't have to arrange for a room. cetera.

Interviewer 30:43

Thank you very much. So there's another thing. We're going to talk so. So there's the advantages, what worked well. So anything you can think about the dean work? Well, just if you want to go find out the opposite way?

Interviewee 31:01

I think that I am worried that there may be too much reliance on remote work. Because for me, it's just a short term solution. I would like things to go go back to normal face to face meetings. Right. But I have not have noticed that there's this trend. And it's not only with P. PPI but with with even with health care like if you have a say some mental health issues that are most likely solution will be that you will be referred to an online course. And I don't think that's that's the the best solution that you have to deal with your problems on your own. And the same with ppi. I don't like remote work to become the new standard.

Interviewer 31:58

That you were why is this important? This is interesting as well, as you mentioned about the mental health Can I can I ask that? Has PPI helped you with with any mental health or connecting connection during isolation during COVID-19 as PPI duty

Interviewee 32:17

I think it gave me a bit of a purpose in life. Because when I know that I have some meetings that I have tasks to do, than I am probably better organized. And I have I make better use of my time.

Interviewer 32:37

That's great. So yeah, so I and another thing is do you think you’re doing more PPI work now than before COVID-19 started?

Interviewee 32:49

Oh, yes. I am definitely involved in more things. Yes.

Interviewer 32:53

More PPI you're in?

Interviewee 32:54

Yes, yes, exactly. Yes.

Interviewer 32:57

Okay, thank you very much although you have mentioned that your preference would be going back to face-to-face meeting once the COVID-19 is over?

Interviewee 33:05

Yes. At least let's say I would like half of the meetings to be face to face. Yeah, are happy to have remote work faced out.

Interviewer 33:19

Do you think so you mean half and half… So once people go back to their normal routine, no restriction. Do you think remote work still be practical?

Interviewee 33:34

I think so that perhaps it will be incorporated in face to face meetings.

Interviewer 33:44

So you want to see a balance between zoom mode and face to face meeting?

Interviewee 33:47

Personally, I would.

Interviewer 33:52

But But would you? Would you go for more face to face meeting there?

Interviewee 33:59

I would think so. Yes, I would think so.

Interviewer 34:03

So is there? Will there be any, any anything any preference? Like? If you want to go somewhere just staying overnight? Do you go to face to face meeting? Are you

Interviewee 34:13

I would i would i wouldn't have a problem with that. And I was perhaps leave online meetings for some, I don't know urgent matters something that cannot wait that has to be discussed immediately? Or perhaps what for some meetings between two three people?

Interviewer 34:37

Thank you very much. So we're nearly at the end of the interview. So the last question I would ask, from your view from your own opinion, what could have been done differently? What could have been done better? And how please

Interviewee 34:52

Ah, that's a difficult one.

Interviewer 34:56

You can share anything you want.

Interviewee 35:06

I think that irrespective of a meeting being face to face or online, I think that the public contributors should always be paid for the time. Some meetings, do not offer anything and no vouchers, no anything. Also, I think that there are some people that struggle with new technologies or simply cannot afford them. So there could be a scheme to rent devices to people or something like that.

Interviewer 35:58

Supported so..

Interviewee 36:01

I think I think we discussed that in my group that, perhaps, because the issue with that it's most prevalent in PPI work is how do we involve underrepresented groups? So people who normally do not have voicing that? And that would that would have to mean like, giving people equipment, providing translation? Things like that.

Interviewer 36:34

This is another important point, which you raised about digital divide, when some people do not have the equipment and other thing is, you mean, the language barrier?

Interviewee 36:51

Yeah, the language barrier.

Interviewer 36:57

If these two can be solved, waiting, more, more people will be joining PPI?

Interviewee 37:02

I think so even like basic things like that, translating all the resources to, for instance, the NIHR has into different languages, that would be a start, or translating that say, research summaries, lay summaries into different languages and have them published, that would be a start because people could easily access them and start to learn.

Interviewer 37:30

Thank you very much.

Interviewee 37:32

Like having even having even introductory courses, to PPI in different languages.

Interviewer 37:40

That's very important. They're interested, thank you very much. Anything you would like to add anything to have not discussed? Or I didn't ask anything you would like to add?

Interviewee 37:57

I think that PPI in England is in a very good position is evolving. And it's really I'm really happy to see that a lot is being done to involve people. Because in other countries, for instance, I come from xxx, so ppis, almost no non existent. does some patient organization charities, but they don't have so much say, as we do here in England.

Interviewer 38:34

Thank you very much.

Interviewer 38:46

Thank you, it's been a really pleasant to talk to you.

Interviewee38:50

No problem. Likewise. Thank you.