Interview 7

Interviewer 00:01

No, I would press record one this zoom recorder, you know. Have you managed to get some time to read the participant information sheet please?

Interviewee 00:07

Yes I did, no questions arising out of that.

Interviewer 00:13

Thanks a lot. Now, that’s great you have managed to get a chance to read the participant information sheet so I do not need to go more details about the study again.

Interviewee 00:28

Yes, that’s right.

Interviewer 00:28

Thank you. So basically, the main purpose of this interview is to gain a better understanding of your views about and experiences of remote working in public engagement were working. Also, we are interested in your thoughts on how we could improve remote working facility during this COVID-19. Your thoughts and contribution will be much appreciated. If Could I start first by asking you to tell me about any PPIE work you were involved in prior to covid-19.

Interviewee 01:13

The work that I've been doing up to the point that COVID started with a lot of it involves reviewing online advocate proposals patient facing materials. And I'm on a wide number of different panels, review for the xxx. This time, number of different organizations. Since before COVID-19, I would also travel to places like xxx, all around the country, to have face to face meetings in panels and the interviewing process. One of the biggest challenges for the people that I work with, which is the project grant funding Committee for the xxx. And at that meeting, we would leave for a whole day in xx around the table. Since COVID, is a great chance to organize all these meetings, I would attend in person by zoom. And see more Microsoft Teams. The benefits the pros and cons to meeting by by remotely remote meetings. There are a lot of positives, meetings are more productive people tend to focus their thoughts more concisely. They tend to get get through the agenda more efficiently. What you can't do on remote meetings, it has the fluidity of conversation that we would have had because of the delay that the technology creates. The fluidity of conversation is is which does impair opinions upon the creativity of thinking. And there are meetings call a number of meetings where you have a certain number of people who like to dominate the conversation with more than more they're thinking rather than spend a lot of time listening to others, which means if you have a meeting with more than say eight participants, they can some people who are more reticent and need more need more encouragement or better chairmanship to have their views taken into consideration or less either not saying anything at all or making any contribution at all, or making a contribution only for the advantage of a child child however, does mean to say that when you have two or three people talking about a particular aspects of the topic impressive that people have that could contribute to that discussion. But then, but then there was the flow of things diverse and risk diverse in the conversation. So there are lots of pros and cons to using.

Interviewer 05:11

Thank you very much. So you got, you've covered so many things already, which I was going to ask you later. But thank you for, for sharing this. So you have been involved with so many, you know, great projects and you have been, your contribution was great And also it's very, you know, good to know that you have been involved before COVID-19. So what you mentioned already, all of the meetings were face to face before COVID-19, every meetings you were involved, or any conferences before COVID-19?

Interviewee 05:51

There are lots of meetings. And if I have to go to xxx, go by train. Sometimes. So yes, there were a number of meetings I attended in person. One of the things about drawing these these meetings intravenously is that the nature by disability is that I do have probably spamela tea. And when I had, by what I want to have a meeting, I really could only focus one for PPI that day. And back then, when I came back, I need to rest for the rest of the day. Whereas I can have meetings by zoom and still have to do things online. And because of what happened with COVID, my, the demands on my time, more than doubled, has tripled, I have far more things to do for PPI as a result of COVID that I did beforehand. So the fact that they might have been taken out by the necessary research requirements.

Interviewer 07:27

Thank you very much. Thank you, we'll come back to them later to this very important topic, you mentioned your work has increased because of COVID. So we'll come back to that later. So overall, how do you feel about your contribution towards PPI? How do you feel about your contribution please?

Interviewee 07:48

Well, in my working life, I had xxx, suddenly, I was very often very, very, very long time. And I would never really recovered at all. So it took a huge part of my life away from it. But because I have been patient with a critical illness, because my wife has been xxx. And also because I used to be a xxx. I had I bring to the research conversation, three separate insights because I'm unemployable through my illness. It's very, very frustrating for me, if I didn't have something like PPI to give me a sense of purpose.

Interviewer 08:50

That’s great. Thank you very much.

Interviewee 08:53

PPI's is important for me in terms of giving me a sense of purpose, give me a sense of contribution making contribution to society and in some ways or repay what was given to me when it keeps me alive, thank you very much.

Interviewer 09:16

Thank you. It's great to hear, you know, just your contribution of course, it's it's it gives you a purpose, but is widely helping all the research community is public health, NHS everyone. Thank you very much. Anything in particular, that supported you involvement engagement in in in PPI work before COVID-19 anything in particular, although you already mentioned that, that gives you a purpose. To continue anything any other think of you can think that supported you

Interviewee 09:56

I think so what I was doing before COVID was numerically the what I'm doing now, but it's still the 100 gearing for PPI then and now was appreciative, I didn't feel that my contribution was valued. Bringing three perspectives to the research discussion. does mean that says a lot of recruitment on behalf of research team tried to find people with all these different perspectives. So I would say that there's nothing particularly this distinct between before and after just that after I am doing so much.

Interviewer 10:56

Thank you! And any any difficulties, anything difficult, challenging about face to face working, you can think of, please?

Interviewee 11:03

I enjoyed very much meeting people face to face. I do think that there's huge value in meeting face to face. I think because we are in an environment whereby everybody appreciates that working remotely is a is a necessity to get these things done. It shouldn't be. It shouldn't be. Well, this is over. I don't think that we should totally rely on remote meetings. To do our work, I really get the sense that the face to face meeting is very important. I'll give you an example I give an example. One of the things I do is I work with the University of X on the temporal xxx program, and I'm involved with recruitment, I'm involved with interviews, a couple of years ago, I was at the xxx. And just by chance, I ran into a professor who subsequently we had a conversation about what happened to me in terms of my critical illness legacy. And I told him about something, a particular thing all about in terms of need, and in terms of patient, patient intervention, that wasn't happening. And last year, he got in touch with me and said, based on that conversation, I want you on us to be the lead PPI on my research project. That wouldn't have happened. had everything be done by the the chance encounter. The the author agenda conversations do provide potential and hint opportunities for connections to be made between patients and members of public researchers, academics and clinicians. So it would be it would impoverish the research. compensate the research project, if nothing was ever done face to face with between members of the public and specialists.

Interviewee 13:51

Yes, thank you very much. are you leading that PPI project in the University of X?

Interviewee 13:58

Yes, I am leading and I lead on a number of PPI projects. I mean, it's safe to say, so fingers crossed. There we go. Move forward.

Interviewer 14:15

Thank you very much. So now we'd like to move move to our current PPI work, which is after COVID-19. So although some of the PPI work is continued. You said that your work has increased because of COVID-19. Is there any new PPI you have been working on during this time? Or can you

Interviewee 14:50

Oh yes, a number of projects that we're going ahead before COVID a number of those as stopped because I didn't succeed in getting any faster funding. Others have. There is a research study on xxx that I'm involved with, that has got funded. And that's moving ahead. So things are well, the reset project have lasted maybe two or three years, at most three years. It's actually five years in his lifetime, from the very beginning to the end of dissemination. Things are still moving on. I strongly believe that if you're going to be a member of the public giving a PPI opinion, it's important to be involved in research as a participant itself. So I'm involved as a participant on something called the xxx study, basically, the University of X and that has been suspended twice, because of covid 19, I had recruited, I was supposed to have had the follow up from that, as have another that was canceled on that as we booked through February, this month, that's the cancel. So lots of studies going on that are held in advance. xxx, they've all got their projects at different stages. And a lot of them are being sort of held held the base.

Interviewer 16:54

Thank you, although you have already mentioned some of the different and change about your PPI work. Now could you particularly what is different/changed about PPIE now? Such as limited face-to-face working or remote working?

Interviewee 17:18

Oh yeah. The one thing that comes to mind is that with COVID, you have a study, and you want to steer intimacy, there's a number of different things. One of them is the xxx study, base, the other books. And this is a study where we be funded by the xxx. But the nature COVID has meant that a lot of the lab work that would have been done has been suspended. So all the levels that we would have been doing, hasn't been doing, and we try to negotiate the recommencement for that. And the time has been spent doing other things like organizing and disclosure agreements with and to offer letters of cooperation between companies has caused an awful lot of delay. And the longer it goes on, the more technical it becomes.

Interviewer 18:58

Thank you very much. Was there anything new for you? any impact on your involvement, anything new because of COVID-19?

Interviewee 19:08

I think what's new is I've had to get used to doing different bits of ppi using different technologies. One of these projects I'm involved with is to do xxx and they have been slated to buy into Microsoft Teams. Microsoft Teams facility that they've got the great involves a lot of file sharing. But I have a Mac. And Microsoft seems really doesn't work with Apple Mac. The xxx uses Dropbox, which is attached. getting messages from Dropbox, or Dropbox files or folders holds

Interviewer 20:28

Yes in Dropbox only two gigabytes free. So

Interviewee 20:35

spending money I haven't got the money. I don't have an income. Yeah. So what's new is having to adapt to the new technologies that people are using. I think this isn't particularly new. comes to my mind.

Interviewer 21:05

Many storage choices..

Interviewee 21:07

yeah. My mind is that the the National Institute of Health Research then invented, PPI. So all these different computer systems, we don't have any training in the xx. And it's a case of having too much alone. And of course, there is no money for development of research projects. So well, PPI is highly valued and considered really vital by the funders by the xxx. Also, PPI is considered really, really important. Nobody wants to pay for it. So it does require a huge amount on behalf of people like myself, to be willing to give up what we give up in order to do this. And we do gladly do it willingly. But we often feel that our contribution isn't as valued. as well.

Interviewer 23:03

Yes, Yes, I understand. Yes. So yes. So they have a project they have. I mean, but they suffer from lack of funding. As they rely on people public involvement, but as you're saying there's a lack of funding towards them. [yeah] And everything is the everything makes difficult without funding. Thank you for sharing your thoughts. So are you saying, training, would you prefer to do get people train I mean,

Interviewee 23:41

Well, I've been doing this for more years, and I can't remember I can't remember when I started. I think it was 2012. And because I built on my, my my working life by working life as a xxx, this and the other. I started one of the things that's helped me with recovery from a critical illness is I started off intellectually from a really good starting point. And then based on all these things, anyway, my training needs are fairly limited now. But I knew I was gonna be been doing now is to be involved in training of other people using PPI program for adverse patient panel. Design is so that people can just sit at their computer and go through. So my training needs quite a few, because of my spirit and the other people who are coming. They do struggle, because one of the things that I saw important when it comes to training is the face to face component. In meet with people, you get somebody who has got a particular condition, you recruit them to study as part of this focus group or a steering committee, they go along, and they feel a bit sort of thing, they feel a bit uncertain, should they speak what's sitting is a big thing for them. But when you're meeting people face to face, on an equal footing as a member of the public, you can then say, relaxed conversation and say, don't worry about these things, I will I will help you through I will support you. Because it's face to face meetings are not happening. When the meeting ends, somebody clicks the button, and it's all gone. And you don't have this connection. So when it comes to increasing PPI retain PPI and training PPI they're done. There is going to be there are going to be some potential problems in the future. Because people are leaving work and being made redundant. They are the very skilled and intelligent people out there. They've got really good insights of disease, and medical disease and caring for people with diseases and long term problems. But the opportunities to bring them home, and the opportunities to recruit them, retain them and train them and nurture them greatly reduced, because of COVID it was kind of back to what I was saying at the beginning that is be really, really good to have API's still on a remote basis, but not not solely, but exclusively on remote places face to face meeting are still important for the future. Thank you very much.

Interviewer 27:34

That's pretty important. Thank you. Now can I ask you to tell me a bit about the resources you have available at home to do this work remotely, please?

Interviewee 27:49

My my camera, my internet connection, the only resources that I have used for for COVID sources I use now. And without them I couldn't do I couldn't do any any research. I spend when when something comes in for me to review. I like to get it done. straightaway. I turn things around usually within 24 hours with just a simple patient information leaflet or full application. It's very, very rare that something is in my inbox for more than three days without having to that haven't been. So it really is highly dependent upon both isn't working and my camera working. And my internet connection.

Interviewer 28:51

Yes. Great. Thank you. So you’re using a Wi Fi?

Interviewee 28:54

Yeah, yeah.

Interviewer 28:56

Any support that that helped you with remote resources? Did you need any support? Or did you ask for any support from any IT team?

Interviewee 29:08

I think when it came to the xxx thing because it wasn't working for me with with a with a Mac. It didn't require the intervention of somebody who understands Microsoft Teams. They try to resolve the problem. But I think they had to give up because there's there's more than me who's having problems with Microsoft Teams. And it really doesn't work. So if there is a problem, I go back to the originators and say it and when whenever we get around it if somebody puts something on Microsoft Teams and I never seen And then they will gradually eventually become aware that I haven't seen it. And it was sent to me by traditional email. But when suppose needed someone to go to and ask for it and get something most of the time, I don't need anything else because everything runs fairly smoothly.

Interviewer 30:24

Thank you very much. Thank you. Was there anything in particular that helped you involvement in PPI was during COVID-19? Any influence that have do anything in particular?

Interviewee 30:41

I don't think so. I really am. I, I think what time management is a difficult skill to get getting wise, when we have days when there's nothing that nothing goes on sale to work in tab. And when I have got two videos in my diary, we take the day out and go somewhere or if with COVID, we just stay home and read the papers and so I'm lucky that I've got such a supportive wife in times in the past tense to visit the city before COVID and when I was driving to meetings, sell no more than two or three meetings a week. Somebody says having sort of five meetings a week says he has to be very, very forgiving. But we work together very well as a team.

Interviewer 32:07

Thank you very much for for sacrificing. Thank you. So how do the organization or groups you are involved? We are communicating with you the people who are working with it for example, is a university or other university How do they normally contact you

Interviewee 32:34

Via email my phone number and contact email and really work very very well.

Interviewer 32:52

So okay, thank you! Any support you might require in relation to specific challenges you may be facing you may face during this time regarding physical or mental capabilities this time did you ever need any support?

Interviewee 33:11

I don't think so. Has anything specific? Last a lack of needles I've been doing this for many many years. I'm I'm I'm in a position whereby I am able to see for other people can PPI and I can spot where people are struggling. I can say that Are you okay, do leave me down. There's the chairman of the xxx group. I noticed that particular problems with trying to balance all the balls in the sand the other so I approached her and said would you like to have a conversation and sort of talk through things. And when we met up by zoom, we had a conversation and was to see a clear path through the member of of the of the xxx projects as a member of the recess staff there who was clearly showing signs of stress test the focus. So I go and talk to their parents. You need to take time off, you need to take time out. And throwing up red flags saying that I need I need a break, I need support here. With me saying that you do need to take some time off, you do need to take some holiday, he's able to sort of pocket cards to apply for. So I'm, I'm lucky in the sense that the not that many opportunity whereby I need support. If I do need support, I know where to get it from my people. And I'm also able to identify some cases whereby others need support and no further.

Interviewer 35:53

Thank you very much. Thank you. So was there anything in particular that made it more difficult to be involved in PPI work during COVID-19?

Interviewee 36:07

Maybe more difficult, very different. difficulty. adjusting to doing things by by zoom was a sharp learning curve, trying to understand how how these meetings are going to work. The necessary etiquettes the learning how learning what the problems are with, with a technology bug, for example, the delays that go on and how difficult it is to, to have a conversation by remote when you're meeting face to face. You're able to communicate with each other and I didn't realize just how much it actually happened. Actually, we were no longer able to do that when you're when you're in a meeting room around the table, talking about something rather, you're able to indicate by body language, whether you agree or disagree, or you want to contribute. And the chairman is a good chairman is able to pick up on those signals, resolve them and say, let's hear from xxx or whatever. But that doesn't happen with remote meetings. The body language signals are not possible they're not present. And I think that's that's one of the things that takes away from the research conversation. The broader thing, research conversations by Microsoft are pared down the some of the conversation you'd have face to face. And the functional, they get the questions answered. And they get the decisions made by these various pared down things like so. If you can imagine an apple. If you take recall, as an apple, that's what you have with remote working. But the fruity, juicy, tasty flesh of the whole of the whole Apple is what you get with raisins face to face. And is that fruitfulness? That doesn't happen?

Interviewer 38:41

Thank you very much. So for any opinion, what could have been done differently? What could have been done better?

Interviewee 38:49

I think given the given the constraints of COVID I don't think anything could have been done. I definitely we don't have a choice about remote working, you can't possibly meet face to face. Even with a mouse in the sunshine, especially with masks. The conversations really would become so artificial and so difficult. In bizarre worlds, people inside the research team decided to have a meeting face to face around a table and everybody wearing masks. That would be worse than meeting with zoom in here relies upon body language because it relies upon effective communication. Sometimes people around the table who have hearing impairments and they need to see the facial gestures, the lifts to make sense of the conversation. People who've got impairments, hearing impairments they need to see the full face re meeting missing or missing around the table to discuss research projects with masks on would be absolutely awful. I can't see it working at all really, really. I think given, given, given the offices we had either don't meet at all, not having any conversations, or having only conversations by email, and not making by zoom in conscionable is a reset, can't stop cardstock research is so important. It's got to move forward and find ways of overcoming the obstacles and driving that forward.

Interviewer 40:47

Thank you very much. That's very interesting. So you mentioned that even when you sit around around the table, if people wear a mask, that would be worse than zoom meeting. Yeah, yeah. But in zoom middie, you can see faces.

Interviewee 41:08

So your body language, if you've got several people have a really engaged conversation. Whereas before, you'd be able to sort of wave your hand and it certainly changed move forward with indicate you want to contemplate, if you can't do that with the zoom, at least you can chat, you can say, Excuse me, I want to say something, or put a little sticker on say, raise your hand. So having meetings with masks is absolutely awful. It really would want to take you through it would not work at all. If you're thinking of encouraging people to have recessed meetings with masks. Tell them to think again.

Interviewer 42:00

Thank you very much. That's very interesting point you made. So you want to I mean, you want to see the face plus body language to in order to understand properly other people and in order to make you understand to other people. That's pretty distinct. Thank you very much. So once. So once the pandemic is over. How do you want to see PPI work? Do you want 100% face to face? Or do you want some half and half or a balance?

Interviewee 42:31

I think a good balance has got to be made in the first place. Face to face meetings are expensive. There's no two ways about the research budget. It's been severely squeezed. So what I really like to say that when it comes to initial meetings where you try to get in those brothers bringing the team together, we've got we've got to know the chemistry between people making productions. Have that create the chemistry that makes the research meetings work. Have that beginning, again, when it comes to putting the pinhole research project to see how we will disseminate the events in terms of conferences, and it's certainly other, but the actual working exchanges that go on in terms of steering committees, have you done this? Have you done that? are we are we basing our recruitment targets, things like that, the working the working nuts and bolts of of research recently, they need to be done remotely? It all depends when it comes to focus groups where they can how well they can to work. Remote, I think if there's anything that can work remotely, I think it should. I don't think there's anything you can do justifying meeting for the sake of meetings, face to face. You can't justify that in terms of Human Resources was the financial. But when it comes to these things, whereby you've got a tendency of team of teams, that's when you need to have face to face meetings, and that usually happens at the beginning.

Interviewer 44:28

Thank you very much. That's very useful conversation we had. So we're coming nearly to the end of the interview. Is there anything that I have not asked you, would you like to share something would you like to add on top of our interview questions, please?

Interviewee 44:50

I have enjoyed the interview I will anything more than I could do for you. I will happen.

Interviewer 44:58

Thank you. Please continue, it's a great contribution to be making to the community to the research, community, academics and medical science, everything, everywhere. So if you would like to add anything, you could share Now, before we finish,

Interviewee 45:16

thank you so much. I can't think of anything at the moment.

Interviewer 45:22

Thank you, all right. So, I will email you again shortly about your gift voucher.

Interviewee 45:53

When it comes to the end of the no particular project?

Interviewer 45:56

anymore, do you I mean, of course, yeah. So what do you do once so this project is it should be finished by the end of this year. So and reports should be should be ready by this by the end of the year as well. So once it is finished, and the report is produced, we will contact you.

Interviewee 46:20

Thank you very much.

Interviewer 46:27

Thank you take care.

Thank you very much. Bye bye.