Interview 9

Interviewer 00:00

So on zoom we're going to record this interview as well. So I'll press record if you give me permission on your side as well. And if you prefer not to record your video, you could turn this off as well, it is up to you.

Interviewee 00:15

That's fine. Thank you

Interviewer 00:28

Thanks a lot. So this interview is shouldn't take more than 30 to 40 minutes. It depends what you would like to share. So basically, the purpose of this research, okay can I ask please have you read the participant information sheet already, which I sent to you?

Interviewee 01:01

Yeah, I've glanced at it. Okay.

Interviewer 01:03

That’s fine. So the basically, we'd like to gain a better understanding of your views and expectation about Remote Patient public engagement work. And we're also interested in your thoughts on how we can facilitate and improve remote working during this COVID-19. So basically, first of all, I would like to ask you some questions regarding your previous PPI work before COVID-19 so if you could please share what PPI you were working before COVID-19, please?

Interviewee 01:43

Okay, I signed up with a volunteer for with Xxxx, for xxxx and attended a number of face to face meetings, which are about patient involvement in cancer matters. Let me get rid of Hello. Yeah. So we met at a venue dimension city center. every couple of months from the law that we discussed, opportunities for public and patient involvement in cancer matters. And so we were quite actively involved in that process. And that went ahead. And then the late stages were involved in receiving the feedback from that. medical people implementing it and then looking at the National publicity that arose as a result in contributing to that, that was quite fulfilling really. And then round about the same time as COVID came millon as sources of funding halted. So he managed to cancel themselves to go over the process. And so that process then continued until COVID, came along. I think we had the last of those regimented, again, two meetings. In February of last year, we should really reinstate group that was there before and trying to work out what we're going to do. And then COVID came along. And so since then, we've had relatively few zoom meetings. And it's not been it hasn't progressed particularly well.

Interviewer 04:48

So before COVID-19 so you normally was it face to face meeting used to attend?

Interviewee 04:55

Yes, yeah. Quite so it was quite convenient for me to travel by public transport to it. We met in a room there with two or three patient experience people. Yeah. And as I say we met about every couple of months.

Interviewer 05:30

Thank you very much. So how do you feel? How did you feel about your contribution towards PPI?

Interviewee 05:40

That was quite fulfilling, because you could see how the contribution you were making was contributing to setting the trial, then you got feedback as to how the trial was going on. And then you saw how it was implemented. And then we saw the national publicity that he got. So it was really fulfilling to be part of the ongoing.

Interviewer 06:03

So do you feel that your contribution was to was put on action?

Interviewee 06:10

There, yeah but the combined contribution.

Interviewer 06:14

That's good. Thank you very much. Could you please also share what did you most enjoy about face to face working?

Interviewee 06:27

When you get to know, people, you're meeting every every couple of months, particularly the the other patient representatives, you got to know them and you had some interaction with them in between as well about the topics about cancer generally. And you got to meet the medical who was obviously actively involved in the in the development process.

Interviewer 06:56

Anything in particular, that was helpful for you to get involved engaged in that, in the time before COVID-19 in was particularly supportive.

Interviewee 07:16

It was relatively easy to get involved and I've been a supporter of Xxxx as a donor to for probably 15 years. And then prior to that, probably five years ago, then they started offering opportunities for patients to vote. And that that's so the carry forward that that interest The reason I got involved with Xxxx was that I had had cancer diagnosed back in 2005. Very, very, very quickly, I'm appointed the tests through to being referred to C. And once I got the diagnosis it C, one of the first people that I met, there was a mother nurse who was probably most helpful for people who were there. And they gave me support throughout the treatment, my wife and myself support throughout the treatment process. Just wanted to give something back to the organization to provide me the help and I need

Interviewer 08:32

Thank you. Anything difficult or challenging for you to get involve in PPI work, please?

Interviewee 08:42

It wasn't particularly difficult now. Towards the end of the time period, my wife had a stroke and it was quite a little. So I had to, and I was sort of made I mean, we had errors for time today. I was the unpaid carer. And so somebody always had to be with my wife at home. And so it was sometimes a challenge just arranging for somebody to be with her long enough for me to go to the patient development make them generally managed. I managed to do that. Okay, my daughter is very good and they they slotted in one step at a time and attended to go by 1000 feet get that cleared back up quicker than going up public transport that was devoted to that person.

Interviewer 09:38

That’s great. Friends and family supported you. Thank you very much. Now we'll move to current PPI award. And so you have been involved with xxx about last 15/16 years. You mentioned

Interviewee 09:54

Yes, financially 15 years but by volunteering, I believe so it’s probably more than that

Interviewer 10:00

Yes, you have been a donor for a long time. And so after COVID-19 started, was that carried on? Did you get involve with any more PPI work or just the previous one?

Interviewee 10:15

The group that started to form in February, which was a version of the PPI group that I was involved with, had probably two preparatory meetings. One was at the C one was somewhere else. And we started the process. We sort of agreed what our support would be like. But we didn't actually get very far very quickly. For some reason. What was particularly noticeable compared with my previous experience, there was there was no medical professional present. So it was a somebody from xx, but there's not really much I can say that was sort of leading the group. I think we've missed him in having there a professional there.

Interviewer 11:23

Ok, was it a virtual meeting?

Interviewee 11:29

Well, before COVID, we had a couple of physical meetings after COVID.

Interviewer 11:33

Okay, thank you!

Interviewee 11:35

Then had they had to become virtual means since I think we've had one virtual meeting. I mean, I get to weekly email from xxx with action development opportunities in it. And when there is to be a meeting of the user involvement group with them, a member of them, they tell me that the meeting was being held? And I think since go with this, probably no more than 250 now. Okay. So

Interviewer 12:14

Not many meetings like it was it used to be before? [Yeah]. Anything different or changed about your PPI work now? Could you please share?

Interviewee 12:28

What I said earlier, it's the lack of the professional lead thing in the in the zoom meeting. You know, the weekly email is very rarely anything in it that interests me, particularly. Our last meeting, we agreed to be part of another email distribution system. Well, not not email exactly executive at some sort of website with links. And I suggested in the meeting that, that maybe try that for a month or so and then come back and see how it was working. You started fairly quickly, I signed up for it. With like, 10, not even to understand the notification that I've gotten, there's been no reconvening to see how it's working and how it's helping us to be involved in patient development.

Interviewer 13:38

So before COVID-19, used to see medical professionals there, but that's how the meeting then the COVID-19, a zoom meeting, you normally don't see them,

Interviewee 13:53

Though, I mean, the first couple of physical meetings before COVID, there was no medical person there have been no medical people there. Since they've become virtual.

Interviewer 14:04

Would You Do you know the reason or did you ask anyone that why there was no medical?

Interviewee 14:10

No, it was only in thinking about what I'm going to talk to you about today. I realized that was one of the significant differences. I mean, we do still see professionals. So last week was world cancer day. And how the virtual was on zoom. It was one of the platforms set of presentations, including with his support for the cancer. And so yeah, and there were professionals who spoke at that meeting. But that's the closest we've got to know we want professionals. I mean, it was said in that meeting that after the problem at the moment So isn't it rationally able to transfer to COVID or frantically catch up with cancer? They don't have time for the patient involvement. Time.

Interviewer 15:14

That's a very interesting point. Would you able to share that how that impacted on your involvement? You felt that professionals were not there during PPI meetings, which you felt very important. So how did that impact your involvement and engagement?

Interviewee 15:45

Well, professionals were there in the early meetings meant that they had a sort of vested interest almost in progressing the methods that you discussed and reporting by? Now they just seem remote, the process.

Interviewer 16:03

So your expectation was it more or less from zoom meeting if you compare your zoom meeting with a face-to-face meeting?

Interviewee 16:18

Yeah, I mean, there's, well there's no professionals there anyway. But the the admin lead from xxx didn't seem to follow up on the points that the people in the meeting. So yeah, not terribly happy. I mean, I tend, therefore, not to devote a lot of time or thought to the process of when I do look at the weekly email will be I appreciate PPI opportunities. And I have just signed up behind the conversation yesterday with somebody from xxx sign up for a particular role. Because of the experiences that I've had, so my wife had a stroke, as to where I used to retire ago, and I was looking after her. And an opportunity arose. So I signed up for that. And I have a conversation in probably two days ago, with a professional and that seems to be on your head so that it's much more like it was before. Like it's been much more satisfactory. I think the process has only just started.

Interviewer 17:50

So would you know any future zoom meeting is coming soon anytime soon you’re going to attend a zoom meeting?

Interviewee 17:59

There's no zoom meeting scheduled for the the more routine and professional meeting, the one I just talked about to do with and the person that spoke to Tuesday, I think it was, was going on annual leave for a week, she promised to be back in touch the week after, to set up a zoom meeting with myself and two professionals, just so that I was clear on what the expectations were from the guy process with a view to signing up fully. So I think that'll be much more like what it was before. But it certainly does start.

Interviewer 18:47

So would they provide with the list of names that will be in the meeting beforehand? Do they do this normally? Like an agendas do they say beforehand that this and that persons or these professionals would be in the meeting?

Interviewee 19:06

As I say that the ordinary PPI meeting professional there anyway, don't think we know in advance who has been invited PPI people are the one that spoke to on Tuesday. She's promised I mean, she mentioned the name better remember the names now. But you know, she's she's, she's letting me know that she will arrange a zoom meeting involving me and three other people. So that was much more like us.

Interviewer 19:34

Thank you very much. Thank you. Though, can you please share something a bit, a bit of resources you have available at home to do work remotely?

Interviewee 19:49

Yeah, you probably tell them using my smartphone at the moment speaks to you. That's which is fine. I mean, that that that works and I can Access most Zoom type platforms using it. There was one, exactly nothing to do with xx. But that used a platform for WebEx, which was absolutely awful. I couldn't get sound and I couldn't get on zoom. I'm okay. You started using zoom. So I may have to have to do that. So I do this by hand, I've got a computer as well.

Interviewer 20:49

Is that one that I can see behind behind you?

Interviewee 20:51

Probably yes. Yeah. I don't use that because it's not the web camera. I don't know why it's not the web camera. But something that hasn't bothered to fix it. So I use the smartphone which works.

Interviewer 21:06

It's good. The aid looks very clear. I'm talking to you. So smartphone is

Interviewee 21:11

The disadvantage with the smartphone. is if somebody is showing slides, yes, you can't see slides. Another group that I'm involved in is xxxx. And they always show slides as part of the meeting. But they also physically mail out the contents of the slides of the meeting. So I can have the slides coming back for me at the same time as I'm watching whatever's on screen.

Interviewer 22:00

So how about downloading things on your smartphone? If someone send an attachment? And if I was there, easy, easy, easy on your smartphone to download? Or to use your computer for download?

Interviewee 22:15

Use computer, Yeah. So if it was out of a zoom meeting, I wouldn't be able to do it, if it's an email after that.

Interviewer 22:23

So a lot of people during zoom meetings share their screens, do you find it difficult to see them on your smartphone because it's small screen.

Interviewee 22:32

Yeah, in zoom meetings, you go on the smartphone, you can see all the participants you can on they go into zoom calls where they need. So the disadvantage is you can't see all the people

Interviewer 22:53

Have you sought for any organizational IT support if you required during during this COVID-19 for working remotely.

Interviewee 23:43

No, my xxx is pretty good. I mean, when I was having the challenge with this with WebEx.

Interviewer 24:39

Thank you very much. So given the difficulty we are all having during this COVID-19 but you continued your PPI work remotely. So could you please share if there’s something that influenced you to carry on your work during this time anything,

Interviewee 25:05

I think the the main thing is to have things to give you an attentive time for things to use before over them and lock them. So used to attend meetings of xxx have been jolly couple of times a week and physically attend meetings, something to do with PPI some to do with other things. And those are all disappeared. In a sense. I think I'm continue to be involved in PPI remotely as a way of using up the time that otherwise would be wasted, probably losing or watching the telly.

Interviewer 25:56

Yes. So how do the groups and organizations you’re involved with communicate with you? How the communicate with you mentioned our email is, is there any other way? How do they contact you before or after the meeting?

Interviewee 26:19

Well, there's this thing that they introduced a couple months ago, which is, which is an email introducing you to this other online system, which is the bit that doesn't work. Don't think of anything else that the doing that we have as well, which is, you know, physically sending things to supplement what you're going to be doing online as well. I think that's about it.

Interviewer 26:48

Now, could you please kindly share something, which was particularly difficult for you to do the work remotely during this COVID-19?

Interviewee 27:00

I think it's when the whatever reason, zoom or zoom equivalent systems have fall out. So we have an interface group that I'm involved in, we meet every couple of months, and generally the zoom meetings go fine. But then there's one aspect in the meeting, who seems to have some Wi Fi problems in his home. And so whenever he starts to speak, and nobody knows what he's saying, he doesn't know people value what he's saying, in the end, so we can carry on with the meeting, he's got to be muted and probably doesn't even know that's happened. So it doesn't know that you know, what he had to contribute? Hasn't hasn't been been accepted. So that's never happened to me. But nobody's telling me the I mean, where we just couldn't get the system to allow us to talk to each other properly. So we reverted in the end to using the landline telephone. And then yesterday, yes, last week. And generally it all went very well. And it's been fairly highly organized that was cancer related, sent messages through the chat saying I couldn't hear you know, then it seemed to be a problem with the system rather than with my end. And they never even acknowledged that it had been a problem as in that one or two people seem to be having sound problem. But you know, during that whole pre recorded bits of the, of the program, the screen was blank. They didn't put it right later on by emailing out. The whole of the content of that particular content was put on Twitter, so I wanted to catch up with it and he was already moving. He couldn't feel part of how all the participants in the meeting had been moved by because you haven't had that experience at the time.

Interviewer 29:49

So mostly the difficulties around technologies, those zoom meetings, getting connected remotely err..

Interviewee 29:59

And some, some people are better than others that are conducting an organizing zoom meeting. I mean, it's frustrating when you're in one and you don't know who else is there or who they are or what they are. And it's frustrating as well, where when this happened, which was a general capsule obsession for all PPI people, that was probably a couple weeks ago. But we've been told to zoom in a particular time. And zoomed in, as I did today, a few minutes before the time during the time that the meeting should have started, and several minutes after, there was a bitter argument taking place between the person conducting the meeting, and another participant, I think about sort of removing with funding for some of the PPI work, which was an argument probably similar to the one, but there was never any proper start to the meeting. There's obviously been people involved in a primary thing, it was carried on from one meeting to the other. And so people coming into the second meeting, got involved in an argument arising from the first they didn't even know about until later.

Interviewer 31:26

Yes, great. Thank you very much for sharing. So unfortunately, the experience you had about zoom technological difficulties not only about you, its about all of us… This is the you know, one of the technologies thing problem. So anything positive

Interviewee 32:35

What surprised me in talking to this lady, couple of days about the new group. She was asking me if it was convenient for me, etc, explained that there will be other technology I will be using, I think they were using goto meeting return view as well. And eventually, when things get back to normal, we'll be meeting face to face again. And her view was the perhaps that might have been necessary, it was more convenient for the professionals to be in the zoom meeting, rather than have to get somewhere physical meeting. So there was a bit disappointed about that. But she wasn't absolutely the definitive about it. And the groups are just starting. So yeah, we'll see over time.

Interviewer 33:25

Yeah, so yeah, that's the thing a lot of people are thinking, you know, they have, I mean, I think all will be counted, like some people would prefer going completely remotely. And some people would say half and half balance there. But maybe Yeah, we'll see when the times come but

Interviewee 33:49

Yeah, I'm in the meeting through C University. For me, it has been very convenient than being on the go for making the use. The meetings tend to last two hours if the university takes me an hour to travel there and travel back, that's four hours of time. Whereas if it's all on zoom, then it's two at a time. But we do fit we as a group for that group started just before lockdown. So we've met physically once. And you just don't get to know people as well on the zoom as you do by being in a room and having a chat, you know, otherwise the toilet another way back or whatever. But, you know, you don't get that sort of

Interviewer 34:41

Thank you very much. Would you still prefer to work remotely once this COVID-19 is over, working remotely afterwards?

Interviewee 34:49

I just said really about the saving of time saving up to go the route meetings every couple of months. So rather than. That is an advantage to be traded off with the advantage of actually physically engaging with with people, which was was the process that started with that with that group, and we move on at the moment, it's some administrators, one professional person, and three or four volunteers. We're moving on now to the stakeholder engagement stage which will be coming up. Not actually meet him physically.

Interviewer 35:42

Thank you very much. We’re nearly coming to the end of the interview, could you please share your views that it was there anything that could have been done differently for couldn't be done better? Anything you thought.

Interviewee 36:00

I think the point that I made earlier on against the PPI group the time is not met regularly enough, has not been followed from the meeting. And there hasn't been a commercial there. So I think the things that could have been better and will continue the process better.

Interviewer 36:22

Thank you very much. Was there anything else? Anything else you would like to add? Which I haven't asked you during our interview?

Interviewee 36:31

I don't think so.

Interviewer 36:34

Great, that's really kind of you for sharing your thoughts. Thank you for your time.

Interviewee 37:08

Okay, thank you. Yeah.

Interviewer 37:15

Okay, thank you. Take care. Thank you. Bye bye.