Interview 8

Interviewer 00:00

Thank you very much. Thanks a lot. So, have you read the participant information sheet already. [Yeah]. Then I do I don't need to go through again.

Interviewee 00:13

Yeah, I read it.

Interviewer 00:15

Thank you very much for your participation. So this interview should shouldn't take more than 40 minutes. 40 minutes or it depends would you like to share with us. And so the basically the purpose of this interview is to gain a better understanding of your views about an experience of Remote Patient public involvement work. And also, we are also interested in your thoughts on how we can facilitate and improve doing PPI remotely. So we'll ask first, we'll start by asking question before COVID-19 then at the second part will will will talk about the current COVID-19 situation. So first of all, could I please ask, could you please start by telling me what PPI you have been doing before, COVID-19, please?

Interviewee 01:11

Okay. So I've been involved in PPI for a long time, probably 17 years or so. A lot of that's been with the National Institute for Health Research. And I've sat on a number of xxx for different parts of your right for use abbreviations. And I also am involved with research, particularly around autism. So I'm involved in a project called xxx which has to do with autism mental health. And as part of my work with xxx I've sat on the xxx advisory group, and have been involved in a lot of sort of what you might call strategical developmental stuff to do with ppi. And through that work, so things like I'm part of the what was called the xxxx team. And I've been involved with some impact work around ppi. And I am was part of the xxx yeah, lots of different things. Yes.

Interviewer 03:14

That’s brilliant. You have got long experiences for nearly 20 years plus, many research various organizations, you are involved with. research grants which is brilliant, you must be very busy all the time. Thank you very much. So how did you do PPI before COVID-19, please?

Interviewee 03:44

Lots of tracking off to meetings. And so lots of meetings in xxx, and occasionally in places like xxx. So there were options to phone in, but it was always so some things were done via teleconference, and but most of it was face to face meetings. So you, you know, or or done, you know, some some work would involve working at home, but it'd be reviewing documents or whatever. So if you're a public reviewer, you do that set at home and review that way. Whereas if you're on a panel, it would involve going to often to xxx, wherever it is that they're based.

Interviewer 04:46

And some teleconference as well. Okay, thank you. That's great. So how do you feel about your PPI contribution?

Interviewee 05:05

I'm very positive actually, I think I've sat on. I mean, I've sat on a lot of different funding panels now and I think over the years, so I think it is welcomed. Sometimes it can be difficult contributing what might be an unpopular view. Because if something's really good, but the PPI is rubbish, and it's not always what people want to hear, so it can it but I think over the years that we've become furniture, as it were, like everybody else's around the term, so I think that that's improved a lot. And, and I think, I think you have to see PPI as something, you know, a lot of it's about culture change, changing the way people view and accept public, the public speaking to about research and being involved in research. I do think there's been a lot of change. And but it's slow and gradual. So people don't always see that change. And, and certainly, I've seen since we've been doing the xxxx work. There's been I think it's been welcomed, and I certainly see it. I mean, I so having been involved in the development of the xxx been quite interesting, because I see in the funding stuff that I do reference to the standards, and PPI in a way that wasn't the case 15 years ago, so that there's definitely a change in in the visibility of the way that people present PPI within, you know, particularly within NIHR are, and there's certainly a lot more conversation. So the standards is UK wide thing. And it's involved all the nations and I HRA places a lot more cohesiveness about the way that ppis talked about and encouraged and presented. So I do think there's been a positive change. Over that time, generally speaking, I would say

Interview 07:23

Thank you very much. So. So you can feel that your contribution is, is is putting into action, it is working, adding values?

Interviewee 07:34

Yes, so when you look at the big picture, over that period of time I A, that I feel what I've done has been worthwhile, because it's contributed to that overall change. Sometimes on a day to day basis, you think, oh, why was I even there, you still get that in that you're always going to get that I think in whatever you do, you feel that from time to time, but I am a big picture person. So okay, I'd say over time, I feel it's, it's been a positive thing to be involved in.

Interviewer 08:04

Thank you. Yes, it's nice to hear that in. So since you joined PPI about 15 years, 17 years ago you can see a lot of positive changes are taking place. That's good to hear. And so obviously used to do a lot of face to face meetings. So what did you enjoy the most about face to face, please.

Interviewee 08:32

Um, I think it's I mean, I've personally, it's, I've a kid, I'm a carer for my son. And so I'm home a lot, and I used to work from home. So doing something that involves me going places, personally, it was nice to get out and have something meaningful to go and do. And it's nice to come together with other people, although for as a public contributor, and you might you might know nobody in a room, that can also be uncomfortable and difficult. And so, so it is nice. And it's particularly nice when you you sit on a panel, and it's the same people every time and it's a regular thing, and you get to meet the staff who organize and all those sorts of things. That's so it's quite as more personal. Well, you know, I mean, it's nice to be with other people in a room. And there is something about the interaction that you have when you're all in the same room together. Because even if one person's speaking, you can still see people's physical reactions to what's being said. So the conversation is, is more complete, I suppose, when you're, you're in a room, if you'd asked me that before COVID whether I'd have been able to set those things, I don't know. But it's a sort of post COVID understanding of meeting on a face to face basis, I think. Thank you. It was You know, it's and, and you can have those the the conversations over coffee or lunch or whatever it is. And there's a sense of feeling as a public contributor, being taken care of. Because, you know, people provide you with refreshments and that, you know, people ask how you are and all those sorts of things on a one to one basis. So there's something about that, just meeting face to face that that that's listening to the speaker plus, he could understand the people's body language. So that's, that's.

Interviewer 10:35

Yeah, thank you very much. Anything, anything in particular that supported your involvement engagement at that time, before COVID?

Interviewer 10:47

Sorry, the video broke up, could you repeat?

Interviewer 10:49

Sorry I could feel that as well. Some moments are breaking up sometimes the video or something. So we'll see if any more difficulties, then maybe one of us will switch off the video? Sorry I would like to know uh, before COVID-19 anything was supporting, anything helped you to keep going with your PPI work, please? Anything in particular? Of course, you've been doing PPI work for 17 years.

Interviewee 11:32

Before COVID? [Yes, Yes]. Okay before, um, just just sent me this is my I had to give up my permanent job, which was part time job, because of my caring responsibilities. And what what doing PPI work does is give me an opportunity in a supportive environment to have something for me, and that stimulates my intellect. And so for me, that's really important. And so doing interesting things. And I've been able to pursue things that are of interest to me as well. So doing all the strategic stuff and the development stuff and things like the work and being involved with things like plain English summaries and stuff has been really interesting, since it's about the the sort of development of the process of being able to be involved in that nuts and bolts stuff has been really important to me, and really valuable in terms of my own personal well being and mental health. And, and the fact that the environment is really supportive. So everything I take on, I take on on the basis of I'm a carer, and life can be unpredictable. So I, you know, it's like living with a long term condition that can knock you down one day or not one day, and there are days when I just have to say, I'm really sorry, I can't be there. And having the understanding that that's okay and acceptable, which is different to being in a permanent job, there's only so much you can, you can play that card. I don't mean it like that, you know what I mean? So I think that's sort of the generally supportive environment and understanding of how difficult life can be at times. And the fact that I'm doing this stretches me intellectually, and in a way that nothing else can at the moment, my life doesn't allow for me to take a job that would involve that sort of intellectual stimulation.

Interviewer 13:49

Thank you very much. That's really interesting. You've been involved with academics government staff, so intellectually you have been supporting, helping you've been helping others as well. That's great. Did you find anything difficult, anything challenging about face to face working, please?

Interviewee 14:07

Yeah. I mean, as a parent can be really, I mean, you know, there's, there's always two sides to everything. And it's a really, it's like a mini break, sometimes again, to a panel meeting that's covering three days or two days, and I get to be away for two nights of that, that's, that's quite nice. But also it can be challenging. To do that when you're a carer so being away from home can be very difficult, especially. So he has to be able to then be present or we have to work out whether he can cope on his own if we're not going to be in the house for 24 hours or you know, for the day or whatever. And, and it's particularly difficult. Some ways the longer meetings the four day meetings were always easier but you know, short meetings, when you We're gonna be in xx for two hour meeting. And actually, for me, that's essentially the whole day gone. So it can be a very expensive trip out. And, you know, if you happen to go to xx or something, it's a long way to go for a short meeting. So some of those things were issues, really, although they they came with nice positives, as well, actually, that just pragmatically can be very difficult. And I'd say that was the biggest challenge. And I mean, it's hard now. But I guess right back at the beginning, there was probably some trepidation about going to meet things where you didn't really know who was going to be there. I mean, it doesn't really bother me these days. Because I there's always somebody I know when I saw I turn up. But and 17 years ago, Introduction to things was very different to what it is now. So, but those I think were the biggest challenges were that if you couldn't go sometimes that meant you couldn't attend, as well. And look, not everything had the possibility of remote sort of dial in via teleconference thing. But yeah, I think it's mainly the just the fact that sometimes practically, it was difficult to manage. And a short meeting could take all day, which was frustrating. So I think those are the biggest issues and you know, the trains were difficult or whatever that you know, that sort of practice, the practicalities of getting there. And being there were would be the biggest issues, I think.

Interviewer 16:48

Thank you very much. I am little curious about because you have been doing PPI work for a long time more than 17 years. So could I briefly ask you, when you joined 17 years ago was there was there anything in particular in your mind that influenced you to join PPI?

Interviewee 17:14

Thanks, yeah just it was it was completely and utterly by accident. So I was at home, I wasn't working. And I had, he must have been two or three hours, 20 hours so that it's that sort of length of time. And I responded to an email advert from the xxxx to help produce a leaflet. Because I just wanted something to do. And I thought, Oh, that sounds interesting. And it was trip to xxx once every couple of months or something to spend a day with, or cup a few hours with people. And they gave me vouchers, like a day out that somebody was paying for I thought, That's really interesting. That's the sort of thing that I used to do. So I got involved through that. And it was really interesting, somebody who organized that, that afterwards, she said, Oh, you might be really interested in this opportunity. And it was I think, almost just started and involving public members in panels, funding panels. And so I applied to this, and really had no idea what I was getting involved in at all. And that was my real that was. And so there were a few things that came up as a result of that. And it was just like this whole suddenly open doors, and it was like, What is all this? So it was really so I came in from a very different angle, a lot of people got involved all those years ago was because they'd had an experience with a particular condition like cancer or stroke or heart or something. And whereas I came at it very much from a public point of view, and I was involved in a number of xxx things for a while, but I very much came as a public member and it was completely by accident. And I just sort of fell into it. And then once you're sort of like once some, it's got you there's all these as one thing comes to an end something else comes up and I'm remember when I applied for the involve advisory group and after the interview Someone said to me, You The only person we didn't already know who applied for this, and I thought that was really telling us I don't think that would happen nowadays, which says something about how much it's made. So it was completely by accident, there was no, just purely looking for something to engage my brain. And then it opened various doors. So it was completely happened by accident.

Interviewer 20:23

Thank you very much for sharing this. Now we will move on to our current PPI work. So what PPI Are you taking part in at the moment? Since COVID-19 was started since last year?

Interviewee 20:39

So pretty much all the same stuffs carried on. So there's a lot of stuff stalled at the beginning, as people scramble to try and work out how to do it. And there was stuff I think that people weren't involved in. But I've done a lot of the COVID research, funding stuff through NIHR, but pretty much everything that was happening is continuing either COVID related or as things sort of, sort of bumbling along and carry on. So all the the sort of strategic leadership stuff has happened on and off during that period, and is sort of stabilized now. So pretty much the same stuff, I'd say slightly different focus from time to time, a lot of COVID research, a lot of COVID reading of application.

Interviewer 21:33

Thank you very much. So well, presumably there will be some differences. So anything in particular, you could share what is different and changed about PPI now please?

Interviewee 21:46

Well, how we do it? And so it's all virtual? And I haven't been to anything for Well, probably since March. I think I went to stuff in March last year, and certainly February. But other than that it's all over COVID chill and varying degrees of quality over time, as I'm sure you've experienced. And but yeah, so it's all and and I mean, it's really hard to say what what's different, I think beyond the fact that it's virtual. In some ways, it feels more robust, because people have to think about it so much more because it's new. And so in some ways it feels more robust. And because I think there was at the beginning of the COVID Research stuff, there was a sense that PPI was forgotten within COVID research. And, and so there's been a scramble to, I don't mean that in a negative way. But you know, there was a pushing up the gears to try and avoid that happening. And there's been a lot of conversation around that. And various things like the xxx and things that I've been to so there's been quite a lot of COVID related strategic stuff that's gone alongside the the COVID research funding stuff, as well, which has been quite interesting and is, as made people take a new look at how embedded is PPI really within the system, when it's the you know, you see, you'd see applications that we had to turn this around quickly. So there wasn't time to talk to anybody. And it's kind of like, well, you ppis either embedded and you've got people that you know, that you can go to and say would you have a look at this with us, or, or you're not that embedded really you're not developing the long term relationships with people where you have those, you know, in the same way that you would with other colleagues, whether they're, you know, economists or methodologists, or whatever. So, so I guess that's, that was a, that was a negative thing, but as maybe resulted in some positive stuff about how we change that going forwards. But the big changes obviously been that some stuffs stopped, or seems to, you don't always know what's happened to things you've been involved. As a result, I think sometimes communication isn't always great. And other stuffs ramped up because of it. And some stuff has been replaced by COVID related stuff. That's that's the agenda.

Interviewer 24:49

And it's in there anything was new for you. Any impact on your PPI involvement, please?

Interviewee 25:06

Well, I mean, all the all the zoom stuff, all the guests becoming familiar with new technology was all very new. And, and that was interesting. I think probably, and I think that was the the newest thing and using being more electronic focused. So everything has become electronic because people aren't, you know, I didn't really ever have paper sent to me if I'm had for years, I've had that it's all been done virtually but, but more more of that more, sort of working on Google platforms for editing documents and stuff like that. So meetings, I think it's meetings, not it's not funding panels, so much, but meetings where that's changed, where things that you're involved in, suddenly, you've gone from having paper copies that you annotate, and feedback on to everything's done on the Google platform. And it's all sort of done in that way. That's been quite new. That's, that's quite new for somebody who is not in, in a permanent job. And that's been quite, quite new, along with all the sorts of virtual working and via zoom and things like that. They're the they're the big new things, I think those ways of working, and all payment systems going online, and stuff like that. So so the mechanics of doing things remotely.

Interviewer 26:49

Great, thank you. So now, can I ask what access to resources you have available at home to do PPI work remotely?

Interviewee 27:01

I mean, we're really lucky we have we have various you know, we have iPads and stuff like that. I mean, our biggest issue, I can't remember. So I'm on the laptop that moment. And because we only have one PC in the house that we can use. And so I can't remember whether we'd got it before or after lockdown. Now, I think we must have had it before, but it would have been a problem if we hadn't had it. And because we have iPads and things, we have various different devices, whether it's phone, access to phone, iPad, laptop and a computer. And, you know, unlimited broadband. Yeah, and, but but with with reasonable Wi Fi, but we just become more had to become more robust to be able to manage to do this, particularly if there's three of us in the house or using the internet at the same time. But yeah, so we had, we had everything that we needed to be able to remotely work from the beginning, but we're in a very lucky situation.

Interviewee 28:14

Did you ever need Have you ever needed any support it support? While doing work remotely?

Interviewee 28:31

Um, well, I'm very lucky because I happen to live in a house with somebody who it is part of their job responsibility, and a son who's highly capable of it. So I usually have somebody who can help me. But right at the beginning, though, I mean, lots of people have provided really good, written guidance to how about how to use things like zoom, and stuff like that, I think the things where it would be really useful to have support or information about how to use things like the Google platform stuff where, you know, you're doing Google documents, that's all learn by trial and error, the zoom stuff, all the all the zoom. The thing that's been really good is guidance around how to use zoom. And that's been available where it's teams or Google stuff that's less readily available. People don't seem to provide us the the sorts of documents stuff on the Google, whatever it is, and that that's, that's not there. Technically, in terms of things like joining zoom calls and stuff. You either work it out by trial and error, or somebody here can help me or There's the you know, when there's written stuff that's been really helpful, or, you know, you can go and look at the online resources about these things. So I haven't really per se needed it. And because I usually have somebody here who can come on fix my problem.

Interviewer 30:22

Brilliant, so you didn't, you didn't need to contact any any organizational support or existence. You have you have support from your family members. Yeah. That's great. Thank you very much. Was there anything in particular that help your involvement and engagement during COVID-19.

Interviewee 30:41

So there's the written zoom guidance that I talked about stuff like that, it's been really helpful. And the, the lot of a number of the people that I do stuff with have changed their payment policy, to include a remote working fee fixed remote working fee for meetings, if you attend a meeting in plan, five pounds, or whatever it is, which I think really is really helped, because it doesn't make you worry about, you know, if I have to use my phone, if for some reason the Wi Fi was down, I can use my phone on 4g, and I'm not worrying about my day to day usage, stuff like that. And and I think those are the those are the the main things have been really helpful, I think. But yeah, and I think those are the main things is that sort of people have thought about accessibility, and they're available if you can't, so when, if if for some reason you're having difficulty, so most of the meetings I attend, there are what they call troubleshooters, who are available. So if people if you're having a problem, there's that sort of cushion of comfort zone and most people give you, you know, you there's the telephone contacts that you get if you for some reason, your zoom fails. So you can join by phone, often there's a help number, if for some reason you get checked out and you need some help. So there's lots of that sort of feels like there's a safety net if it goes wrong. So you're not worrying about what, right at the beginning, there's that bit of sort of what work what happens if I can't get in. Whereas as things have progressed, there's that safety net around you that I've never had to use it. But if I had to. I know there's somebody on the zoom call, I can message in the chat who can help me if I'm having a problem, or there's somebody I can call if I'm kicked out and I can't get back in that sort of thing. Yeah. So. So there's a lot of that put in place. And and I think just a sort of general acceptance that, you know, if you turn your video camera off, you're not being rude. Because your bandwidth is good enough, that sort of thing?

Interviewer 33:12

Yes, Yes, that's correct. Yeah. Thank you. So how do organizations and groups you are involved with? How do they communicate with you normally before a meeting or after a meeting during this time?

Interviewee 33:26

Email, email, mainly, which was probably not so different from before COVID. To be honest, I mean, we've had quite what we have done, they have done, particularly funding panels, is they've done quite a lot of pre meetings. So we might have an hour as the PPI, part of the meeting, the group people in the meeting who meet beforehand to talk about how it's going to work. So I missed that really that support thing around voting and stuff. They've been quite proactive about doing that, which you probably wouldn't have, if they were face to face meetings. And so they there's been quite a lot of that. But a lot of it's by email, and which would have been the case beforehand, a lot of written confirmation about what meetings there's going to be and when they are and the timings of them says a lot of that and about when to join and how to join, you always get the blurb about the zoom stuff, especially first time every time. But yeah, no, think about there was that the extra support that's been placed for those sorts of our briefing sessions for PPI people, so they understand how they're going to vote and stuff like that.

Interviewer 34:43

Thank you very much. So you mentioned earlier that you've got caring responsibilities for your son. So is there any support that you might require in relation to specific challenges you may be facing for example, physical or mental support during this time?

Interviewee 35:06

Um, I don't think so. I mean, I think for me always, um, compassion and patience are the most important things and tolerance and and, you know, people are always very good about how are you asking about how things are, and understanding that you might be interrupted because the disadvantage, of course of being at home, and is that he can come and burst in and knock on the door tension, which he can't, he can only try and do that by phone when I'm not actually at home. So that just sort of understanding that sometimes in a meeting, I may just turn the camera off and mute myself. Because that's the only thing I can do at that moment in time. So it's that it's that sort of it for me, in terms of my needs, I think other people maybe have found it different. I'm, my life hasn't changed greatly because of lockdown. Because I would say where I'm fairly home bound most of the time, which is why going to things was always a bit of a treat, because it it was easy to get out of the house, and was a reason to get out of the house rather. Whereas lockdown hasn't isn't particularly that hasn't got a particularly negative effect in our household. So it for me, it just continues to be the same thing. The support that I need is compassion and understanding. If for some reason I can't participate, but if he came now I might have to turn the video off and say, hang on a minute, I'll be back. And and that's that's for me is the most important thing, because that allows me to manage my mental health. Because if if I was in a situation where I was getting trotted out, because I had to, to just distance myself for a moment, that would be highly stressful.

Interviewer 37:17

Understandably, it’s for everybody with young children at home. Even on BBC news people appear with their children background.

Interviewee 37:31

Yeah, I agree. Yeah, and I think and I think that's absolutely right, because there is this sort of, you know, if it wasn't there before everyone sort of, you know, people got, you know, lots of meetings I've been on children appear, or dogs or cats or something. Yes. You can't control that. And, and so everyone, to some extent, has become more tolerant of other people's circumstances. And, you know, for me that that that will be the thing I would find stressful if that wasn't, and there are some things I haven't done. Because I say some of the stuff I do. I said, I don't think I can do that. So one of the things involves me as the lay rep, chairing the meeting, I said, I don't think I can do that. Because I can't guarantee that my son won't walk in and demand my attention. And I don't think that's fair on the candidate. And, and I said, I don't think that's fair on candidates that I might have to be distracted. Whereas other things where you're observing or your parts to them, you know, group in a meeting is easier to manage. So I've had to make some choices about that, about things that I feel it would be unreasonable for me to be involved in because I can't control and people and people have been understanding about that. So that's it as well.

Interviewer 38:59

Yes. Thank you very much. So was there anything in particular that made it more difficult for you to get involved?

Interviewee 39:08

Apart from I mean, some of those things, I guess I've talked about that. It can be it's not a charger for my son to understand where the boundaries are, because I'm at home, and I'm accessible when I'm at home. And, and although I'm contactable when I'm not at home, I can ignore the phone. And until I can do that, so that that can be a challenge. I think it's also it's difficult sometimes not seeing other people in the real way. You know, there's there's lots of positive things about doing it virtually. But there are some things that make it difficult to engage with new stuff because you don't know anybody. I don't think there has been any real Barriers to, to being able to do stuff apart from what I've talked about about things where I just felt I chairing something wouldn't be difficult, more more of a challenge than just being a participant in something sitting around a table.

Interviewer 40:17

Thank you very much. So you mentioned some positive groups could you please share some positive experiences if you have any about doing things remotely during this time.

Interviewee 40:25

So it's much more accessible for me, I don't have to because my, because of my son's needs, I don't have to arrange for somebody else to be here, I don't have to think about somebody else providing food for him which it because so the difficulties normally are that we have to think about how we feed him when I'm not here, because it's very, very difficult. I'm the only one here let cook for him. So that's really channel prepare food for him. So it's very challenging, if I'm not here for a day or over mealtimes and things. And you make, we make choices about you know, what's right, and what's wrong to do. So being present in the house for meetings is a real positive, because that's easier to manage. And it's so much easier if it's a two hour meeting, to do it from home. Because the without not having to travel on the same third day meetings because meeting started. So I have a very clear rule that I don't get up early to go to my mental health is I woke up at five o'clock or six o'clock in the morning to get something. So something starts at nine o'clock, or even 930 or 10, in xxx and I go the night before. So travel, not having the travel makes life much easier. To be perfectly honest, I miss the opportunity to be away, but not having to travel is much, much easier. And I think so I've been involved, I'm involved in some global health funding streams. And they're they mean, not for me, but for everybody else, they must be easier to organize apart from some of the ropey internet that not least in the UK, and and various places that that can be a challenge, I guess. But But yeah, I think the biggest bonus is being at home is makes a lot carrying easier. And not having the travel is a huge bonus and not having to travel for very short meetings that then take all day. So I have more of my own time to myself,

Interviewer 42:57

Thank you very much for this very interesting conversation, you know, I’m looking into the time but you know, by you have so many things to share which is very interesting. So, I think this would be last question. So could you please share that what could have been done differently? If there is any, any limitations? What could have been done differently in better ways? During this time?

Interviewee 43:26

I don't know really. Because I think actually, people have responded really well to this. I mean, when I think about some of the some of the one of the global health things I was in, I've been involved in for some time. They tried to do remote and pre meeting thing with people from all over the globe. Before COVID and it was awful, it was just awful when I think about that experience, and some of the teleconference experiences where I've dialed into things or other people have dived in and you can hear them and then you can't hear them and then they've gone and the those things that have sit in the middle of meetings that we went and you go from that to there so we're not really talking a year in the year pre COVID to where we're now I mean Crikey. So much people you know, it's it's incredible how people have and even from right from the beginning, you know, when things changed in March last year, and people using Google Platform stuff and and there were teething problems people didn't understand about having been muted when we're talking and and while somebody else was talking and stuff like that. And people didn't know how to get in and people would disappear. And, um, we've learned together as a community, I think about how to do this. I mean, they're always going to be things that could be done better. But it's not. It's not, not for not trying. So I don't, I don't really know, I think there could be more information or when people use teams or the Google platform stuff, having some guidance on that I would really really love somebody to produce some simple, you know, like Idiot's Guide to how to use the Google Docs kind of, and stuff for me, you know, commenting on papers and stuff like that, because that's, that's been the heart that I'd say, that's the hardest thing is, is using all and, you know, something came up the other day jam boards, I mean, I've no idea what the hell's a jam board. I mean, I can work out because I'm not stupid, but I wish there were, um, you know, you can go off and you can find, you know, online, helpful resources and things. But actually, I'm not motivated to do it. I think I'm not, I can use technology. And I have people who can support me to do that. But they don't know all these other things that suddenly appear. And I'm not particularly I'm not particularly interested in tech and stuff like that. I just like things I'm familiar with. So so I think more guidance on some of those interactive things, and how to use how to, to do comments on a Google document and things because that, that always feels a little bit longer than if I'm doing this right. But goodness knows what happens if I do this. And, and just knowing telling people that they have to change the thing about whether it's commenting, or whether you're actually changing stuff live, that happens a lot, you know, I find I've changed a lot. And didn't really know because I have to change the little thing. So things like it's that's what could be done better. I think it's how you how you participate in that way, because that's quite that I think that's difficult if you don't use it every day. And it's difficult, depending on what what platform you use, whether you've got an A, you know, an iPad, or phone, or a laptop, or, you know, an apple rather than a PC and stuff like that, though, it's all different. And some some deep somebody could you produce some basic guidance on that it was the thing that made so lot of I don't know if you know, but people like net cc and cc, line management information system platforms. And right back at the very beginning of being involved, when they started using the online platforms.

Interviewer 47:51

Brilliant, great…so you er uh.

Interviewee 47:51

If you were downloading documents, very difficult to download documents from an iPad, because all the instructions were were for PC is basically and full of money, I couldn't make it happen. And they produce guidance on it eventually, cuz I kept saying, I don't know how to do this, I cannot download Doc, and then they you know, in the worlds move forward. So it's much easier to do. But you needed to have file managers and things like that, and apps and stuff on your iPad. And it was only once somebody produced that somebody went away and found fell. So foolproof way to do it, that it was possible. And I hink that's the same things like the Google Doc, and stuff like that, that there needs to be some guidance, you're gonna use those sorts of tools and resources to get sort of that interaction and sort of interactive thing going on, then you need to really help people who for a lot of us, we know where we don't do this in our day to day lives in our jobs. And we don't have opportunities to learn how to use these things. And just some kind of written got a better while probably written webinars, you know, training sessions, whatever it is something around how to use some of these online tools, because they're just,

Interviewer 49:11

yeah, just general.

Interviewee 49:12

That’s really hard to use.

Interviewer 49:14

Thank you very much. That's brilliant. What do you have been sharing? Actually, we have a plan in this project, they have a plan that by the end of this project will produce a how to guide the information you share. So for for people who are involved in ppl work for them. There they will be preparing a how to guide so how to do this then. So that's the interview you share. That's very helpful. Thank you very much. So my final question would be just before we finish, is there anything that I have not asked you? Would you like to add anything on top of that, please?

Interviewee 49:52

I don't think so. I think you've been very thorough. I mean, we've covered the good, the bad and the ugly as it were. I mean, it just I just like to say generally, I think I think there's been quite a lot of negativity, some points around PPI, or during COVID, that's maybe been overshadowed in some ways by the fact that COVID research hasn't always involved patients, but actually, I've found most people to be very responsive and looked for ways to ensure ongoing engagement. And that hasn't didn't happen brilliantly in the first three to six months, because everybody was on a really steep learning curve. But actually, a lot of the stuff I've been involved in, people have been absolutely brilliant. They've all learned new technologies and new ways of working, we've all done it together. And, you know, I think it's been absolutely brilliant. As always, the biggest issue is there's not consistency across the piece in the way that it's done. But I've certainly learned to say, Well, you know, what, this is what NIHR was doing this is what central engagement and development, dissemination of, here's their new payment policy, why don't you look at that sort of thing. So it's, um, it's been really positive. And I think the other thing that's really positive that's come out of all the remote working is the capacity and ability for people to be involved in things when it's not in their region, their geographical area, because there's a lot of stuff that goes on in the past that's been artificially about people who can get involved having to be in London, or having to be in Oxford, or having to be in Liverpool or wherever it is. Whereas now because of remote working, suddenly, that's not the case. The people who get involved can be can live anywhere, because it remotely. So I think that's, you know, people have found that not just within the UK, but you hear about it, you know, people getting involved and stuff in Europe, or in Canada, or the states or Australia or whatever. So there's suddenly the it's like the borders have opened a lot with borders, shutting, the PPR borders are open, because suddenly it's possible to be involved across, you know, regions, counties, states, countries, whatever it is. So that's been a real positive, I think.

Interviewer 52:18

Thank you very much. Thank you. That's really great. To hear all your thoughts, and you know, ideas. That would be really helpful. Would you like to see the report when we finish? Yeah, yeah. Okay. So then. Thank you.