Interview 3

Interviewer

I think you'd have a pop-up message about giving permission for recording this meeting.

Interviewee

I am about to tick the box, saying I'm happy for the meeting to be recorded. There we go.

Interviewer

Okay, thank you very much. As you have already read the participant information sheets, so I don't need to tell you more about the study? [no ready to go]. Thank you. So first of all, I would like to ask you, if you could please kindly share. Could I start first stray by asking you to tell me about any PPIE work you were involved in prior to covid-19, what PPI you were doing before COVID-19 please?

Interviewee

Well, I've done a lot, because I've been doing this now since xxx. My main role in patient and public involvement has always been various, various roles within the xxx. and then I've sat on various research groups committees, I have worked on individual trial studies, mostly xxxx, but I've also been doing one I was chair of a steering committee and are funded study on mental health users and their satisfaction with inpatient care. And whether or not today we're actually recording their real feelings on patient satisfaction surveys while they were in patients, because of course, most of them wanted to get out. So there's all sorts of issues around that. And did their satisfaction surveys actually do anything to improve or change their care in any way? So it's been mostly xxxx, really interested in research into patient and public involvement, various ways in which we might measure whether or not we're adding quality, and if so what quality are we adding? And is adding value? or adding quality, a better description than having an impact? Because if we want to have an impact, it's too easy for PPI people to say no to something. It's much harder to say, Well, yes, but do it this way. That's actually much harder. So I'm really interested in that quality of life, because I've been a cancer survivor for 20 years. Now, that really interests me, because most of the quality of life measures we use, were designed when people did not survive cancer, certainly not for 10, 15, 20 years. So there's all sorts of things I've been involved.

Interviewer

It's amazing. It's very interesting, you know, it's fascinating stuff you have been doing and you have been helping is like, is like you are helping a patient. It will be helpful for any patients that you are experiencing from comorbidities, multi morbidities, like heart failure, cancer, so and so it will be worthwhile to hear your story and your experiences.

Interviewee

Like many patient advocates, too, it's a mixed bag. It's it's particular studies. But there's also regional groups, national groups. In my case, there's also working in research but occasionally touching on service delivery, and occasionally moving from being patient public involvement in research to actually patient advocacy. So for example, during the Brexit process, and also during the passage of GDPR

Interviewer

And you've been doing internationally as well.

Interviewee 4:18

yes, yes, I've been involved in a couple of projects with with xxx.

Interviewer 05:49

Very interesting, so how do you do PPI before COVID-19? Face to face meetings teleconference, and

Interviewee 05:56

Well, that that's the interesting one, because in the UK, we tend to we do like face to face stuff. And it is a small island, though, we always protest about long train journeys of two hours or more, you know, actually, there are people who commute that distance. So face to face meetings were really popular. And I like them personally, I'm really, really like them. Because you can touch people, you can have the little asides. You can have the chats it typing things in a chatroom online is not the same. But for it face to face, it's still important, especially if you don't actually know people that well, it's still important. But but obviously for the distance involved and make the logistics, they are fewer and far between. So I've always been used to doing things online, I remember when Skype was a novelty. Before we had zoom and teams and everything else Google meets me. So it does depend. And we also use the phone each other a lot. And of course, when you do the phone, it's FaceTime. So patient advocates, I think those of us who have fingers in lots of pies, as well as professional researchers, we were used to working online, I think what's changed is the extent and the fact that we simply don't meet face to face full stop.

Interviewer 07:49

Okay, so were you supposed to go there for PPI?

Interviewee 07:52

If Oh, yes, because it's not it's not just meetings. A lot of it is you arrange to meet people at conferences. So if you have something, that's a six day conference, but built into that are loads of people meeting up to talking about starting studies, studies, they're already running, you arrange your meetings around the conference. But of course, all that has now stopped.

Interviewer 08:26

That's just just to go there as a face to face meeting public contributor.

Interviewee 08:46

What what what has been lost, I think, is the bright ideas that come out of the chance encounters.

Interviewer 08:56

Great, okay, we'll talk about that in just a moment little next part. B, please. I will be very interested to hear that. So how do you feel it? How do you already you have already touched one that so how do you feel about your contribution PPI a contribution you're doing over the years? You've been doing for a long time? I have

Interviewee 09:19

Haha Yeah. Well, I would like to think it's been useful. You know, people keep asking me to do more things. So I'm assuming it's useful. There are one or two things I do occasionally like to think about thinking well because one of the problems with stem cell harvest is that people were waiting till the chemotherapy course had finished, and then finding out if the cancer is still there or not. So one third of the people having them didn't survive, you know, if you if you can predict whether or not the chemotherapy is going to work after one or two cycles, that that helps everybody. And that is now standard, wherever there are PET scan, pet scanners available. It's really popular in Belgium, which has more pet scanners per head of population than anybody else. It's amazing the things you find out doing this stuff. So I can actually point to to changes in medical practice thinking, Well, I didn't do that. But I was part of building the evidence base. I helped, that I helped. I helped promote the study, I helped recruit people in that way, I helped write some of the information, I helped in the discussions about how often you should be doing this, about the inclusion exclusion criteria, all that kind of stuff. I was part of the conversation. And I'm sure that that's the kind of thing where I don't know how much my views shaped things. But nevertheless, I was in the room, part of the conversation

Interviewer 11:27

Brilliant, you’ve made great contribution, you did a lot, I'm sure because you said you are the 6th person,

Interviewee 11:30

But then then a few years later, I actually sat on a trial management committee, looking at the evidence I had helped provide. And then actually taking it to, which has now become clinical practice. It's like, I always use sporting analogies are afraid, because that's how I used to play team sports. But But for me, it's like being part of a rugby team, where I haven't scored any points myself. I didn't make any game saving tackles. But every now and then I got the ball. I gave it to someone in my own team. And at the end of the day, my team has won. And I was part of that team. Of course. Yes.

Interviewer 12:16

That's great. Thank you very much. And so what did you enjoy the most about face to face working? Please?

Interviewee 12:26

It's just meeting people. It's it's the odd jokes. It's the hideous it's human contact. In terms of my colleagues, my fellow PPI people, if I can call them that patient advocates, it's the handshakes, it's the hugs. It's just knowing that people are still doing okay, because most of us come into this because we have something wrong with us. Yeah, we've we've either had an illness, or a bereavement, or both. And some of us are still having treatment for whatever the condition was often the late effects. So that's, that's it. It's also the sparks, as I mentioned a little bit earlier, even in professional meetings, talking with professionals, or talking with patient advocates, in other diseases from other countries at conferences. It's just having chats, while you're in the coffee queue, or while you're getting your lunch. And somebody says something and you just think, Oh, I was talking about that with somebody else. And suddenly there's an idea going, you know, have you have you thought, is there a website that shows this? Have you talked to so and so, I was doing a study on this last year, and we're about to publish, and it's that kind of stuff. And it's it's the bright ideas that come up from the casual conversations.

Interviewer 13:48

So meeting people because of the casual conversations and anything about traveling.

Interviewee 13:56

Personally, I I, yeah, I'm, I'm okay with traveling. There are many people who aren't because especially if they have to get home because they, they're caring for someone else, or because they've got kids. Or of course, some people are trying to hold down a day job. I'm perfectly okay with traveling. I actually enjoy now going to other cities, especially especially in Europe, I usually add a day or two to my journey to actually go and see places. So I, I quite enjoy the traveling. I find that time spent on a train or on an aircraft. That's the time you can read and think and make the odd notes and catch up on stuff. I'm afraid but you can always use the time as long as you can get a Wi Fi signal.

Interviewer 14:55

Okay, thank you. So anything difficult, challenging about face to face PPI working? Anything that anything challenging while you are doing face to face meeting?

Interviewee 15:06

I think, yes. But it's often it's often it's often a challenge that comes online as well. I think one of the challenges about face to face working is that it's, it's easier to see body language and to interpret or possibly misinterpreted. So it's easier, for example, to join in a meeting face to face around a table. Because you can just lean forward and catch the chairs eye. If it's online, you have to make sure your button is working to actually raise your hand, and then it doesn't work. And you press it again. And it was about to switch on. And now you've just switched it off, even though you didn't know that these are personal things. Also, of course, it's not easy to see at a glance who else is waiting to speak. So I think in terms of chairing, or in terms of timing, your own intervention, which sounds really cynical, and but it's not, it's true. Sometimes the conversation moves on before you can make your point. So it but but it's easier, I think to make an intervention face to face, but same time to it's easier to read or miss read people's body language.

Interview 16:19

Sorry missing body body languages… is it difficult online or face to face you mean?

Interviewee 16:26

I think it's easier to miss read people face to face easier. Yeah, easier, easy to miss read people. And sometimes people will frown and fold their arms. And you think while you're talking and you think oh, they they disagree with what I'm saying. In fact, in fact, they've just realized that it's another half an hour before the tea break. Okay, whereas all online, you might see the facial expression, but you can't see the arms folded. And also, it's hard, it's harder to tell who's not listening and catching up with their emails. Whereas in a room you can, so that the big disadvantage of face to face is that you have to get there. So that's the disadvantage.

Interviewer 17:12

That's very interesting viewpoint and made and it's very tricky. When you said in face to face, you can see the hands moving on there. Yes. But in online meeting, you can he can we cannot see the hands. So is it like we are missing out something that What? What is going on in underneath the screen? Maybe?

Interviewee 17:35

Yes, yes, I think I think it can be both advantage and disadvantage for for someone like me online is a disadvantage. Because I do tend to I mean, you can see it now I am actually using my hands even if you can't see them, I see you're waving around all over the place and making points like this, but you can't see that. So for me personally, it's a disadvantage. For someone watching, it might actually be an advantage because there's less, there's less wavy distractions. But I think the big disadvantage of face to face meetings is simply the logistics. It's for the organizers trying to arrange it, but it's also for the rest of us just getting there. And in particular, that can be a real hassle for researchers, of course, but also patient advocates who have some sort of disability, no face to face stuff can be a real issue. And one of the advantages of the way we've been working in the past year is that it has in my opinion, it's allowed us to hear voices from people that we certainly hear less often if we've ever heard at all.

Interviewer 18:45

Thank you. Thank you. It's very thought provoking. Very interesting. So now we will move on to our current pandemic situation current PPI you are. So what PPI Are you taking part at the moment?

Interviewee 19:01

Oh, loads of stuff. Much of what I'm doing now is is increasingly in the world of data, and making better use of what we know, especially in the UK, where we have the NHS and we have comprehensive records, if only we could get them recorded in the same way and can get computer systems talk to each other, and can get ethical and regulatory approval to share the data. But assuming we could do all of that. It's a goldmine. But then there's also the use of data in the sense of how do you capture it industry are really interested at the moment in digital stuff for patients where you know, where whether it's Fitbit apps or whatever, but patient reported outcomes, patient reported experiences where we actually report stuff in real time as opposed to waiting around. A week or two weeks till the next appointment with the clinician when either we forgotten it. Or we may well tell fibs tell lies about how bad it was. Because we've got, say, and what we actually want is the next dose of the drugs. So we don't reveal the bad time we had last week, we want the next dose. So that there's there's that side of data, then there's also of course, artificial intelligence, you know, and actually, what could we use with really big, big data. And I think we're only just exploring that, especially in terms of predictions. But then other forms of data like risk assessment, if that's not just important for the individual, that's got to be increasingly important for the health service, you've only got to look at how, certainly in this country, we've carved up the groups, the priority groups for getting the vaccine that is all based on use of health records, and then putting it through systems with with algorithms to predict who's going to get the stuff.

Interviewer 21:00

That's very interesting. So what is different now about PPI work now? Do you think that your work has been increased since COVID-19?

Interviewee 21:10

Oh yeah, my work personally, has increased enormously over the past 12 months. And I'm not actually doing a lot of ppi or PPA in terms of COVID I'm actually a participant in three different studies, that it's all about psychological impact, because I don't have the virus and haven't had it, don't want it.

Interviewer 21:36

Is that study?

Interviewee 21:40

No, they're not trials, they are ones a really big study. And we started doing weekly surveys. And it's basically around around mental health, around physical health around what activities we're doing. About, do you feel you are complying or less compliant? How are you spending your time? What are you watching on TV? Is it COVID news? Or is it escape his stuff?

Interviewer 22:08

Of course that has that has increased your work because of the COVID situation. If there was no COVID, there would be no studies.

Interviewee 22:16

well know that that's true that there's there's a lot more research into how people are feeling now that we have something that does affect us as a nation. That that is slightly annoying, because we know that 50% of us will get a cancer at some point in our lives, so to say, and COVID hasn't hit anywhere near 50%. And it won't. But we are panicking. [Yes]. And cancer still kills people, kills more people and COVID is killing even with the current death rate

Interviewer 22:51

Yes, you’re right. Have you felt any other differences or changes about PPI other than those you have mentioned already, please?

Interviewee 22:59

Yes, yes, I think what we have lost is a lot of the connectivity between patient advocates. Because we're now also busy with our own lives, of course, I mean, many of us are shielding, we have worries about relatives and so on. But also, because we don't have the face to face meetings, we don't have the opportunity for the catch up chats. Which actually builds half an hour chat time into its online meetings. So we can keep up to date with what each other up to. But but that's still it's only 30 minutes, and it's online and it that cannot replace sitting, sitting grabbing a couple of people saying let's go and have lunch over there. And let's talk about this. And that's that we have lost. So I think there is there is actually more PPI now than there was 12 months ago. And certainly more people doing it now. But it's much more fragmented. And after, after all, this is over and we get back to normal. One of the gaps will be who is going to try to bring it all back together again. There's research researchers talk to each other. They have conferences, they have strategic bodies, there isn't a strategic body pulling together patient involvement. There isn't a national conference for patient involvement. We used to have them but obviously there's there's funding issues, all sorts of problems.

Interviewer 24:32

This is very important point that you’ve made that once it is over the pandemic, who will be you know, just acting as a leader that bring all the people together again, it will be a big challenge you think?

Interviewee 24:49

So they could do it for cancer. The NIHR has a brand new dissemination and Engagement Center, they could actually do it, certainly for all the people working for the NIHR, but that might actually increase the fragmentation and it so we don't have involved anymore that that's, I mean, it still exists, but it's not the it's not in the same format. Plus, Scots and Northern Irish have their own different ways of doing things. They have their own different regulatory systems, they have their own different PPI setups, they're actually really good at it in Northern Ireland. But most of their research funders over there do not pay their advocates, whereas in England, certainly the NIHR does. So there's there's real differences it regionally or nationally, if you can say that, then in Wales, they have their own way of doing things within what are basically the English rules only You mustn't say that anywhere near someone from Wales. But it's it's, it's, yeah, it's going to be really interesting. I think what what we actually need is people to pull it together in their own area. So I don't think there will be one national organization or one national leader. I mean, even where there are national groups like the patient forum. I can't remember what they call but there is a national, the patient's Association. That's it. There is so there is a national patients Association. But they don't act. They are a lobbying force. Not and they don't work in research.

Interviewee 26:49

Other work to do? Yeah. So is there anything new for you? any impact on PPI involvement engagement because of COVID-19?

Interviewee 27:01

Oh, well, I think yes. What has been new for me, as I mentioned earlier, it has been talking with and listening to people and groups that we used to have a phrase called hard to reach. I mean, we knew where they lived, they weren't hard to reach. So I think it's hard to

Interviewer 27:34

Yes there is some controversy about this term, it's hard to reach.

Interviewee 27:37

Yeah, no, I prefer hard to hear. And actually, of course, sometimes they're hard to hear, because they don't want to say anything. And actually, could you have a screening program that isn't based on PSA testing, we want something that's a bit more reliable without using physical biopsies. But one of the things that came out of that was that one of the highest risk groups is his middle aged males of West Indian descent. And one of the reasons behind that is not they're more prone to prostate cancer, they just, they just don't report the symptoms to their doctors. And it's a cultural thing. And that's not the only example. But it's the one that comes to my mind immediately. But now, because we do things online, and people don't have to turn up to meetings, and they can actually block their video. You know, there are people joining in meetings with physical disabilities, who wouldn't have been able to get to meetings before, even if they were, even if they weren't accessible. They just can't be bothered with all the travel hassles. And I don't blame them. But also people, people joining who would be most unlikely to speak in a face to face meeting because they're shy. But actually, you give them the online opportunity. And if you know they're there, you can ask them to speak and they make a contribution online, where actually if you ask them to speak in a meeting, they probably just turn away and not now, not now. But actually. So I think one of the things that has changed is that the online stuff gives us the opportunity to talk with colleagues that you I wouldn't normally talk with. And of course there are other groups arguing that they're disadvantaged because they live in xxx, and they can't get the Wi Fi connection. And the Wi Fi was rubbish. We have now definitely become dependent on the internet and Wi Fi.

Interviewer 29:44

Thank you! So could you please now share something about your access to resources for PPI remote working?

Interviewee 29:53

Oh, yes. Is there a follow up to the question before I interrupted you or was that it not? No, no, no, it's okay. I can I'm a reasonably literate person.

Interviewer 30:10

Yes, I can imagine, you are a very intelligent person. I can learn many things from you while you're talking. So I could

Interviewee 30:16

Thank you! I know about PubMed, know how to use search terms if I'm looking in a journal and things like that. So too many experienced patient advocates. What most of us do miss is the ability to access resources that are behind paywalls because we do not have University subscriptions to the journals. And that's that that's nothing to do with COVID or the current situation, that has been the case for donkey's years. And that is a real disadvantage. And it's one of the reasons why patient advocates often will argue against publishing behind a paywall. That is it is actually keeping knowledge secret. And the patients who joined that clinical study, assuming it's a clinical trial, they did that so that their knowledge would benefit patients everywhere. And if you're publishing the paper behind a paywall, that is not happening, or it's certainly not happening fast enough, and it's wrong. And I'm glad you're recording this. It's morally wrong in this day.

Interviewer 31:20

Thank you! That’s a very important point. You’re right and we can see open access journal articles are growing you will see day by day is more open access paper.

Interviewee 31:39

I agree. The Journal of Research involvement and engagement, it is the only academic health journal in the world that specializes in looking at PPI II. That is that is not only open access, and has been since it was started, that has a patient co editor in chief with editorial control. So the only Health journal in the world that has that it has patients as reviewers, their reviews are on an equal basis with the academics also review. Every submission not just every published paper, every submission has to have a plain language summary. And when they're published, the plain language summary is on page one.

Interviewer 32:22

That’s great. Thank you.

Interviewee 32:27

Yeah, It's very that's a patient led journal leading the way. I can't remember what your question was now.

Interviewer 32:32

No problem, some what facilities access you have at home at your home?

Interviewee 32:37

I have I have a PC. I have a laptop. I have a tablet, and I have a smartphone. And at any given time, three out of four of them are working. Okay.

Interviewer 32:51

Thank you. You have of course you have it. I'm sure you have Wi Fi as well at home.

Interviewee 32:55

Oh, yes, yes, sorry. Yes, I do. I do have Wi Fi. I also have a a dongle for when I'm sitting on trains, because my final trains never works. So I mean, yes, I have deliberately kitted myself up, but all of that was before COVID. Now it's some of it. Some of it beforehand was just in case or as and when I need it. Now it's daily. It is every day

Interviewer 34:25

Thank you very much. That's very interesting. Did you ever receive any support from anywhere from your organization? Any IT team support for your equipments?

Interviewee 34:40

Some well not not not technical support. I occasionally receive some simple plain English instructions on which button to press which which personally I find helpful. I have all this it. I know how to make it work. Whether that's the right or the wrong way. I don't know. I know how to make it work. on my machine, and that'll do me. So I don't have any IT support like that. I like like most patient advocates in the UK, I am paid differing amounts by different institutions for different pieces of work that I do, or I'm not paid at all. There are, there are one or two people who do this to make money and good luck to them. But most of us don't.

Interviewer 35:29

Yes, so. So thank you very much for your contribution.

Interviewee 35:40

Yeah, I repeat, people who do to make money are usually spending four days a week working for the xx are 150 pounds a day. And and others, of course, have contracts with industry. And there's nothing wrong in any of that they're all doing good jobs.

Interviewer 35:55

That’s very interesting, brilliant. But I’m thinking about our time. Are you okay with another 10 or 15 minutes?

Interviewee 36:07

Absolutely. I’m okay with time. I'm worried that you've only done six questions out to 32 or something?

Interviewer 36:15

No, no. ha ha. How do you know it's 32 Question? I don't have that many questions, I just say, No, we don't have you're talking about it based on the survey?

Interviewee 36:23

No, I was I was just guessing I was? Well, I don't know. I don't know,

Interviewer 36:25

No we don't have that many question. It's just not 32.

Interviewee 36:31

I meant my warning earlier, I do tend to keep talking until you start my brain just my brain just triggers up. Oh,

Interviewer 36:38

That’s great that you’ve got oh, my God, you have so many things to share. And that will help our research and everything is there. So now Could you please tell us? Is there anything like any particular influence that help your involvement in PPI during this COVID-19 anything was influential for you.

Interviewee 37:02

during COVID? [yes] No, there's there's been no external influence. Internally, I've decided that when I am on online meetings, I will make a point like I'm doing to you now with my face, and maybe the finger waving and verbally. And then if it doesn't get across, or if people raise other points, which I think are going off track, I will then make a follow up comment, but I do it in the chat. Because I think people's time on screen, you know, we should all be careful not to dominate. Whereas if it was in a face to face meeting, if this comes back to body language, if it's in a face to face meeting, I might well actually lean forward and get a bit more physically assertive, and make the point again, but of course, there's there's no written chat in face to face meetings, you know, you don't pass pieces of paper around like you do online. It's kind of like online, you almost have two meetings at once or two conversations at once. But that's that's personal. And that's just I think that's making best use of what you have available. I do worry about some of the online meetings, that where people come off mute, to speak, and then they stay off mute. And then you end up with six people talking at once. And in my experience face to face again, that stops or it doesn't start, but it certainly stops more quickly than it does online. It's a perhaps it's down to good chairing, but actually I think it's not it's our behaviors. Sorry, again, I've lost what the question was.

Interviewer 38:50

No, no that’s great, So that's the confidence in using IT systems, which was, you know, for remote working? Oh, yeah,

Interviewee 39:00

my, my biggest problem is actually I have a laptop, which the keyboard in the systems and the Wi Fi are not as responsive as I want them to be. And like like many other people, researchers as well. You know, you press the button to speak. And someone at the other line, you're still on mute. Know that you have to wait for the thing to damn well change.

Interviewee 39:29

So you feel do you feel that you are okay with your IT skills? I think you mentioned earlier that you are quite skilled in using technology. So there's no problem with that. That

Interviewer 39:38

I'm okay with the basics. It has been a learning curve. No doubt about it, but because because I don't have a day job if you like because I am doing this every day including weekends. It was a steep learning curve but a rapid one.

Interviewer 39:54

How do organisations/groups you are involved with communicate with you at the current time?

Interviewee 40:21

Well, I that that's interesting because I don't think I don't think they've changed some of the big behavior. So there are some organizations which are very good at engaging involving people. They've been doing it a long time, they've adjusted to these methods, they've adjusted to online and working from home, and others don't do it. And the important thing for me as a patient advocate is not is the meeting face to face? Or is it online, you know, many of us can now cope with both. What's important is that whatever you want me to do, you set out the timescale. And you set out what the remuneration is, if any, you've set out deadlines. So I've had a proposal actually, that came in last night, which clearly says, and it will be February, March and April. And in February, it will be two to three hours worth of reading. In March, it will be a four hour online meeting date to be arranged, but it'll be morning or afternoon, it won't span lunch, morning, or afternoon for hours. And then in April, there will be another two, three hours reading and writing, you'll be expected to do a 500 word summary. And for me, that's brilliant. I may not know anything about the topic, but I know exactly what it is they want me to do. And I've got a pretty good idea of when I don't know the exact days yet. The meeting fitting the meeting in the diary might be a problem. But can I find three or four hours to read in February? Yes. Can I find three or four hours to read in writing in April? Yes. So I know in advance exactly what the time commitment is, I know what the remuneration is going to be. That's really helpful. Other people, we'd like you to come and sit on this committee, we're planning to meet fairly soon. It might be online, it might be in person. It's an advisory committee about this topic. Are you interested? To which my reply is? Well, you know, yes, I'm interested. That's why you contacted me know that. But I need a bit more detail. So I just, I'm not sure. I can't speak as someone who is really new to this, I do know that the people like xxx which I always come back to, they are really good at recruiting and supporting new people, they give two days of training to people when they're first joining. In my situation, I'm always happy if someone offers me training. But I actually spend more time giving training than I do receiving it now.

Interviewer 43:09

So any any support you might require in relation to specific challenges you may be facing, for example, physical or mental abilities, or reduced physical or mental abilities that now

Interviewee 43:24

I'm very, I'm very, very, very, very lucky. My, my health problems don't get in the way Fingers crossed of what I'm doing. It's so So no, I'm, I'm okay with support. If we're talking about face to face, I'm still physically capable of carrying my own luggage getting in and out of cars on a date, you know, all the basic stuff, which which makes people smile, and I say, so. The biggest support I get and, and this is where I look for, not not mental support, but where it's nice to have a chat is my colleagues, it's other patient advocates, especially those like me who are doing it full time. Because they know how weird this life actually is. But but but but great fun and really rewarding.

Interviewer 44:18

So when you earlier when you said when organization contacted you for many opportunities, and when when you ask them, I need more details, anything. So did you always get the support that you asked for?

Interviewee 44:35

No. No, I'm it ironically, in some respects, you're given now of doing this in academic research, I actually find the industry are a lot better. They're a lot more specific about what it exactly they want you to do, how many hours it takes, partly of course because that's how they draw up contracts for paying you so do find industry is better at that academics. academics are much vaguer. Don't wanna get into cliches, some are good. But again, it does vary. If they've been doing it a long time, and they know what they're doing. That's fine. I think to the problem also goes the other way. People like myself, when you are new to this, you actually don't know what questions to ask and what what you should be told. I don't mean moral imperative, I just mean, common sense. So it is a two way thing. And they're also well, the problems we have in the UK now is so many funders, you know, having patient and public involvement engagement in your research project is a requirement of getting funding. But nobody asks what value it's adding is that the standards of how you involve people, the NIHR has produced it standards, and they are excellent. But no one is actually measuring outcome, which is the value that patient involvement adds. So we actually don't know where we're supposed to be going. We turn up to focus groups thinking, I saw, I spoke twice, and I've got my 10 pound Amazon voucher that that's a good day, or at the other end of the scale, you get people like me saying, for goodness sake, let us have a decision, there is 3 million pounds at stake. If we do not commit that money this year, it's not going to be available next year, that different ends of the scale.

Interviewer 46:34

So you want to see more value for your contribution.

Interviewee 46:38

I would like to see more assessment of the value, I would like to see more evaluation of value. But why do we have patients from public involvement? Yeah, there are there are those who argue that the research is supposed to benefit the public. So the public should be involved in research, the research is funded by public money. So the public should be involved in decisions about where that money is going. The research needs to recruit members of the public when they become ill or not in the case of screening or whatever. So the public should be involved. The research question needs to be relevant to the public. So the public should be involved. All of those are perfectly legitimate reasons. But depending on which one you think is the most important does point you in a particular direction. So if you think that the public must be involved, then all you're going to check is did you involve members of the public take? If you're actually looking at the other end? Is this research question relevant to patients? Actually, which patients did you ask? And what did they say?

Interviewer 47:49

Thank you! Thank you for sharing this now, just a couple of questions about e negative, positive and negative outcome or PPI doing PPI remotely? So was there anything in particular that made it difficult for you to involve in PPI, anything that particularly make you difficult during this COVID-19?

Interviewee 48:24

Yes, yeah. For me personally, COVID-19, because it has stopped face to face meetings, because it has travel, or indeed now in the UK, it stopped local travel. That has made my life more difficult. Because I do like seeing people I do like sitting down over a cup of tea and having a chat. You know, this is lovely, but I can't see you. Like I said before, I know it's for me, it's not the same. And I also think you do miss you do miss, I keep saying it the coffee, q the lunch, you miss the social aspects. The really good meetings that people have where they have a two day funding meeting, they take everybody out at the end of day one, and you have a dinner, and you actually get to know each other as people and it makes working relationships so much easier. You know, it's not just about the focus on this project. It is about how you work with other people, especially those of us like me, where there's been a lot of investment in my training, learning and development. So if I'm going to carry on in this, the continuing working relationships, the networking, the putting my friend day in touch with my friend be about all of that is much harder to do because of COVID, but it won't be forever. But I think that's especially true of international cooperation. Obviously with with all the problems added on top of that, with Brexit and all the fears mostly unjustified. About what might happen to international research and Britain's involvement in it? It just is.

Interviewer 50:07

Yeah, that works as well. So what has worked well for doing PPI remotely? What has been good for doing PPI?

Interviewee 50:14

What has worked well has been the way some organizations have adapted to on line working. And it's not, it's not just the online meetings. So one of one of the best things I've seen, industry, for example, has done some really entertaining online presentations in their conferences. But actually, they still stuck with their will the conference was scheduled for three days. So we're going to pack three days in and you're asking someone to watch television for three days, in effect. And that's that's not the same as being at a conference where you can duck out, have the chats have the lunch, etc. chose to break down its annual conference, and they have been running a series of weekly fortnightly, monthly webinars on different topics. And they're not the only people, lots of the Academy of Medical Sciences, lots of other big charities, Royal colleges, they've been doing the same. And I think that stuff has been really, really good. There is so much more material available now, for patient advocate. goods to learn from then there was a year ago, there's actually far too much none of us can ever keep track of it all. But I think that has been really, really useful. What we now need to do is translate training materials, learning and development materials, specifically targeted materials, to the online way of working, because there's going to be a long, long time before we get back to face to face training sessions. And even if we do, it will be a long, long time before people feel entirely comfortable about going to them. And they'd be saying when the when it's all over? Yes, they're looking forward to getting out and meeting their families and their friends. But actually coming to meetings, training sessions, etc. They are still going to be cautious because they've said the whole population is not going to be vaccinated. The virus is still out there.

Interviewer 52:31

Yeah, so do you think it's gonna be a new normal, a new way to live and work?

Interviewee 52:35

Yes, I actually think we are we are going to be working a lot online. Not just because people don't want to go to meetings, but actually nobody can afford them. Especially in my in my line of work. And the UK, generally, a lot of patient involvement is funded by charities and charities haven't got the money. Universities won't have the money.

Interviewer 52:56

Thank you! So over the years as it has been more than a year now. So what could have been done differently, done better way to PPI remotely?

Interviewee 53:06

in terms of patient and public involvement, or in terms of our governments chaotic, in response?

Interviewer 53:12

In terms of PPI, what could have been done better? differently? Please?

Interviewee 53:20

I honestly don't think I don't think anything could have been done differently. There are probably some things we might have done earlier. But actually, if it if we if we knew then what we know now we probably would have put new arrangements in place a lot sooner. But one of the issues was never about PPI, it was all about how the institutions were going to work. And who was going to work from home again, you've probably been through this yourself. And initially, and let's be honest, everybody thought it was all going to be back to normal by June and July. And indeed in August, it was. So I'm not sure. I think I think now there is a harder, more realistic edge about the next couple of years than there was a year ago. But a year ago, we didn't. We didn't know. We could have been much more cautious in terms of our approach to the disease. We could have been much more innovative more quickly in terms of the way PPIE was working. But that's that's really with hindsight, it PPIE I don't think we could have done anything differently. We might have done a few things sooner. Thank you. One of the things we did do well was many patient groups actually did start off let's get through this. And we were having weekly online drop in meetings that has now stopped because we're all bored to tears. But so so it's and that was different and a couple of patient groups. Again, xxx was one started that really, really quickly, you know, we're not going to be meeting face to face the next few months, no matter what anybody says it's not gonna happen. So let's do it online. But let's not have one big meeting this month with 50 people, let's just set a slot every week. And if we get 20 or 30 people each time, that's fine.

Interviewer 55:22

Thank you very much. So my last question is, so what, if any, do you think are the limitation placed on PPIE through working remotely, any limitation placed?

Interviewee 55:33

The limitations are that we don't see each other, we don't develop the human relationships that come from seeing sitting next to people shaking hands, sharing a cup of tea, or any old fashioned breaking bread, or stuff that that humans do need to do. Online contact even if it's face to face like you and me now. That is not human contact. It's It's It's avatar contact.

Interviewer 56:04

You that's interesting. You mentioned quite a few times about shaking hands. So just thinking was the pandemic is over. Do you think that people will shake their heads or just No,

Interviewee 56:14

I think for a while, we'll probably be touching elbows,

Interviewer 56:17

Elbows, oh yeah

Interviewee 56:18

I I had an email from a friend last week who actually said, I'm looking forward to going back to hugging but we'll still have to wear masks. Which I thought was a really interesting point. I don't know.

Interviewer 56:33

Thank you very much, Mr.

Interviewee I56:35

Sorry. footballers seem quite happy. But they probably get really good medical care.

Interviewer 56:43

Thank you. So you have many interesting topics and ideas to share, glad that we have got a valuable information from you. But unfortunately, our time is limited. So before we go, before we finish, could you would you like to add something else that we didn't cover? Or you want to, you know, emphasis to put put things in our research just that we didn't cover in the interview? Yeah,

Interviewee 57:09

I I do think that there are no benefits from COVID-19, hitting the United Kingdom or any other country. However, there is an opportunity, when we go back to the new normal, there is an opportunity for patient advocates and for organizations that use patient advocates to actually think about doing things differently. And the opportunities that that then in turn offers. And I am really keen that we should pursue this avenue of we may have found new ways for people that weren't engaged before, to become engaged and to stay engaged in future. And I'm not saying we do everything online, because not everyone has access to online stuff. And I appreciate that. But there are people who are now getting engaged and involved. And we need to think carefully about what the new, not the new normal, the new balance will be. And I do believe strongly there is actually an opportunity here. And this is why I'm really keen on having some sort of national network for people to discuss this. And I don't quite know how that would work. It just is

Interviewer 58:30

So new normal, would you want to see a balance? So can I.. balance

Interviewee 58:37

We've we've we've done things like menus of involvement before so and that's been based on what tasks do people want to do? So do they do they want to read patient information? Do they want to write to patient information? Do they want to work in basic lab research? Do they want to work on clinical trials? Are they interested in quality of life? That that's all things? What we've now got is actually the opportunity of well, would you like face to face meetings? And how many years do you think we need to do this piece of work? Or would you prefer the online stuff? If so, is it teams? Or is it zoom? is one or the other? How do you like to get engaged? So not what do you want to do? But how do you want to do it? I think that's a really interesting idea. Instead of a menu, it becomes a matrix.

Interviewer 59:30

Thank you very much. You've mentioned quite a few times that I'm missing out people meeting people because oh yeah. So when everything is over, as you might as you're saying everything is over, we are going back to normal. Would you prefer to see and engage more on remotely, online or you want to do half and half? How would you want to see them from from your perspective?

Interviewee 59:54

I would actually like personally, I would like to go back to the face to face meeting. schedule, especially for conferences. I think conferences, conferences work when you have people in the same place, full stop. But I do think this online stuff, you know, whereas before you used to end up with great long chains of emails, spread over two weeks, you know, maybe now actually, let's not do the great long chains of emails. Let's have one of these. At the end of the fortnight, and let's, let's just talk it through. And then it's done and dusted. So it's one or two hours of everybody chipping in. I just think there's, there are different ways now of using the technology.

Interviewer 1:00:41

Thank you very much. Very interesting, very useful. As I really enjoyed this is a very interesting conversation. I wish I could talk more with you. So lastly, just couple of, would you mind

Interviewer 1:01:38

Oh yes, very interesting. Yes, thank you, You have a good day. And I wish you all the best and I am looking forward to you know, meet you another time maybe for another, at least on email. So would you like to see the report once a week?

Interviewee 1:02:01

very definitely. I think this is absolutely fascinating piece of work. You You will be part of shaping the future.

Interviewee 1:02:26

It's been very enjoyable. Thank you for your patience and your time.

Interviewer 1:02:30

Thank you for, thank you for your time. I'm really grateful to you for your time. Thank you very much. Brilliant. Thank you. Take care. Thank you. Bye bye bye bye.