Interview 4

**SPEAKERS**

Interviewer, Interviewee

Interviewer

So welcome again. Could I start first start 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? Thank you very much.

Interviewee

I've been involved in various things with with Universities. So I've done quite a lot of different things over a period of time.

Interviewer

Thank you! How did you do PPI before COVID-19? Was it face to face? Or you mentioned our conferences?

Interviewee

Usually, it's it's always been in the form of a meeting. I mean, you have emails, you have telephone conversations. But usually it's always been in the form of a meeting or a workshop or a forum or a conference or something.

Interviewer

Yeah. Do you have to travel the travel too far? For?

Interviewee

Well, I was I was the the thing I was involved with xxx and I was getting on the train and then walking to a venue to have meetings. And fortunately, I can walk and mean to answer questions later on. But you actually spent as I was spending as much time shuffling as I was in the actual meeting. And then claiming the expenses, because, you know, why should I pay to go to a meeting, you know, to help an organization was was often so much trouble. It was wondered why you were bothering on there wasn't doing it for the money but you know, ridiculous.

Interviewer

You need to fill a lot of forms to claim the expenses?

Interviewee

Ahh.. forms! The forms are not quite right. I was also involved in research coming back to me Basically, it was all about digital pharmacy. And I was going down to xxx. Yeah, well, I carry on. I mean, there were some expenses to start with. And then they decided, actually, they were supposed to the forums. But honestly, it's just an absolute nightmare. Absolutely. And you know, not not talking about making money out of it. Just talking about expenses costs crazy.

Interviewer

Okay. Thank you for this. So how do you feel? Now of course, you have been doing a lot of work and academics, not academia, government. So how do you feel about your contribution, PPI contribution to this work you have been doing, please.

Interviewee

It's difficult to say I mean, I've been involved in participation, and whatever you want involvement, engagement, whatever you want to call it doing going way back, introduced the idea of, of participation into xxx programs. And so we held the regional regional conference to discuss that. And they all had, they all they all knew that they literally needed to get the ticking the box skills for care was another one, that they needed to get a tick in the box in all the departments of health to give them money, because not the only thing but it was really important that you tick the box to say use our participation. And they all they all have varying ways of doing it. What is it paying the expenses, remember, one of them use one outfit used to take is literally a bag of gold along and give people the money for their tickets when when they got that. But other people did it differently. But the most important thing was that you'd be asked for the views. And the views would be sucked in. And it would be usually a relatively small number of people that would give their views. And then you'd never hear what happened with the views. Or the outcome. It was always done. It was kind of done to you. And then the information taken away and used. And you've often, I've often thought that many of the ways that this was done was very much a ticking the box. And then we developed a strategy, and if I remember rightly, and, and I selfless service user talks about what we discovered and what you know, the ways to do it, and all the rest of it. And then walking out to one of the senior managers said, Oh, well, that's good. That means we're guaranteed to get the money from the Department of Health. So it was like we don't assume this x exercise just in order to get funding. Now, I'm not saying it didn't inform it. But I have to say, I've seen many examples of where some of the things we've proposed didn't get followed through. Because I've always felt that you should feed things up from the from the bottom. So instead of just sort of picking somebody to be your patients or your service user, you should engage more people. Now, I realize at the same time, that's very challenging, because you can't get everybody there. But the trouble is, you can't get people to a meeting or a conference, if they've got a disability, or if they're a carer and they can't get rid of their caring responsibility. And, and therefore, whatever you get is somewhat skewed. And because the other thing that used to happen early on, you'll be aware of this. But the other thing that used to happen early on, and I think it still does is as soon as you have some sort of meeting and I suspect even a little bit on zoom. One person can be very angry and almost put other people off speaking because they're so angry because of that person experience. And the trouble is then you go you get the lead not really representative. Well actually, sometimes they are and remember one of the one of the things we had in xxx was I remember we had rusted out 30 service users carers sitting around the table and this lady started talking about how her husband died from a heart attack. Because she was complaining about something. But in reality, there will be hundreds of people like M, remember, and I know, there will be hundreds or 1000s of people like M, but her voice suddenly got hurt in that one meeting. She was I mean, and that's that's the problem. But having said that, of course, it's difficult to get people engaged. And but that's something I could go on a bit more if you want.

Interviewer

Absolutely. Thank you very much. So anything in particular did you enjoy most about face to face working please? When you worked face to face?

Interviewee

Well, I mean, if you can imagine having been a xxx, although, to be honest, but I like dealing with people. And and, you know, if you have some fairly accurate empathy, if you if you relate to somebody, if you listen to them, as well as talk to them, they tell you things that go beyond the question that you asked, but you've got to have that. And that's the thing that you get from face to face, that you'll never get easily in an email, or even in a phone call. Because you, you can't hear or see. You can explore nuances of expression, and so on which, which you can, in a face to face situation. And then also, of course, when you've got a number of people involved, you know, they can spark off each other. And then you find common themes and various other things and lots of advantages of face to face and working in groups. But then equally, there are the disadvantages I was referring to

Interviewer

thank you very much. Yeah, that's very useful. Thank you. And anything in particular that supported you supported your involvement in PPI anything, anything you could tell us?

Interviewee

So yeah,

Interviewer

I would ask two questions. One is anything that's supportive or anything challenging? So there's two parts we need to just before COVID-19? If you please.

Interviewee

Well, certainly one of the challenges is the way we started off this interview. And that's not a criticism of having been to ethics committees with proposals and having listened to ethics committees, and just just that first form, with all these boxes, makes you feel very, you know, like, whoa, hold on what they're going to do with this data, I'll be putting this set up, don't worry, we're not losing anything awful, but it almost feels like, you know, it's it almost feels like terms and conditions when you sign up to either purchase or something. You know, it's there's something to be concerned about in that in that process, rather than that kind of getting into the interaction. Having said that, I mean, I do understand why there's an ethical process as they will understand why there has to be those guarantees or whatever. But the way the process has gone about not just that, can that can make it more difficult. And and the other, there are other things about about language. Many academics will slip into Aqa Damnit language acronyms, you know, terminal terminology. And I'm not saying that, you know, service users, carers patients are not capable of understanding it. But having been in many different environments, each organization can have its own terminology to get into. And I have to say that I found it quite irritating. And that's putting it mildly when people talk about public and patient involvement. When, from from an ethical point of view, we're not just talking about patients, you know, how do you how do you define a patient is a patient somebody who's receiving the prescription is a patient, somebody who's in hospital is, is why he does not want not think about somebody who might have a condition that you don't want them to be a patient, in hospital or at the doctor's, you want to keep the home. And that's one of the things that are pleased about in this white paper. So terminology is important. So in actual fact, many people are,

Interviewer

Technically

Interviewee

Yeah, patients, were all registered with a doctor, you can say we're all patients. But a lot of people say I'm not a patient, if I'm not actually being treated, and I don't want to be a patient, I don't want to be sick. I want you to keep me from not from being sick. I mean, again, the white papers talking about doing stuff about obesity, for example, diabetes, and I can understand that, but it's just a question of terminology. And it's, it's very nice to use the acronym ppi. Public and patient involved with that sounds great. Well, what does the involvement mean? Does that does that mean, we're involved? But actually, we don't have any say, because the academics and the doctors and the government and all the rest of it, we'll just do this thing? Is it? Is it just a tick in the box? Are we involved? Or are we picking issues up? that come through us? rather than coming from an academic who wants to write a paper? Forgive me if I sound a bit cynical?

Interviewer

No, no, you're absolutely right. You know, the point to bed is absolutely. So that's, that's the reason nowadays, we see more papers, more articles, that's they're saying, people with heart failure, people with dementia, not patients with dementia. I mean, they're, they're using people instead of patients. So that's what he made actually, that contribution really hard when you say there are people not patient. So not a big right, we have all of us registered with general practitioner, that doesn't mean we have all our patients.

Interviewee

With the service uses, we went around the country, all around the country. And one of the one of the things we have problems with was terminology. And, you know, once upon a time, you worked with people who are clients, because client because clients suggests you're giving a professional service. But of course, clients unfortunately, professional service, as in prostitution, which isn't terribly good. If you then start using users, that sounds like people taking drugs. If you use if you service us again, it sounds like you're using something that you really shouldn't be using. And at one point, we were into people who use services, which has a pretty unfortunate acronym, p w. s. And that gets very long winded, but I've always believed that you're dealing with people. And essentially people, people don't want to be a patient. People don't want to be the carer, people don't want to be lost. Because, you know, I think you're right, using using the term people, people have a condition is much better.

Interviewer

Thank you very much. And now if we move into the current PPI work, the since COVID-19. So what PPI are you taking part in at the moment? After COVID-19 is

Interviewee

What kind of continuing I'm still involved in in he as a lay person are still involved in in N (CHARITY ORGANIZATION). So we're picking up issues. I mean, I got a really good. There was a really, really good piece of internet came as a result of that one from somebody who's been in a virtual world. And she was describing the experience of being in a virtual Ward with COVID. And how that was handled. That was obviously much better than being in in hospital. So that was that was a couple of good things. came out, actually, and still involved with X University, in terms of looking at potential research, to some extent, trying to look at, use an Edu search, I mean, you, you'll be aware that the National Institute of Health Research, a little while back produced some funding orientation towards xxxx. So I'm hoping that one of the things that made the university livable. So one of the things to look at would be we've looked at, with WhatsApp with a smaller group.

Interviewee

Yes, but I, on behalf of the National Institute of Health, so he has a presentation on there to a number of researchers about our ideas around xxx, and what actually might provoke provoke some research. But out of that, in talking to a smaller group.

Interviewer

Thank you very much. Do you feel any differences in your PPI work now comparing before and after COPID-19?

Interviewee

Obviously, it seems troublesome. The fact that you know, everybody can interact fairly quickly. But the other the other thing is, of course, is that you can involve people who otherwise wouldn't have been involved because they couldn't travel. Now, clearly, it's difficult to get out there into into the community. And having done a bit of kind of involvement in my local community through parish councils and various things is still face in this in this world. The problem that people think that their views never count because because there's a silent majority don't actually say things. Some people think that they've used an account. And I think that that applies with with service users, carers, people, and so on. You can involve quite a lot of people, but you can't involve enough that the beauty of the online thing is that you can, in theory involve more people. I mean, you can, you can, you can have a couple of 100 people involved in a zoom session. So they can all hear what's going on, and they can ask questions, and so on. So it's a bit like a conference without the travel. And without all the difficulties. I remember we had a, we had a lady who worked with quite closely who was wheelchair bound, and she was heavily involved in skills for care, the backflips and arrangements to get them the carer to a meeting, which is unbelievable. And it was a complete physical strain. Now, she could have done an awful lot, using zoom, all the rest of it without the physical and mental stress that it puts on us to do it. So there's huge, huge advantages. The key thing always is going back to participation is the feeling that you get the information, but you never then find out what's goin on. I think sometimes it can be a bit slow to to say, you know, right. Okay, a lot of you have said all these things, we think these the key points, do you agree, that can be done quite quickly, even if it's a bit rough and ready, is that responsiveness and that feeling that something will happen? Because Another thing I noticed is sorry, I'm rambling. Now, many, many of the people that we talk to recognize that their participation or involvement would not necessarily involve any change for them. But they did feel that this is a good line to take in a sense that it would help to shape the future for for their, their children, or, you know, the rest of the community. So there are also people who are prepared to be committed to that, but can't put in a huge amounts of time or travel in order to do it.

Interviewer

Hmm… it's very interesting to see, see those changes that you recommended or commented didn’t go through…your didn't go through, wasn’t put into action. Now I wonder if 100 or 200 people's people, you know, involved in a PPI meeting how many people would feel that way? It would be interesting to know that what percentage of population thought that their contribution didn't work or didn't, didn't put in an action or didn't see anything come out in the reports? It will be interesting to see.

Interviewee

Of course, it’ll be very interesting. I mean, there's there's a basis of research, dare I say, to look at the history of involvement in various schemes, not just patients or service users, and to see do a meta analysis of how many people were involved when they got the results? What impact that has, and how people felt about it. I mean, you could probably that would probably be quite effective, because I'll bet you more people continue to be involved when they see the results of their efforts. Yeah, we've got a couple of members who were involved in, in a lot of things. In fact, most of our board being involved in lots and lots of different, we network into other things. I don't know the website, but having a belief it will make a difference.

Interviewer

Thank you, the idea that's very helpful. And it was very interesting. I've been to that website you sent me through, it is very interesting. I just got

Interviewee

networks of networks, because this is this is another way of doing it. What I proposed was skills for care, which never really got follow through was that different organizations, you know, you might have a dementia organization or an older people or a mental health or whatever. The they sent sort of service user reps into a kind of regional conference, if you like, and then from that conference, you elect People who will then go forward to the skills for care board, for example, so that they would then take views to the board. And they would say views from the board, and then it would permeate back through those organizations. And that seems like a fairly good model. I mean, you could say that's not so in theory, Parliament works. broadly. But it but it never really happened. Because it because it was ultimately, at least not too difficult doing it through through a kind of like this, because you can talk to lots of people without necessarily having a physically together. But it did seem like quite a good model. And then what what happened afterwards, that actually skills for care just kind of almost advertised for, maybe I shouldn't have mentioned skills to get, let's just say, organizations and look around for a patient service user rep, to go on their board. And then they get somebody and if they're in a wheelchair, or they've got some difficulty for great, we've got something pretty nice. So it's tokenistic in terms of sometimes in terms of race and gender as well. It's just like, you know, I mean, I will say where I went somewhere, and I thought, well, this is this is great. You've got a range of people here. And you've ticked all the boxes. Well,

Interviewer

Is there anything new for you? Post COVID-19 PPI work…

Interviewee

the feedback from, actually, in this research, development services and PPI in our region. What she was reporting was she was having much more involvement in this way than they were before. Not necessarily zoom, either. Because this is another bit of a hobby hosts. The trouble is, when you academics, get yourselves a survey monkey, or some sort of tool, we like to call it a tool, which actually is actually a form or a questionnaire, but he call it a tool, because that sounds better. And then what you think is, well, is this blast that will last that before you know where you are? You've got loads of questions, with loads of boxes to tick with, with scores, and the color scales and all sorts of things we all have, which is great data to have. The trouble is, the more questions you have, the less data you actually gathered, because you're gathering it from less people, because so many people put off. If there was a way that you could ask some simple questions, literally only two or three crucial questions or three questions where there was a score of one to five, you might get a response from more people through a kind of app and I for a while I actually had a, an app, which is the wrong way of going about it. In a sense, the technology was wrong, but it was anonymous. And the idea was that you could ask, tell me more about the idea. The idea was that you could ask people anonymously, various questions, but the way you set it up, it would identify, if you like, what group that person came from, without them giving their name. You know, it might be the you know, they're older, younger, you know, whatever, whatever. But but then you could, you could you could actually work through the answers. And you could actually ask particular groups of people to expand on something. But the idea was that you were only asking a couple of questions, and you've got more responses from more people. And that gave you more data. It might be a bit thinner, but it would be broader and therefore more substantial, rather than getting a little bit of one of our group said I think it was an 80 page questionnaire or suffering from a hospital workers only got about 100 people who filled it in. Because, you know, you have to be pretty bloody determined just dozens and dozens of pages, either online or whatever. So

Interviewer

yes, thank you. So what access do you have that tool while you're working remotely? replays says that you've mentioned about your iPad, any other

Interviewee

I've got a rather rather old Mac, or using an iPhone all the time. I've got all the facilities.

Interviewer

Did you need any support? Or have you any IT support for you?

Interviewee

Well, it's I was, I was regarded as being like swimming, I'm just saying to my wife, she's like swimming, you have to get into it, too. You can't harm yourself what you can with assuming you can't harm yourself by trying things. But the struggle is everybody starts getting a bit twitchy about it. And you do need support, you can you can give them you can talk to people. But again, the technology, the way you use, it needs to be as simple as possible.

Interviewer

Thank you very much. So there's a question about the influence you’ve had… Was there anything in particular that helped your involvement and engagement working during COVID-19?

Interviewee

That helped my… Well, I think what we're doing now, I mean, it's, this is, you know, much, much more productive. in many senses, it's gonna be a productive moment. Because if this piece of research confirms, the hypothesis was, this piece of research confirms that more people can be engaged more effectively. And this is one of the upsides of COVID through these mechanisms, well, that kind of confirms what I was saying years ago, I mean, there was a zoom around them. Losses we know is that you can invoke with interesting Actually,

Interviewer

Thank you. Was that now Was there anything that made it more difficult for you working during this time of COVID-19?

Interviewee

Well, PPI do you mean?

Interviewer

Yes, PPI work

Interviewee

Well, only chat you miss. I mean, we have our N (CHARITY ORGANIZATION) board meetings on on zoom. But it's more difficult to have the, the in the margin conversations. You know, before you start the meeting, while you're having a cup of coffee, a little chat afterwards, you know, ideas spark off, and that doesn't happen quite as easily on zoom. Because it's more difficult to see the nonverbal cues you know, on a tiny screen, you know, when you're talking you can you can see that somebody physically wants to say something, which is a bit difficult when you've only got a tiny face on screen. You know, it's a bit more difficult to have that kind of interaction.

Interviewer

Are there any positive things about remote working that you could share, please?

Interviewee

The positive thing as far as I'm concerned is what's the expression? Imagine you get more bang for your buck so to speak. If you consider your time to be valuable. You get up more involvement for, you know, less time, if you see what I mean. I mean, put more time in, but you know, time you walk into the station, get the train to train station have been walking back, you know, waiting for the train, you know, see, you know, meeting for an hour, which was costing me three or four hours. So, you know, doing it this way, you know, an hour is an hour. And then I can be involved in more diverse groups. And the other thing is that I know that more people can be involved. And I think more people being involved is much more important than hearing somebody like me banging on. Because I've got a big voice and I'm loud and you know, being around a bit. [ha] ha. dominated that way.

Interviewer

So less less travel… thank you! What could have been done differently or better?

Interviewee

It’s a hard question. I mean, as I suppose potentially, I've not really participated in this, once were on a zoom conference call, you can you can break into smaller groups, he will have done it, I'm sure. Find it a bit disconcerting, because I'm not quite sure what groups are all the one I was doing. But that could be something to be said for doing some of these things and breaking it down in smaller groups, you know, who are interested in a theme? Yeah, a bit like going to a workshop or conference. So that you can explore with other people, but you always have that mixture between people who go to somewhere to learn something, and other people who who go knowing something, you know, sometimes people go for the safe issue that they know about, or actually what you want to do is get them into the unsafe, very safe, exploring issues and understanding broadly on Sunday. So it's interesting. One,

Interviewer

You mean so breaking the larger group into smaller group? As you mentioned earlier, that we could have hundreds of people in zoom meeting. So how many people would be ideal for a zoom meeting, which would be good for everyone, your preference, I mean?

Interviewee

Well, ha if I put it this way… It's almost a screen full. Looking at the screen now, I mean, you're probably talking about a maximum of maybe 10 people, eight or 10 people I would say, because then you can see everybody, you can see some of those nonverbal cues a bit. You know, once you start scrolling through screens, or pictures are sort of small, then then it kind of loses something really.

Interviewer

Thank you very much. We have reached nearly the end of the interview. I would like to ask, Is there anything you would like to share, which we have not covered in this interview?

Interviewee

Blimey.. haha. You're asking a question or the appropriate questions anyway, he can. I don’t think so. Very much the, if you listen to the patient service users, I mean, listen, and give them the space. But equally, you also listen to the workers, you can often find ways forward because, you know, they're the kind of coalface and if you're talking about the National Health Service, or talking about the department of health and social care, then the the issues that are faced by the coalface workers and that's what's happened with with COVID. It's, it's not faced by the managers or consultants that consultants who you bring in. I don't mean the consultant doctors, not managed by them. It's managed by the people at the coalface. And my experience of being in hospital for four months was whilst I would see the consultants and the registrar's once a day, but we hadn't and I might one of the registrar's is very good he used to come. She used to come around in the evening as well. That The actual work was was done by the nurses and healthcare assistants and my interaction with them. And I think so many things emanate from that that interaction at that level. And it's getting into that that is so important. I mean, yes, of course, is going to be a strategy, but it's, you know, it's that kind of one, if only they'd done this, or this would have helped or, you know, I didn't like that, and why those are the things that lead you to try to make the service better, rather than some sort of academic overview. It's cut. It's a bit, you know, to me, some of this should be research should be kind of patient service user LED,

Interviewee

I’m not something special. a bit unusual, in the sense of kind of both sides of the fence. I mean, we've all we've all had some experience of hospital or the system. I mean, I was I was in hospital for four months effectively, So then it drains in me and then I had to go back to hospital several times, then then then I had to go back and have the drains out in my gallbladder out. And then I took some time to recover the infection or whatever. And it was fascinating that they asked me to go back to the hospital to one of the rooms in the outpatient clinic that I've been to. And there were scans of my body on the screen. And I was there to be a patient for the registrar's who were wanting to become consultants. So there was a very senior consultants who were overseeing this exam process and they were coming in to see me and watching these registrar's examine me. And it was it was a fascinating insight into medical education. And, and the fact that these registrar's were nervous, some are very nervous and quite human, it's the other side that I've never seen before, because they always portray themselves as being very confident. So it was Really, I felt like I was really giving something back

Interviewee

Thank you very much. Thank you.

Interviewer

It's been very helpful. I will I will read your website. And if I have any question, I will, I will email you. Okay, thank you. Take care. Thank you. Thank you. Bye