Interview 12\_RPPI\_22.02.21

Interviewer

If you please give me permission on your side, to make sure it be okay. [Okay], thank you very much. So because I am very much aware about your tight time. So we'll get started then. Thank you for your time. So the purpose of the discussion today is, is to help us to gain a better understanding of your views about an experience of remote working of what we're doing at the moment and we are also interested in your thoughts on how we can facilitate and improve doing PPI remotely. So your views and contribution will be really appreciated on this recess.

Interviewee

I just talk easily just on remote PPI activity? Or are you also trying to understand the difficulties?

Interviewer 00:48

Yes, we will cover everything.

Interviewee 00:50

Okay. No problem

Interviewer 00:52

So our first part will be before COVID-19 will discuss everything whether he's been advantages or disadvantages everything and and then second bird will be after COVID-19. So they will experience the last graph. So could you please start by telling me the what PPI work you have been involved since COVID-19 started, please?

Interviewee 01:17

Well, I as I said, I'm a carer and with the with my carers responsibility. I came across the healthcare provider and then the social care provider. And my mother is on a palliative care. So I got involved with xxx. So I got involved with that about three, four years ago. And I found it interesting, getting involved in it not only from my personal perspective, of actually the challenges and difficulties that I and my mother were experiencing, so from a patient and from the carers point of view, and, but also in understanding of what generally in the community, others were experiencing, to hear about that. So it was a two way thing. It wasn't just me, giving my bit of information and someone goes away. I felt taking part as a PPI that it was a two way road that I was also learning a lot from the xxx. And I have thoroughly enjoyed my time working with them on a PPI activity. And that has encouraged me to also now getting more involved with the xxx network, which is a patient's participation groups. So it's allowed me to get involved more because of the PPI activity.

Interviewer 03:16

So this group?

Interviewee 03:24

Yeah, patient and public participation group.

Interviewer 03:29

Okay.

Interviewee 03:37

All volunteers, they're all separate. They're all volunteers. That's great. That's great.

Interviewer 04:07

Thank you, PPI meeting before COVID-19 normally?

Interviewee 04:20

Predominantly our attendance. So it was face to face as physical location and my physical presence. There was some engagement on telephone, we will talk and some communication on emails, but very little, not, not a significant amount. So most of the sort of discussions meetings were taking place. face to face. I was receiving a lot of documentation in the post, which allowed me to read the documents in my time. I'm still an old fashioned guy. I suppose that I I like to see things in front of me because of being able to sort of read documents, mock up documents, which is difficult on electronic copies a lot of the time, then PDF, we can't do anything. Even if it's in the Word document, you can't mark, it's difficult because it takes too much time. But if it was the physical hard copy, you can sort of write scribble on it quite quickly. And you can go back to it to remind what you've read what comments you thought, whereas on a electronic copy?

Interviewer 05:36

Looking at the screen for a long time, it's something

Interviewee 05:53

Yeah. visual impairment, because I get double vision after a while. And if I'm concentrating, I also tend to get neck cramps, because I can't sit for too long in one position, because of my back problem. So I have the same problem.

Interviewer 06:14

Thank you. So as you were saying that you got eager to read a lot of documents, do you do a lot of review and paper and comment as well?

Interviewee 06:33

I will review and comment Yes, and send them comments during the COVID, because everything has become much more remote than less. I was doing a lot more before because I can also make my thoughts and comments put down on the paper and send it back by post to the PPI coordinator. And the PPI coordinator will then consolidate all the information or call me to say is this the correct understanding? Because now that is bit more difficult of reading the documents, my PPI work has diminished. I'm doing less,

Interviewer 07:19

Thank you, we will discuss more about this. Thank you very much. So from your perspective, if you could share, you know, the the more you share, it will be more benefit for our research. So if you you can share anything, please. So how do you feel about your contribution, from your perspective from your carrier or from your patients perspective?

Interviewee 08:11

Right. How do I feel before I answer how do I feel? I'll probably just make you aware of you talked about reviewing documents? Yes. Just really continuing on that topic. The biggest difficulty coming from the BME community is actually understanding the language, the words used, because not all documentation is out very simply laid out in layman's term. In a general public term, they're sort of sometimes very technical to understand. Some people tend to use a lot of jargons. So from my perspective, coming from a BME community, I tend to find sometimes, and I'm friendly, I think I'm fairly educated, I have a good understanding of the language spoken as well as return. And despite that, I find some documents very challenging to understand exactly what is being said. So coming from the BME community, particularly when you come you have all kinds of people with sort of English as not being their first language, they may find it difficult and that's the biggest challenge that the BME community have in a understanding what is being said to them, but it's written or spoken. And then for them to translate that into their own minds. And then to communicate back to the to the recipient or to their opposite people. You know, this is what's happening. It becomes difficult and challenging. It takes time. It's not that easy. When you're doing that face to face. You can explain it might take it might be But you can explain to the body language, doing it remotely, telephone through email, through videoconferencing becomes a bit more challenging, and it puts off the BME community quite quickly. So, so,

Interviewer 10:19

So for so if sorry to interrupt is very interesting point you were making. So from your background education, when you get a document, it's not difficult for you, but when you, you know, transfer when you try to communicate with your community members, you find it difficult to make them understand through remotely.

Interviewee 10:39

No, no, no, it's opposite when it's other way around. I even though I'm educated I am. I'm fairly adept with understanding the English language. I personally find some documentation that you find, I find it difficult to understand, for me to communicate to my fellow BME community is easy. Easy, okay. Oh, yeah. Because I can speak in their language, I can understand I can, I can understand the cultural background and all that. So it's easy, but me personally understanding it digesting. So there is the first thing is reading it to is understanding and digesting it. Three is actually analyzing it. And four is then communicating back to the researchers, you know, what do I mean, and I have to explain in such a way that I am explaining what I'm trying to say, so that they can understand. But communication is not just about one way, it's about two way, receiving it, digesting it, analyzing it and playing back. And that is the side, which, although people when you tell them that understand that, but they don't always think about it. And that takes time. And so that is the biggest challenge I have found being an educated person. Having lived in this country for many, many years, I still find it difficult to understand clinical documents, technical documents. So you can understand from those who come from less educated backgrounds, less economically, well, well off background, they will find it even more challenging.

Interviewer 12:30

So it's challenging. If you share your experience too with fellow and other BME community members, then do you think it might put them off to become a PPI contributor, because now,

Interviewee 12:43

I think getting a representative from a BME community to talk to another BME community, to telling them about the benefit of getting involved in the PPI telling them, you know that because I believe everyone can make a contribution. Of course, that is my starting position for me to go and speak to another BME community, especially from the same community that I come from. So I'm not an expert in all BME community, but certainly in the community that I come from, for me, to explain to them will be very easy. And those people will listen to me, because I'll be able to communicate to them in the language that they understand with the cultural and sensitivity that they can understand. Because if there is an art to actually empathize with those people, and I'll be able to do that, and they'll understand, and they may encourage them to participate. Because ppi. Most people who get involved in PPI do it voluntarily. They're sacrificing the personal time, their personal emotions, they both know well being to participate, because they think by contributing into the PPI, it might not necessarily help them, but it will help the future generation. So everyone wants to do the right thing. But most people give up because they find it too challenging. The other problem is that advantage of face to face, is people can build relationship with one another. So researchers can build relationship with the ppi. When you're dealing remotely, everything becomes How can I put it, it becomes clinical, it becomes artificial. It becomes like you go into a doctor's surgery. everything is nice and clean. It's not like going to someone's home where you are comfortable and people are comfortable and they can talk to each other. It becomes like you're going to the office or you're going to the surgeon And everything becomes too formalized. And that is what this remote working video conferencing telephone has done. It is breaking that relationship issue. And if you don't have that relationship issue, then that motivation of people getting involved in the PPI I fear will get reduced. Because then that's contentment, that satisfaction, that joy of taking part in PPI will get reduced. And most people who take part in PPI they're not doing it for money, they're doing it because they actually enjoy it. And they feel it will be valuable for future generation.

Interviewer 15:46

Thank you. So as you were mentioning, there's difficulties, the loss of either using lots of jargon, clinical words. So if I would ask you what what would be your suggestion to make it no more accessible or easy to read? Could you make a suggestion anything to so that it could

Interviewee 16:09

I think, I think it's a chicken and egg situation, you almost need few PPIEs the lay people to come in to effectively help the clinicians, the the health professionals, the social professionals to translate that information into a language. So you need PPI contributors to help those professionals to put the document into a language that is simple enough for ordinary people and patients and carers informal carers to understand what is being saved, and what is being required. So you need that. You also need the second. The second stream, I suppose, is you need ambassadors, champions, whatever you want to call it, you want people from all under engaged communities, to be representative ambassadors to encourage others to participate, if you can get them to work like champions to act like champions to go out into their neighbors into their communities into their families, and say, Look, this is what I did. And I really enjoyed it. And I feel really satisfied that they are becoming the voice and ambassadors for the PPI for all institutions, not just many specific and they will encourage their friends and families to get involved. And then the third element is the respect element. I understand any project any research has a finite timeline has a finite budget. I think most people will understand that. But what when the projects are being planned. The researchers and certainly their managers or lead researchers should recognize or allow sufficient time to to get what I call productive or effective feedback. It's not like an engagement. you communicate what did the information and say yes, I've communicated 200 people and that's it. If you want PPI, it should be a two way thing you communicating and then finding out have people actually understood have people actually do they believe that is the right thing they're doing? And it's the answers to solutions that have been proposed or recommendations that have been proposed. Are they relevant? Are they reasonable recommendations or should something else be considered And finally, the last thing that can the ppis can do is help with sharing that information and research output any results any reports which are published, PPI can actually help by going out to their network to their communities and saying look, that was the document that was the research that was done and how we can all participate to improve the system. So I think all that can be achieved if we have a good PPI but the good PPI starts with getting the language right with getting the right people involved and also respect by all parties, both by the PP eyes as well as the researchers.

Interviewer 19:51

Thank you very much. So is there any other way that you are you are pointing out that when you get the document like clinical document to read, before preparing the document before producing the document to send out. Do you do do you think you need to get someone involved in the preparation of the document someone from BME community?

Interviewee 20:21

It's very difficult. Again, it's a chicken and egg situation. BME community is just one community. It is just one part of the project team. A project team will be made up of researchers, the providers, the users and all kinds of people. And BME is just one small part. So it doesn't have to be necessarily from the BME community to get involved in the project team. But what is absolutely essential for my experience of last four years in the PPI world, and and certainly for my experience as a carer as a patient for the last 20 years. What sorry, last 20 years working with the voluntary organizations and the one thing I have understood, it is absolutely important that the documents are simple enough for them to be understood by laypeople. And that can only be done if you have what I call a lay member, a PPI member in the project team, that PPI member in my opinion, depending on what research it is what document it is, of course, if it is very biased towards the BME community, then it is good to have a PA me lay person. But generally on most research, if you have a lay person who is from a public from the patient from the carers background, the user's background, then they may hopefully get involved and put the document in a layman's term. Now, I'm not saying that one individual will make sure it is absolutely right. But if you give a score to a document, one to 10, a document which has been written by professional health professional clinical professional, it might be four out of 10, understandable and digestible by the lay community. But if you have a layperson putting the fingerprint on that document, changing few words here and there, my feeling is that document will then probably be seven out of 10, eight out of 10 understandable by the lay person. So there will be a substantial benefit. I think in terms of information dissemination.

Interviewer 23:04

Thank you. That's very, very interesting, very essential input. So now can you share some of your How do you feel about your contribution in the last four or five years since you've joined the PPI?

Interviewee 23:18

Personally, I, I feel very happy, contented motivated. That because I was lucky that I worked with excellent professionals, who were very respectful and willing to listen and always shown a lot of respect to me to listen, to consider my views. And more importantly, I have actually felt personally that whatever challenges experienced good things, bad things that I have experienced, being as a patient as well as a carer, I have managed to share that. And, and people have recognized the challenges difficulties I've gone through and others have gone through and some things are being done. So I feel very motivated. I've been very contented. Unfortunately, over the last 12 months, the world has gone through radical change of COVID. And and therefore it has created new challenges. I have not been able to contribute so much purely because my first priority is as a carer to my mother because she has had she's a palliative care patient. Her health has been deteriorating very, very fast, and therefore my priority is her. Secondly, just being able to do things remotely has not been easy. So I have not been able to share as much contribute as much as I would have liked. But overall over the last four or five years, I feel very motivated and contented. I would love to be able to be a champion to be able to encourage others to participate. But in the current circumstances is very difficult because I also recognize not everyone has, he can afford a computer, not everyone can afford a time to sit down for two hours in front of a computer and participate. Not everyone can understand the language very easily and digest in two seconds, you know, it takes time. So I think we need both, we need face to face as well as remote because the remote. I'm not saying it's all bad. Because remote PPI and remote consultation has brought in new communities, new people, new participants, you know, those participants who were not able to attend meetings in the daytime because they were working, or they were doing something else or they had a responsibility and couldn't get live on. They could not participate by remote consultation and participation. You've encouraged them to participate. But then you've lost some of the traditional participants. So I think going forward, perhaps we need both. And we need to find a new ways of how to go forward.

Interviewer 26:38

Thank you very much. So could you please tell me what did you enjoy most about doing PPI face to face while you’re doing?

Interviewer 26:50

Motivation, I think the social side because being a carer, I was in my own cocoon. I was isolated. I was on my own. Getting involved in a PPI, I was hearing stories, challenges. joys of others. And that gave me inspiration. It gave me motivation. It made me hungry for more. So face to face, that social interaction, it got me out, it was like a respite. Getting out of the house, having to three hours of break, from my care responsibility to think about something else, meeting other people that allowed me to do that. To build relationships with people I didn't know at all. I only met them through PPI, I only met researchers and academics and professionals because of the PPI had to actually, you know, certainly I thought this professionals and clinicians, you know, health experts, they were not some highly sort of disjointed experts who didn't understand the real people, the real challenges, they meet people like us, the individuals like us. And therefore, that respect, mutual respect of each other, of being able to put a face to the name was the joy. And they gave me motivation. It gave me inspiration. It gave me joy. This last 12 months I've been I've done less of that. So I have, I will say in a way gone back in my life journey of being again, isolated and not so involved. Not having so much social interaction.

Interviewer 29:13

Thank you. So could you share anything, any challenges for face to face meeting?

Interviewee 29:20

Yeah, the biggest challenge was obviously time because you have you know, I'm a carer so if I went to face to face meeting, then I had to make sure my mother was being looked after there was someone here to look after. And then that fear issue okay or not. Every time I left her was the biggest challenge. But it gives me what I call physical and mental strength because it gave me a break from my air. challenges. So, be having an ability to be able to do that from home will be obviously that fear will be taken that challenge will be taken away straightaway. And hence, I say that PPI has to have both sometimes for us, who are the PPI members an opportunity to be able to go out if we want. But at the same time because we want to contribute to be able to contribute remotely if we want, by email, by videoconferencing by telephone, whichever mode is easy.

Interviewer 30:42

So, the time traveling time, for example, if you attend a remote PPI, it might be two hours, three hours or more. So, two, three hours you are in the house, but you're not with your mother, but you are attending. But if you go to somewhere in the physical location, you go there, the same hours meeting maybe two or three hours. So the time do you mean the traveling time going there and coming back?

Interviewee 31:12

Both both. It's not just the time of attendance. So when I'm attending for two or three hours session remotely and or being at home for two or three hours, if I'm at home for two or three hours, I can easily come out of the meeting or send my apologies on a videoconference and say, Look, I, I need to leave for five minutes, 10 minutes, I can leave and I can join. Um, I can't do that, if I'm face to face on a physical remote location, that I can't do that. Because Because I'm away for two. So here if an emergency happens, I can step out of the meeting, then I can't. However, there is also an added challenge that you have to get to that remote location wherever that meeting was taking place. So my PPI contribution was only where I can travel to for maximum one hour of traveling time. Any there were some times I was asked to attend, not with distance or overnight stay. Because I'm a carer, I can't afford to do that. And I have to send my apologies. But it still allowed me to contribute to that. Because through the post through the to the documentations I will send in my comments and my information, which then someone else was managing and communicating to the rest of the team. Doing that remotely will help because you can do it yourself rather than through another person. However, I still have the challenges because you know, I can't I can't physically sort of change documents sometimes or make comments on the document. I like to do it on on hard copies. So they are benefits and death benefits of working remotely or not.

Interviewer 33:21

Thank you very much. Thank you. So after COVID-19 started since last year, so what what PPI have you been doing? Or have you joined any new PPI since then?

Interviewee 33:37

Very little. I mean, I I still do some work with xxx to solve attended to what I call PPI group session. I do some telephone support on with my xx we've been before the lockdown we were meeting in in in the parks, or in the community halls with other members, not at the surgery. Before COVID were making the surgeries or we were meeting in the community hall. But during the conflict, we haven't been able to meet in the surgery. So we've been meeting in the community halls or in the parks and sharing information. And we're quite lucky that we had the budget to have an administrator to pay for the administrator. So they manage all the documentation and collection of the information and sharing of the information. So some other groups may not have that budget and therefore they may not have what I call an individual who can administer all the information.

Interviewer 35:00

Thank you very much. So could you pleasetell me the difference you feel now? Working before COVID-19 and working now, just briefly, could you please different or change anything?

Interviewee 35:12

Major changes will be that I am disconnected. Ah, in the PPI world, I don't have as much connection with what's going on, as I did before COVID, because I'm not participating as much in the PPI because of my own physical restrictions. And so I'm doing, I'm doing less ppi. But it's given me an opportunity like to meet you, you know, if it wasn't for remote working, I wouldn't have met you and your team. So it's opened up new arenas, it's opened up new horizons for me, as well. Whereas before, I wouldn't have even thought about meeting people like yourselves. Now. You know, I'm getting that information set across to me, which is helpful.

Interviewer 36:15

Thank you very much. So can you please share? What what kind of resources do you have at home to work remotely?

Interviewee 36:26

I do we have very limited resources. I mean, I'm using my son's computer, I haven't got a computer on I have a landline, which everyone else uses. The landline in the house, I haven't got I haven't got a dedicated landline. I'm sitting in a in a dining room in a small part of the dining room. Because it's the only place in my place in my home that I have free, where I can actually sit quietly, without getting disturbed from other members of the family or other activities happening in the house. So yeah, I've only got limited resources, I can only do limited work, or PPI

Interviewer 37:19

So you share this with you any organization?

Interviewee 37:48

yeah, but I mean, you know, the one thing I can do is I can do a lot of the work and reading between 1030 and one two o'clock in the morning, because I know, then my mother is going to sleep computer is free, and I can use the computer, and I have time to myself to be able to do. So I tend to do a lot of that during that time. It's okay, you know, my son's not using the computer all the time. So it's not a problem.

Interviewer 38:21

The smartphone?

Interviewee 38:23

I do have a smartphone. Yes.

Interviewer 38:25

Do you use that for PPI work?

Interviewee 38:29

No, I don't, I'll show you my smartphone, as my smartphone is very, very small screen. So it's not very easy. It's certainly not to my eyesight, it's not very easy to work with the computer. I prefer to work with a hard copy. But if I don't have a hard copy, then computer Yes. For example, when and when you meet when I'm meeting you so this way, we will be on a computer. So if you send me a document, I want to use the smartphone. I don't have a tablet. So I will use competing. And competing is a big screen. So it's easier for my eyes to read that. And then of course, you know we bought a desk to to have a computer and a printer. So yeah, I've got space here to do all that.

Interviewer 39:22

So do do you print out print out documents when you

Interviewee 39:26

Get something usually that's what i if i can print out that that's what I tried to do. So what I tend to do is when I receive a document, then if I can print because not all documents you can print, but if you can, then that's what I've tried to do, or at least I don't know how to print because there's some online documents which I don't know how to print. They might be away but I do not.

Interviewer 39:51

So did you ask anyone or did you require any time to get any IT support from anywhere from any PPI organization?

Interviewee 40:08

I haven't No, I haven't asked. Because you just don't want to bother anyone about that, because it sounds, you know, quite embarrassing to ask that. But I did get some help when the first time I got involved with zoom, I was struggling with zoom, you know how to sort of get zoom to operate and all that. So I had help with that. And then I'm still struggling with MS Teams, I would like in zoom. I tend to get better internet connection at home. But it might be just something to do with my son's computer setup, I don't know. But MS Teams we tend to sort of lose connection. The thing I haven't found out about the technology on MS Teams is on zoom, you can see the chat, and you can save the chat conversation because sometimes in the chat conversation, you get lots of access to you know, look at this document or look at this web link on this website. They put that down, and you can save that chat and you can go and revisit the meeting those those website connections, links. I don't know how to save on MS Teams. And I've asked a couple of people to sort of helped me How do I save the chat conversation in a mistake? And they haven't been able to help me. So I suppose it's because they're trying to tell me what to do. But I don't understand. Maybe it's my intelligence.

Interviewer 41:46

So it's chatting, chatting on zoom, you find it useful.

Interviewee 41:51

So while not just chatting, not the chat function is the safe function. So saving that as a separate file, which I can then go back and read the chat. Because when you talking on a videoconference you can't read all the comments in the chat function. So at least after the meeting, you can see who think what and why. And it's helpful to go back.

Interviewer 42:14

Thank you! It's very interesting.

Interviewee 42:16

To save the chat conversation in MS Teams. I can't do it. I don't know how to do it. Yes,

Interviewer 42:22

Even I didn't try. So I will try next time thank you for sharing. Is there anything of course, there might be more so that anything particular influenced you to continue, PPI work whether before COVID-19 or after COVID-19?

Interviewer 42:39

In all, PPI has educated me has opened up new life for me, because I feel you know, I I've enjoyed doing PPI and I will encourage everyone to because I genuinely believe no matter how little the person is, they can hold make positive contribution in life. And we should encourage more people to participate. More people because I have seen in the last 12 months, I put my problems were difficult and my challenges are difficult. My challenges, I feel now are nothing compared to some of the challenges some of the other people are going through. And it will be really important for those to be understood by as many people as possible. So I would love to encourage, and I you know, I every time I talk to someone, I always tell them and I say to them, please get involved in PPI if you can't understand something, then ask your family to help you to get it and encourage your friends and family to get so I'm always encouraging others to participate and I will have will be sad if this lockdown continues for too long and I will not be able to do the PPI because I would love to be able to do more PPI I I have certain restrictions at the moment. But in future I hope I will be able to do more ppl

Interviewer 44:16

So can I just please ask one thing as you say the you have caring responsibility plus you earlier mentioned that time is limited limitation for you to involve face to face PPI meeting. So once the COVID-19 is over how you how are you going to manage those this time because as you said, you will be able to do more PPI once the COVID-19 is over. So

Interviewee 44:44

hopefully these people will be able to continue sending me documents in post because at the moment I'm not receiving any documentation in the post me. You know I I'll be able to go To the to the meetings and contribute there. Because when I was attending in the past, I was getting assistance for traveling to to the meeting, I was getting assistance for a carer, you know whether it was a professional caterer or my wife, caring when I was going away for the meeting, there was some assistance we were getting. So that allowed me to then go and participate in the ppi. So I was able to do that. And I would love to be able to do that. Obviously, I'm not going to the meeting, so I don't get any assistance. I don't need any assistant. So I think I will be able to if COVID finishes, I will be able to do more ppi. I just hope I can. But also new world has opened up like yourself, which are doing remote and you think you guys are based ?

Interviewer 46:01

Yeah

Interviewee 46:03

Okay. I can do this kind of contribution like we're doing today. Okay, thank you!

Interviewer 46:15

So was there anything in particular that made that make difficult that made it difficult for you to involve remotely, anything in particular to you can add more

Interviewee 46:24

That the biggest difficulty was not being able to get documents in the post. That was the biggest difficulty, and I can understand because from their side, the researchers side, because they were also working remotely, they didn't have facility to be able to print, if they were working in the university or in the in the hospitals, then they will be able to print and send it to me. So that was the biggest difficulty. I think the second biggest difficulty is, is really, you know, I can only sort of do one hour, maximum one and a half hours at a time on the computer, because by after that my neck starts hurting, my eyes starts hurting, I can't do what it is, if I was at a face to face, then I can do there two, three hours contribution.

Interviewer 47:21

You let them know, did you ask them that?

Interviewee 47:30

Yes. I prefer to get get things through my through my door post?

Interviewer 47:30

Did you ask them? Or was it a positive answer or negative there?

Interviewee 47:35

No. I mean, they basically told me was difficult. You know, easy, somewhere else, I can go locally to go and print.

Interviewer 47:42

Because Because I can see the posts coming every day through through my door

Interviewee 47:48

I get I get post every day I get post every day is not posed. The difficulty is for them to be able to print and send it out.

Interviewer 47:58

So because they're working Yeah, they need to go to like for example, a printing office.

Interviewee 48:06

Yeah, the printer, okay, and then send it to me, it becomes complicated for them as well,

Interviewer 48:13

you can so thank you very much, you have been, you share so many very, very important information. So I prefer to ask you more board because you know it, but shame we’re running out of time…

interviewee 48:30

I will have to go Yeah, in about five minutes, sorry

Interviewer 48:32

That’s ok, no problem, Before you go, just could you please tell me that what we can do to improve the last thing you know, everything? What could have been done differently in better ways so that you know more people like you can be involved in it in any positive way.

Interviewee 48:47

I think the the best, the most positive I will say is if my time was respected and I mean, not in terms of money to monetary value. I mean, my time in terms of like I mentioned about the postage, if researchers or professionals actually cared about, you know, my time, well, I'm having problems printing, and they know that I need to be able to to be an effective contributor, I really need documents. And you know, maybe the pride obvious to them look without them. It's very difficult. I mean, I can't read 20 page document on it will just take me too long to digest and I don't I don't have time, I can't sit down for that long. So they they will have taken you know, if they had taken time to print it out to send it to me by post, then I would have thought Wait a minute, they're taking an effort. So I will take more of an effort and I'll contribute. So yeah, I think respecting people like myself. involve me people like myself in writing the summary documents or documents so that people like us can understand Then he will give me motivation to encourage others to participate. But if I'm, if I'm experiencing difficulties, I can actually go to other BMA community and say you participate, because they will have even more challenging challenges than I am. So I therefore don't make as much of an effort, even though I know that it is necessary to be done. I don't, because I know they will struggle even more than I will. So I don't even start the conversation.

Interviewer 50:37

Thank you very much. That's very useful. Would you like to share anything else that I haven't asked you? Do you think anything you need to add? before? I did, because I didn't ask anything you could share.

Interviewee 50:48

I think, I think just that level of respect of any PPI, anyone who puts themselves forward, they're putting themselves forward. They're taking a first step. And, and therefore they're keen to contribute. And if you I don't mean to you personally, professional professionals don't recognize and therefore return an equal level of respect back to them. Even any confidence and positive energy they may have had to contribute, when very quickly die. And then we'll say, Why Why bother? So I think recognizing the PPI. Respecting those individuals being flexible with PPI involvement, making documents easy to understand, making sure that the timeline for any research or any study that is done is reasonable. You don't develop a timeline, oh, I have to do this study in the three months. In which case, what you're saying to the general public is, you've only got one day to review documents and send me your thoughts, not reasonable, be reasonable with whatever study is being done. allow enough time for engagement. I think that's important. And finally, the last point I will say is recognize every one of us have not only the ability to contribute, we have all got our own networks, networks of friends, or neighbors or communities of peers, that we can share that information, the more people we can then share the information with, the better it will be for researchers, because what's the point of doing any study any research, if it is not communicated out there? So we can all help with that, because we've got links to those communities, to the public policymakers, to the decision makers. I think that's the most important thing to recognize that all of us have got links in our communities.

Interviewer 53:27

So regardless, regardless ethnicity, recognizing everyone's voices, everyone's not the color or the race identity. everyone equally,

Interviewee 53:41

Equally, respecting equally, you know, because the people with learning difficulties there are people with physical and mental disabilities, there are people with language difficulties, control difficulties, recognizing all of those people, respecting them, and valuing them that they all have real knowledge they can contribute into. If our if our starting point is from that basis, we cannot go wrong.

Interviewer 54:16

Thank you very much. That's very useful.

Interviewee 54:18

Thank you.

Interviewer 54:19

It was really you know, helpful listening all of your thoughts and it's very important, I wish I could do more not spend more time with you. So what I will do, we'll finish the interview now.

Interviewee 55:06

The other thing is and my own, Feed my own information that I might send across, because I thought that survey was beautifully prepared. It made me think about my difficulties and my challenges. So it's a good one. And it's a good way of me to monitor myself. Maybe in six months time, has things changed or not.

Interviewer 55:29

And would you like to get report from this study as well, the interview

Interviewee 55:33

once I would love to, I love to get sort of after your study has been finished. Yeah, I would love to get a report. If I can help you guys in any way. I would love to be able to help you. Yeah, I mean, I know. Is L, who is was looking for someone on the on the advisory group or something is your project manager.

Interviewer 55:54

She's our principal investigator.

Interviewee 55:58

Yeah. So she was trying to set up an advisory group or something. If you need my contribution into that, I'll be happy to be part of that.

Interviewer 56:10

Let you know, thank you very much. Thank you. God bless you. And you, Mother, you take care of your mother.

Interviewee 56:15

Thank you very much, thank you very much for your time and your patience as well. You know,

Interviewer 56:20

Thank you for your question. And if you you know, I will email you if I need you. And if you want to know something, email us, no problem. Thank

Interviewee 56:27

Thank you very much!

Interviewer 56:31

Thank you. Good bye..