**WORK PACKAGE 1 – SESSION 5**

**Individual interview with stakeholder P5**

**26th March 2021**

Audio File Name: S5 - IDoService - Individual Interview - Other stakeholders - 26 march

Duration: 00:46:05

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

**R2: = Researcher (Interviewer in bold)**

P5: = Stakeholder

P5: You can’t see me anyway, so I can be as reclined and relaxed as I want, record away [laughter].

**R1: Exactly. Do you agree to take part in this study, do you consent, laying on your couch [laughter]?**

P5: Yes, I do [laughter].

**R1: It was really interesting, especially, I think this focus group, it was the second one you were in this focus group, I think it was a really interesting one. It was the biggest, with five participants, and I think quite a lot of very interesting information. I really like the fact, as you have maybe more of a research view, it was very interesting also the insights you gave, so yes.**

P5: [Laughter] You’ll have to remind what I said because I have to admit it was a while ago now [laughter], so I apologise if I repeat myself or if I’m not giving you anything new, just nudge me.

**R1: No problem, don’t worry, it was the same for a lot of people, (over-speaking 00:01:06) time, even for me. So, I transcribed myself, the second… first focus group and a colleague made one and the third one. I was reading that thinking: “Okay, I was there?” [laughter] because (over-speaking 00:01:22 - 00:01:27) don’t worry. Of course, my first question will be more about MCI people as I know you are an expert in that and maybe this topic of MCI or people with early symptoms, mild symptoms, I will say, more like a group and meaningful activities because, maybe, there are some differences with the kind of activities they would like. I think some of them say: “Okay, this activity, I’m not interested in that, it’s for elderly people or it’s for…” I don’t know.**

P5: Yes, for people with dementia, or for people… because, I guess, the big thing with people with MCI is you don’t see yourself as having dementia and it’s so much easier not to see yourself [laughter] as having dementia until we bring in the biomarker screenings and everything that will make a bit more of a substantial diagnosis. It tends to be a bit like IBS, I always compare it to that, I probably shouldn’t but it’s like IBS, a gut disorder that we don’t really know what’s happening, MCI, a brain disorder we don’t… [laughter].

**R1: Exactly, it’s very difficult, because it’s like: “Okay, you might have dementia or maybe not or [laughter].”**

P5: Exactly, I’d be really interested in… I haven’t done the research yet, but I’d be interested to see where people sit on one wanting the biomarkers, because there are ways to find out, PET imaging, and cSS samples and things, to see if you do have excessive amounts of amyloid and you’re more likely to progress to a dementia. It’s such a great time to do something about things, isn’t it, and I think that’s what people do recognise about it and I think a lot of people are quite motivated, but like you say, they maybe don’t want to be going to the generic dementia group. So, I gave a lecture a while ago with the MCI academy, and we were talking with a lady with MCI and a couple of people who are running groups across Manchester and that was a big thing that came back is we don’t want to sit with a dementia group, we want the group that we’re working with to be aware of when we start to progress and may need to move into a dementia group [laughter], if that happens as well. It is a very separate condition; it can be one that never leads to dementia.

**R1: It’s quite (unclear 00:03:58) but you mentioned these things for BAME communities and minorities, I will say in general, and how we can adapt, content of activities or approach?**

P5: Well, I think there’s a lot more education to be done in some communities, I don’t mean that in a bad way, sometimes dementia is not even a word that’s really used and there are a lot of communities… and, again, you’ll have heard this, probably, from other participants, it’ll be more synonymous with old age, “Oh, they’re getting a bit forgetful,” there are certain communities that will see things, like with Lewy bodies, if you get hallucinations, it could be linked to something religious or something… and, generally, can be less understanding but also, maybe, less trust of, let’s say, traditional medical pathways or even traditional community groups. So, I’d say, the first step would be almost an education step and then it would be to work out: “What’s happening in the community itself, what would you like support to continue being involved in?”

**R1: How do you think it’s possible to access these people and to educate about it. It’s not so easy. You said, last time, I think [s.l it’s in Dublin 00:05:24], I have this model for young children, so they have to go into a nursing home and have activities with elderly people in general. I don’t know if it was people with dementia, I’m not sure.**

P5: I think it’s a bit of both, it’s just part of the schooling there, that they spend a week or so, is it, obviously I’ve not experienced it because I’ve not lived there but a colleague of mine was telling me that, which is great. I think education on brain health should start really young. Like, oh God [sigh], what country was it, I was just learning today in one of our policy lectures, was it Finland? It’s often Finland, but I don’t know if it was, but very early on they’ve developed literature and awareness for schools around brain health. So, even at teenage age, about the things you can be doing to keep your brain healthy.

If you’re speaking specifically about underserved populations, I’d say you really need to know people who are working within those fields and connect with them, develop trust. I think it can sometimes be a bit difficult because if so many different researchers are trying to access communities and they’re not already integrated in a way, it can feel a little bit… I don’t know, it can feel like they’re lab rats, if you know what I mean, they don’t want too many people coming and “trying to educate”, it’s about finding a way to just, I don’t know, get to know the communities better if there’s an individual, I know… did I put you in contact with, I’ve already forgotten her name, I’m in contact with so many people, I’ve been in contact with so many people, but there’s a lady who runs an Afro-Caribbean group, which I attended one of their meetings.

**R1: No?**

P5: I can maybe put you in contact with her, I’m not sure if she’ll have time because obviously, she’s really busy but I could see. She ran a group specifically talking about… it was dementia, it wasn’t MCI, but I think the most powerful thing, I think I said this at the last meeting because it wasn’t long after I’d been to that one that I’d been at your last focus group, was that they were just saying just being there in that room and hearing other stories, and hearing it was a real thing, was just so beneficial and so supportive for them and it was something that they didn’t get a lot. I think the power of that was that it was within the community, she’s a member of the community, a very well-respected member of the community, I don’t know if it would have had the same feel if it had been, like, you and I running it. So I think you have to be very aware of that and it’s not an easy thing to do [laughter].

**R1: When I was in Luxembourg, it’s different because Luxembourg is very multicultural, I don’t know if you remember but the last two years, I was working in this information centre about dementia. [s.l We tried but it’s a problem 00:08:15], it was I think maybe 50% of the population is from Luxembourg, or Luxembourgish, but you have maybe 20% of Portuguese people and French etc., etc. So we tried to have access to Portuguese people, but it was very difficult because, it was even difficult to know if it was because, yes, dementia was not really an illness for them, maybe it was just ageing. Or if it’s just: “Okay, I’m aware of dementia but I want to keep my mum or my father with me, so I’m not going to ask for more information.” (over-speaking 00:08:57).**

P5: Yes, actually that came up, about keeping family members at home, there’s a very strong impetus, probably more so in that community than maybe in some others, that they want to care for the elderly at home, they don’t want them to go into any kind of care setting. Again, there’s a little bit of mistrust involved in that because they see some of the care settings don’t understand them culturally and they feel like their elderly relatives won’t get on there. Then there’s that extra pressure, because obviously the younger generation still needs to work, and they don’t necessarily trust care at home as much, so it’s very much that wider family and a lot of pressure is put on individuals in that case, so it can be really hard.

**R1: What we had with these Portuguese people… because when they were born in Portugal it was different, but maybe [s.l the one between 00:09:44], around 30 years or 40 years old, having parent with dementia. They said: “Okay, I’m not really for a nursing home, but why not because I’m struggling with family, my job etc.” My mum she will never be happy with that, it was really something difficult and it was really a very strong contrast because in Luxembourg [laughter] in the past going in a nursing home it was really something great because (over-speaking 00:10:14), the nursing homes there are like five-star hotels, it’s crazy.**

P5: [Laughter].

**R1: (Over-speaking 00:10:22) You have people in the entrance to take your luggage and like with the same thing with like in hotels these kinds of trolleys, you think: “Where am I?” [laughter]**

P5: [Laughter] That’s brilliant.

**R1: It was maybe a 60 or 70-year-old lady, very nice, smiling and [s.l milking it okay, I am in a real world [laughter] 00:10:41 - 00:10:44] and some kind of advertising for this nursing home. Anyway, just to say, we tried to have an information session about dementia with people from the Portuguese community, but it was really, really difficult and I don’t know if it was really efficient in the end, so yes, it’s really a big job. Is it difficult to address the topic of dementia in these communities? I suppose with MCI it’s even more difficult.**

P5: Hello [laughter] again, sorry about that, my computer just cut out, I have no idea why, it just turned off [laughter].

**R1: No problem, I will repeat my question. I suppose is speaking about dementia with BAME communities or people with a low socioeconomic background etc. So I suppose MCI or brain health, it’s something very difficult to address with them two, I suppose?**

P5: It can be, I think it probably depends how it’s done, I think you need to have gained trust you need to know the terminology and you need to understand what the community already knows. Definitely that notion of brain health is apparently quite powerful, so again, I think I mentioned, was it the Alzheimer’s Research UK report, which suggests more people connect with the idea of keeping your brain healthy than they do preventing dementia.

**R1: Sorry, is it some partnership or some collaboration, I don't know, between charities, for example, the one working about dementia and the one about cancer or heart disease, because in the end prevention, in the end it’s still the same thing you have to do for prevention.**

P5: Yes, and I think that’s where we’re going to make the most progress. So, I think in Manchester we’re great because we’ve got GreaterSport and we’ve got lots of structures around diabetes, around heart disease and things. When was it, two or three years ago now, the British Heart Foundation had a campaign, so they had adverts and the output of it was: “What’s good for your heart is good for your head,” and I think it was a little boy or something in a TV advert? I think the way forward is to probably combine them but just to make people very aware that brain health is really important, and it is something that’s modifiable. I think the biggest thing is people don’t think they can change their brain health or change that risk, definitely, of dementia. I really think that’s powerful because it’s something that people are very afraid of, you don’t want to talk about it, but I think a lot of people hold fear because it’s not well understood in the general community and definitely risk factors and a lot of people know someone with dementia and they’ll be like: “What’s my risk?”

So, again, one of the fellows that I work with studies fear of dementia and it’s just really interesting that just that fear of dementia can actually encourage people or put them at more risk because they’ll pull themselves away from society, they’ll be obsessively self-monitoring and worrying about what they’re doing and that, obviously, puts a higher cognitive load on you, then you develop symptoms and then you isolate even more. I think it’s going to be a combination approach and even things like mental health charities, because obviously loneliness plays a big factor, so again, social prescribing. In Manchester it has to be… it’s not going to be siloed it’s going to be something that’s going to have to work across sectors.

**R1: Is social prescribing something very developed in Greater Manchester or in the UK in general?**

P5: Not in the UK in general but Greater Manchester is relatively good at it. We have a number of organisations, Be Well is quite a big one, what’s the other one? I’m talking to someone from an organisation called The Bureau, but I think she manages all the social prescribers. I think they’re not, so far, haven’t been targeted at all towards brain health, if you know what I mean, they’ve been accessed for different reasons. I think a lot of GP practices, I was chatting to a GP who is, again, interested in doing a similar project looking at how social prescribing can work in his practice to bring brain health into the equation. He was saying that GPs have a certain amount of funding that they can put towards social prescribing and that they all use it differently. He was saying that with Covid a lot of them are jumping on the “let’s get people to help us with vaccinations,” but he was saying it’s not really for that. Social prescribing is something different.

I think there’s a reasonable amount of funding and budget for it. The biggest thing I question is if you have too many people prescribing to community services and things within the community, those community projects and those groups might find it harder to run because they’ll have a few too many people and not enough funding, I think that’s something we need to address. If we were to get it right [laughter] we’re going to have a lot of social prescribers talking about brain health and prescribing into the community.

**R1: Yes, because currently, for example, if I was 50 years old and having… I don’t know if I can say diagnosis of MCI?**

P5: Yes.

**R1: Because I have to say, I think it was five years ago, the last time I investigated more in detail MCI, so it’s changing so quickly now. If I have some symptoms, a diagnosis, my GP can say: “Okay, I will give you a social prescription and you will pay nothing,” or I have to pay something?**

P5: No, I think it’s free, I don’t know, I’m actually speaking to them next week and these are the kinds of questions I’m going to be asking them. I believe it’s free at the point of service, I believe they don’t do it for MCI, they don’t do it for brain health at the moment, they do it for other conditions.

**R1: Yes, (over-speaking 00:17:00) or this kind of thing?**

P5: Yes, if you have an MCI diagnosis, you’re probably going to be sent onto either an Age UK… one of the charities for Alzheimer’s Society or something like that or a lot of people just get sent back home and told: “If it gets worse come back,” [laughter] that’s what most people do.

**R1: [Laughter] Come back when you have real dementia [laughter]… see you in two years.**

P5: Exactly, (over-speaking 00:17:26) [laughter] Terrible, isn’t it, we laugh but it’s terrible [laughter].

**R1: It is. It’s really great you can give me all this information; I don’t want to give you the idea I’m taking your ideas and I will use them but it’s really important for me to have an overview of what there is in Greater Manchester or what are opportunities for people because it will help me after that when I will read all the information.**

P5: Well, I think we’re moving in the same direction, so the more I help you I feel it’ll help the greater cause as well [laughter].

**R1: Yes.**

P5: It’s like we’re doing the same thing.

**R1: I really hope you will have your funding for your project, and we’ll be able to do things together and maybe possible to have more things [laughter].**

P5: It would be great, I’ve just applied for a part-time role while I’m doing the fellowship, which is going to be fun [laughter], within health and social care. So I will be, hopefully, working within Dementia United two-and-a-half days a week, if I get the role, fingers crossed, I’m sure I probably will [laughter]. So, hopefully, being in there will help as well, so if you wanted to get hold of me, I’ll have a little bit more leeway and a little bit more access to that team soon.

**R1: It’ll be great because it was one of my questions about Dementia United. It was a four or six-year funding?**

P5: Yes.

**R1: When is it finishing officially?**

P5: It has officially finished, that funding, but they’ve been renewed and they’re going to be a department that’s going to stay present within health and social care for the foreseeable future, however, I think the whole system is now reverting to an integrated care system. It’s this new structure the NHS is taking on, I’m not going to pretend I know a lot about it, but it’s worth looking up. They’re changing to an ICS and that means that the organisation at the moment has rolling contracts. A lot of people have left the organisation and a smaller number are continuing with six-month rolling contracts because of this restructuring but, overall, this funding should be lasting a long time, it’s just the whole department is restructuring itself.

**R1: I have to say when I saw information on internet, it sounds very interesting, I sent an email to them to be part of the focus group and I had not heard, and I was thinking maybe it’s because it’s finished or something like that. It’s great it’s a long-term thing because it’s a good project but when (over-speaking 00:20:15) problematic.**

P5: I think, to be honest, you’ve just hit them at a really bad time because, obviously, the funding has just run out, so they’re running around like headless chickens at the moment just trying to get everything sorted before the switch over and a few people are leaving. I think they would really like to have been involved but it’s just the wrong time.

**R1: Yes, maybe, in some months.**

P5: Yes.

**R1: One aim of Dementia United was to improve dementia friendliness, those kinds of things?**

P5: Yes, it’s multifaceted, really, I wasn’t involved in every part of it, and there’s still elements of the service that I don’t know a lot about. The bits that I was really involved in were understanding the experience across Greater Manchester of the Dementia Well Pathway, I don’t know if you’ve heard of that. It goes from prevention to diagnosis to support to care to dying well. We went across a lot of community groups just to talk to people about what their experiences were in each part of that pathway and how we could improve it. It was about standardising that pathway across Manchester and having that evidence base available to say well, actually, this works, and this is what patients want, this works, and this is… So, for each section, they went through different consultations with loads of people.

Also, something that you’ll probably relatively interested in is Greater Moments App. This was co-produced with an external company and with people living with dementia. The idea is it’s a bit like a TripAdvisor but for dementia support services within Greater Manchester so they can rate it. I’ve not logged onto it myself, I might actually because I think you download it now, and it’s just called Greater Moments.

**R1: In the last focus group I had a girl from Social Sense.**

P5: Yes.

**R1: So, hopefully, I will be able to have an individual interview to have more details about that, because we didn’t talk about that in detail, but it seems interesting, I really like your description, like TripAdvisor for people with dementia [laughter].**

P5: [Laughter] Yes, basically, I don’t think that’s how they describe it but it’s what it is.

**R1: [Laughter] Yes, exactly. It’s great because when I was thinking: “Okay, is it access to information or to give something back?” okay, TripAdvisor is a good definition.**

P5: I think it’s got other bolt-ons as well, I don’t think it’s just that, but I think a big bonus of it is to get this idea of how many things are dementia friendly, so people can feed back and say: “I went to this place and I didn’t enjoy it, I didn’t think they were very good,” or “This one they really made great provisions for me,” kind of thing.

**R1: It’s interesting because the concept is interesting to have this giving information to people but also having information from them to improve your services, it’s great. You said you have not uploaded that or tried it for the moment but what do you think about this idea, is it sufficient to improve the access to meaningful activities?**

P5: I think it depends how it’s used, to be honest, we’ve had discussions with the Social Prescribing Network to suggest that they used this to advise people in the community where to go. I think, actually, if they’re talking to people about it, and they’re using it, that’ll really improve the way it’s used. I think the same with Alzheimer’s Society because, again, social prescribing would be more for the MCIs, the people at risk, whereas dementia advisers would be looking at people with a diagnosis. It’s like anything like that, any platform like that, the more people who are accessing and adding more information to it, the better it becomes, so it just depends on if it takes off. I kind of hope it will because they’ve done a lot of work co-developing it and co-designing it, I’d love to think that it’ll be something people living with a diagnosis would be interested in and would find useful, but it remains to be seen, I guess.

**R1: Yes, exactly, they’re really unlucky because it’s the worst moment to try this kind of thing or to implement this kind of app. I’m really interested in that because when I applied for this funding, I was not aware of this project, so I think it’s really interesting, but I have to learn more about it because I don’t want to replicate something like that because, of course, I will never be able to do that by myself [laughter] in two years, it’s great.**

P5: The lady you said you’ve got from Social Sense will definitely be able to tell you more because they were the organisation that helped develop it.

**R1: I was interested in your view about it because it’s interesting to have some external view.**

P5: Like I said, it’s a very side view because I wasn’t really involved in the project other than attending meetings where other people were talking about it, so it wasn’t part of the Dementia United projects that I was really involved in, but it sounded good.

**R1: [laughter] Dementia friendliness, the last time you talked about one of your colleagues, I think it was a theatre class or something like that?**

P5: Yes.

**R1: You mentioned the swimming pool session specific for people with dementia. Do you have other ideas or something you saw somewhere else in the UK or abroad and you think: “It’s really great,” it’s a level of innovation or even dementia friendly in general, you think is interesting?**

P5: It’s difficult, isn’t it, because I think, again, it depends very heavily on what stage of dementia you’re looking at and what type of dementia you’re looking at

**R1: I would say more early stages or even MCI, you know? Early symptoms I would say, mild symptoms?**

P5: My desire, the thing I would love to be able to do, would be to bring training sessions into a wide variety preexisting community groups because I think it’s great that there are these dementia specific things available, but they tend to be for people… it can be mild to moderate, but definitely not so much for MCI. I think opening those doors to that wider variety of community groups and making sure that they understand dementia and they understand MCI and their supportive would be great, but how easy that would be, I’m not sure. I’ve not actively seen it happen yet. So it’s something I would like to do on my project, actually, is to look at what it takes to train a community group to be dementia friendly and to take on individuals with cognitive impairment, because it just opens that door, doesn’t it? Then again, you get dementia groups across Manchester… Did I mention the FABULOUS Forgetful Friends and Together Dementia support?

**R1: No, I contacted them, but they were very busy too, it seems really great what they’re doing.**

P5: It is, yes, and they do absolutely amazing stuff. Again, they’ll deliver things to people’s doors, during the pandemic they had activity packs and things that they took to people, they have Zoom sessions, they have singing sessions, they have walking, and the FAB Forgetful Friends are kind of, not a pressure group, I keep saying that, they’re definitely not, but they’re a group who try and influence policy and get involved in research and things and they tend to be milder stage. Advocacy group is probably the word I’m looking for.

**R1: Yes, advocacy is really something important too. You said that last time, so it’s great I’m here to remind you what you said last time [laughter].**

P5: Yes [laughter].

**R1: You talked about the participation of people in research and the fact they’re not very aware of what can be researched, it’s not just very medical things, it can also be other things.**

P5: Yes, that’s a huge soap box I will try not to get on, but yes, I used to work in dementia research, specifically around recruitment and involvement, and it was an uphill battle mainly because people didn’t fully understand what research was and it’s not necessarily just members of the public, it’s the NHS staff, and the nurses and the people who are talking to them about it, they often see it as a burden rather than an opportunity. Whereas, often, when I spoke to people who are either involved in projects, or even participants in projects, they tended to find them quite beneficial, they felt like they were doing something for future generations, even if they weren’t going to find a cure themselves.

Some of them have formed friendship groups with people on the study that they wouldn’t otherwise have had and there was a chap who said: “It’s like I’ve found a new family,” these are people who I talk to a lot. They get that chance to interact with clinicians and with researchers and just to ask them all those questions that they otherwise wouldn’t have got chance to ask. I think that’s really important; I think Join Dementia Research is the best way of doing it now, but I don’t know if overall that’s going to be the best. Again, a silly description, it’s a bit like a dating app for dementia is Join Dementia Research, you probably know about it, you sign up and it links you with projects that you might be interested in, that’s good way of doing it but hard.

**R1: Is it in Greater Manchester something, not supervise but to organise a little bit different projects about dementia or even MCI, for example, a woman from Together Dementia said: “I’m sorry, I’m very busy because I have to find new funding,” also I was contacted the same week by another researcher and he mentioned in the end of the email the Greater Moments app and saying, okay, it’s very similar, this kind of duplication.**

P5: Yes, it happens a lot, and what I can I say, it’s siloed, it’s very much like, we’ve got the Greater Manchester Mental Health Dementia Research Centre, where I used to work, and even though they use Join Dementia Research to get participants, they will also go out to community groups and speak specifically about the projects that they’re working on. So, was it [COLLEAGUE] you spoke to from Together Dementia Support?

**R1: Yes.**

P5: I’ve been and visited their group a few times, I also went and spoke to them when I was working with Manchester University again, for a dementia related project. So, it’s not uncommon for people who have contacts within the community to access them outside of other services, so it will happen a lot. There are some, I think, that have regular consort, oh God, Educate, is that Stockport? Educate? They’re heavily involved in research, but I think there’s certain universities and certain individuals that they’ve got better contacts with and they’ll do things with them. It ends up a bit ad-hoc, like you say, you’ll approach someone, and they’ll be like: “I’ve got so much else on,” so it’s not easy.

**R1: Yes, exactly, because I think I contacted Educate Stockport and they said: “Oh, sorry, very busy,” usually our priority is on this network, so yes, I did, it’s not easy.**

P5: Like anything, it’s who you know [laughter], if you’re in those networks. So, Dementia United has monopoly on some of it, so [COLLEAGUE] works with Dementia United a lot, which is why she’ll be prioritising their stuff.

**R1: Exactly, in the end, I have the opportunity to talk to a lot of very interesting people, so it was really not a problem. As, with this pandemic, my supervisor, she’s new in Manchester, so she has no network, nothing, so it’s not that easy, it was just general question about coordination and how we can try on our side. Because [laughter] [s.l now we all 00:32:50] and you know, in PPI and these kind of things [laughter].**

P5: Yes, it’s really hard, I’m a “PPI specialist” and, honestly, I find it really difficult even though I’ve got various connections now within the networks because I’m no longer in Manchester. I’ve had a colleague now who has asked me to get a few people for a project she’s doing and I’m like: “Who do I reach out to? Do I know anyone who is not crazy busy?” The one thing that I’d say that I did while I was living in the city is I would try and offer a little bit more, if you know what I mean? I would say if I contacted a group that met regularly, I’d say I’ll offer to give you a talk, or I’ll offer to talk more broadly about dementia and research and then I’ll segue into: “By the way, I’ve got this project, does anyone want to take part?” type of thing.

**R1: Yes, exactly, it was quite [s.l my idea 00:33:42] when I applied, but now Covid-19, I’m thinking okay it’s really difficult. At the beginning you think… I will go to each Age UK groups and it’s interesting to meet people and offer some services or I don’t know, some expertise if I can help. In the end [laughter] it was not that great. I’ve lost you again.**

**[Interviewee reconnects 00:34:13 - 00:34:52]**

P5: We were just complaining about hard it is to access groups and all I was doing was agreeing is it’s all fragmented, everyone just… if there could be a service, a bit like Join Dementia Research, but specifically for Manchester, that everyone who was doing research used, I think that would make life a little bit easier. At the moment, it’s not there.

**R1: Yes, because soon I would like to have… I’m finishing individual interviews with people that were part of the focus groups and I will have, in April and May, hopefully, interviews with people living with dementia and care giver together. It’s not a lot of people, it’s ten people living with dementia and ten care givers.**

P5: That’s not bad, to be honest [laughter]. I mean, it’s crazy considering how many people are living with a diagnosis in Manchester but actually accessing people is really hard, it’s really hard, so ten is good.

**R1: That’s my aim but I’m not sure if I’ll be able to reach that [laughter] we’ll see. So it will be a second step. Just the last thing regarding innovation and co-designing these kinds of things, have you been part of groups of co-design sessions with MCI people or older adults in general?**

P5: Not with MCI, but [laughter] I’m currently having a nightmare trying to get a paper out, where we were co-designing an app, looking at monitoring cognition on a much more frequent basis, so it’s a really quick little application that people can interact with like three, four, five times a day. Because we’re quite interested in fluctuations with circadian rhythms but also fluctuation with infections or inflammation of things. We did this project a couple of years ago and, again, it was very fragmented, and it was when I first got to know [COLLEAGUE] and that group, I accessed them for this project, and we set up separate sessions and we spoke to them about this and that was really interesting.

The co-design process, I found it really useful because we’d actually all sat down as a team prior to this, this is the first time I went into this type of dementia research, before I was very lab-based, this was the first time I went out and did clinical stuff. We sat down and we thought we’d made this app really quite friendly, we all put our heads together and there were people there who had done a lot of this kind of work and when we took it to the first focus group, they absolutely ripped it apart, which is brilliant, it’s exactly what you want them to do, right? But at the same time we were just shocked that we’d spend so long, let’s put it this colour, let’s put pictures and words, let’s X, Y and Z. The pictures and words, someone came back and said: “Well, the pictures are a little bit ambiguous, if you’ve got the word and the picture it can be more confusing than just one or the other,” and we’re like: “We did not even think about that.” The process was really interesting, and I will have a paper at some point, we’re just battling with the journal to get it in [laughter].

**R1: As often with papers.**

P5: Yes.

**R1: You found this group were really happy to be part of this co-design approach and giving their opinion with that and open to this kind of approach?**

P5: I think when you get a group together, it’s brilliant, it’s just getting the group together. To be honest, for that project, it lasted for about five or six months and we didn’t interact with the same group every time, we had two separate groups that we interacted with because it was just hard to pin people down. On the day, my goodness, they’re really chatty, they have so much to contribute, and we made sure that we explained it well every session as well and didn’t just assume knowledge. Yes, when people are there, it’s really beneficial, it’s just getting them there that’s hard [laughter].

**R1: Great [laughter].**

P5: Sorry, I hope that hasn’t ended on a downer.

**R1: No, you know the thing, with Covid-19 situation, I’m thinking how will we be able to have this co-design if it has to be online? It’s totally impossible.**

P5: What is it you’re looking at doing exactly? How do you visualise the co-design session working?

**R1: It will be one very open… the idea is to have several sessions and give some insight and say: “Okay, we had interviews, and it was a topic, so we had these kinds of ideas, what do you think about it? It’s quite from the beginning, what are your ideas, we have some ideas of tools, maybe helpful for you, or what do you think about this proposition?”**

P5: I think it would be doable online. I know we ran a few focus sessions with Dementia United, just as Covid hit last year and a few of those went online. It’s just structuring it in a simple-to-follow way to make sure that the piece flows and if you’re having… I think break out groups are possible. I’ve been in groups where they’ve separated to break out groups to make it easier to have conversations or just have more of them with a small number of people each time.

**R1: Because, for example, I’m working with designers, they’re just into things having pictures and things you have to touch, okay, [laughter], it’s quite challenging.**

P5: [Sigh] One thing that we did the My Mind Check app, and I’m not sure what the terminology was for it, we were working with app developers, and what they did was to make a minimal working prototype to take to the sessions. It was more of a flick through of the screens, so they didn't actually do any of the deep programming until they had a fair amount of feedback. That, from the developers perspective, really helped the process because they said: “We haven’t committed that much time to this,” and then have people come back and say: “No, it doesn’t work, the flow of it doesn’t work,” so they did these very - I think they called it a minimal functional prototypes which had no backing code - it was, basically, a bit like a slide presentation that people flicked through but it went through in the order they expected it to. I think we concluded, in our paper, that’s a really good way of doing a co-design of a mobile phone app or of something like that.

**R1: Yes, that’s great, maybe in a worst-case scenario with PowerPoint, maybe we can send something at home to people, I don’t know, we’ll see.**

P5: It is difficult online, it is, I guess, like you say, maybe a PowerPoint with the images and the flow through it, so one screen and you move to the next screen, because they will make comments on the screens. They’ll make comments on both the flow and what’s physically on the screen and I think the flow was really important to us because there’s logic that we didn’t realise was wrong, so there was one point where we’d ask the question, was it after we’d shown something and they said: “No, I don’t get that logically,” anyway, it’s nitty-gritty isn’t it, but it’s things like that that came through. So, I think, being able to see the way the information flowed through the app and you used it was really beneficial.

**R1: Yes, maybe, with the PowerPoint with this flow or a very short video.**

P5: Yes, that would work. Good luck, it will be fun, when everyone comes together, I always find them really fun, but it’s just that stressful thing of making sure you can get what you need out of it and to get the right people in the right place.

**R1: Exactly, it’s [s.l my mark 00:42:41] it’s not my country, I have no network in the city and I’m working now in design and it’s really not my background, so okay [laughter].**

P5: You say that, right, you’ve made a pretty decent network from [laughter] these sessions, it seems like you’ve been in contact with some really good people.

**R1: Yes, and the things I have to say, just to be nice with you, you and other people, are very friendly and very supportive so it’s really great. Now I’m just looking forward having the occasion to see you face-to-face (over-speaking 00:43:17) maybe with a mask.**

P5: That would be nice [laughter] definitely. Like you said, if you need co-production, PPI help, just let me know as well because it’s something I’ve done a fair bit of. If you want, I can send you a draft of that paper, I don’t know if it’ll be any use to you but it’s about co-design.

**R1: Yes, if it’s okay for you, it would be nice, yes. Speaking of information, you mentioned doing focus groups, you could give us the name of your colleague, this theatre group, dementia friendly, she adapted a theatre group, so I don’t know if you can send me, one day…**

P5: Yes, I could, she’s not from Manchester though, she’s from Leeds.

**R1: Yes, but it’s not far.**

P5: [Laughter] No, you’re right, it’s not.

**R1: It’s very Greater Greater Manchester [laughter].**

P5: Amazingly, I’ve still not met her in person yet even though we live that close, we’re both on the fellowship, but it’s been lockdown, she’s been writing a PhD actually at the moment, so she’s just crazy busy, so I’ll double check with if she’s okay to do something else, but yes, I’ll ask her.

**R1: In worst case scenario I can just send her some questions, if she wants to give written answers, it’ll be enough. It’s great, so I don’t know if you have some final remarks if you want to ask questions?**

P5: I don’t think there’s that much else, no, I said I’m really interested in the project and I hope, when I actually come back to Manchester, and I start doing work, I can link in with some of the stuff that you’re doing as well, and I can be more help [laughter] and just good luck with everything and I hope it pans out.

**R1: Yes, no problem, with pleasure, our website is not online for the moment, so I will probably send you just emails to give you some updates about what we’re doing and where we are going in the project. My last question for you, for your participation, you can have a £40 voucher or if you prefer you can also make a donation, if you want.**

P5: Can I put it as a donation?

**R1: Yes, no problem.**

P5: I don’t know where to, where are you donating to? Alzheimer’s Research UK? A local group? If you can put it towards a local group.

**R1: If you want you can choose, the university is quite open, as long as they have a link or PayPal things for this kind of thing.**

P5: Okay, I’ll have a think and I’ll let you know.

**R1: Perfect.**

P5: Lovely, all right, well lovely to speak with you and have a nice weekend [laughter].

**R1: Yes, you too.**

P5: All right, bye for now.

**R1: Bye.**

**[End of Recording]**