**WORK PACKAGE 1 - FOCUS GROUP 3**

**Focus group session with P9, P10 and P11**

**Date: 24th February 2021**

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

P9: = Stakeholder

P10: = Stakeholder

P11: = Stakeholder

**R1: = Researcher**

**R2: = Researcher**

(Recording has now started)

**R2: Exactly. Ok, thanks a lot, I will begin with the first question. So, my first question is what leisure and social activities are people involved in and where do they go to attend or participate in them? So, have you got some favourite activities or things like that?**

P9: Do you want me to go first? so can I just qualify the question [R2]. So, is it ‘What sort of activities with people with a mild to moderate dementia involved into my knowledge’ is that what the question is?

**R2: Yeah.**

P9: So, what I found is that in the types of activities that are available for people with young onset or early to moderate dementia seems to be quite thin on the ground. A lot of the activities that were available when I was working for two years, for people living with dementia tended to include things like memory cafes where the people attended the dementia was quite progressed and they tended to benefit the carers more so than the people living with dementia often and therefore they didn't really meet the needs of people with mild to moderate dementia. And people often found difficulties in and so those activities didn't tend to meet the needs of younger people or people in the early to moderate stages and they often had to try and find things that they were interested in themselves. The types of activities that memory cafes tended to be like sometimes quizzes things like that, arm chair aerobics, bingo, things like that. But just because you're diagnosed with dementia doesn't mean to say that you've lost interest in all of those things that you've done throughout your life. Or indeed that you've got the ability to learn new skills so one person living with dementia, in particular, who had a history of working as a manager, and before that was very involved in horticulture - he [WORKED IN GARDENING] years ago and he was in [AN ARMED FORCE]. He's only in his mid 60s. He actually took up, woodwork once he was diagnosed with dementia and in the four or five years that I've known him, I think that's contributed significantly to him staying well and the access that through a community sort of hub that was for people that was experiencing social isolation. So, it wasn't just for people living with dementia, it was for anybody and a lot of people have mental health issues, severe and enduring mental health issues or addiction. He joined that and through that through groups I was running, he invited other people living with dementia, whose symptoms was still in the early to moderate stage to get involved too. That project sadly folded, but what he did was he got a little shed in his in his garden which over time has now evolved to a great big huge shed with electricity and heating and all the power tools you can imagine and he did find another service that we do woodwork, but during Covid that’s also shut, so he's wanted to continue. But his plan is... I think he feels a little bit disappointed and let down that some of the services that have been a life line to him have closed for whatever reason and that can leave people living with dementia with nowhere to go. So, I think his plans are to set up his own in his garden and advertise it for people living with dementia and invite them round to do woodwork in his now fully fitted out shed that's all singing all dancing.

**R2: Great.**

P10: I think one of the things that’s come through... I mean, I only took on this project in [2021], having not been involved with previously lot of experience working with carers and in health and well-being previously but not with dementia. I think one of the things people have said over and over again is it doesn't necessarily have to be a dementia specific activity and people living with dementia are just people, and they're not a homogeneous group who were all experiencing dementia. If you've met one person with dementia, you've met one person with dementia, but it's actually about making broader activities, events and services more accessible for people and if they're more accessible for people living with dementia, they're more accessible for a lot of communities as well. So, it's about finding dementia friendly things. So, one of the things people are telling us that they want on the app, so there's the opportunity to review services, but other important things to them at the moment are- is it Covid safe and what are the facilities like? So, if it's a park walk that we're promoting, is there parking nearby? Are there benches to sit down or not? Where the nearest toilets? That sort of things. And whilst those things might be important for people living with dementia, those things are pretty relevant for lots of other groups in terms of Accessibility to access activities. And people are at the moment reporting a lot back to me that they're missing that social contact, particularly where a carer can go along to an activity with the person living with dementia. And there's no pressure on either of them to join in with activities that they can do, and they can also get that social support and peer to peer support. And I think at the moment, while there's a lot of virtual stuff going on and people are using technology more than they were prior to the current situation. And people really are missing that face-to-face contact, and they're reporting a lot of people are declining quite a lot of people living with dementia because of that lack of mental stimulation in terms of, meeting new people, trying new things, doing new activities for that brain stimulus so that's one of the reasons we've partnered with Bright Copper Kettles so users of the app have got free access to what would usually be a range of activities that would be subscription based. Bright Copper kettles work a lot with care homes providing activities, so with the lack of actual face to face activities, events, and services to put on the app which obviously we didn't know when we were commissioned to do this, and I would never have wanted to have launched such an app during a global pandemic really if I’d had a choice! Because everything that I would have wanted to do and everything that I've done throughout my career to engage with people, whether that be professionals or people in the community has been taken away. And so, after furlough, kind of starting from scratch with contacts, people’s emails are busy. If they don't know you, they're not gonna reply. You can't just be nattering to someone at a table exercise at a conference or when you bump into someone having a brew and you're swapping details. All of that's kind of gone, so I think it is posing a lot of challenges in terms of activities. But there are still a lot of grassroots community voluntary community sector organizations that are still doing lots of work and some of them are still seeing people face to face an whether that be at a distance or because they are particularly vulnerable and need that intervention.

P9: I will totally agree with what [P10] said that when you meet one person living with dementia, you've met one person and they're just people like the rest of us. And like different things and have different interests. And the choice should be there and it's about enabling more awareness around dementia, more widely, and making mainstream what everybody else wants to do more accessible to people living with dementia. So, it's not dementia specific. That said, there's also value, like you said, [P10] in the peer support that can't be overstated, especially if somebody is newly diagnosed.

P10: It's just having that meeting, someone else who's got a similar experience to you, I think it's incredibly reassuring, particularly when people are new to a... newly diagnosed, even like new to go into a service like it takes a lot of confidence to rock up to a service for the first time, so it's nice if the services can be accessible to both the person with dementia and their carer. And things kind of going on within that environment that seems to be really popular with a lot of the people that we've spoken to, and it gives them, potentially if the person that is cared for is off doing an activity that gives the carer a little bit of a break. They can have a natter to someone else so that sort of thing I think is... That's what people tell me time and time again, that they really, really enjoyed and it doesn't have to be dementia specific. And actually, there's quite a cohort of people that don’t want the D word, as they would call it to be used, and would find things like a dementia cafe or something like that, they would see that as a massive barrier to attending that service. So, it's having that variety really and working with other services to make them more accessible. What things would be barriers to access for a wide range of people, but including people living with dementia, and, you start to make things more accessible, they become more accessible to much broader communities than perhaps the one you might have been initially targeting.

P9: I mean, I've seen it with my own eyes. The absolute value of things such as singing for the brain. I went into a ward and when I was in a previous role for people that were waiting to be moved to care home so it tends to be for people where dementia was quite progressed and there was a singing for the brain session on where literally people came to life when they heard a song that regardless of how progressive dementia was, it seems at that part of the brain is unaffected than it was just I was mesmerised, I was just in awe to see.

P10: It's so powerful, isn't it? We actually put on a Christmas show where we got an opera singer to sing a lot of kind of Golden oldies Christmas songs. We did song sheets and some of the videos that were coming in from people sitting at home, singing along and these people who might be quite quiet might not be very verbal a lot of the time, and things like that really, just absolutely loving singing along and remembering all of that. Yeah, it was, it was fantastic. I'm not gonna lie, I cried! Yes, it's really important if you think about like that applies across the board like you hear a song that from a particular era and it takes you right back to that moment in your life. So, it is the music is really, really powerful.

P9: I found that people with early to moderate dementia can also enjoy singing because it's something where they can forget about the dementia for a while. Because that's often a bit of the brain that seems to be less affected because even in the early to moderate stages there’s some activity that ... it can be universal, but why can't it be that people living with dementia can join a choir in the same way as somebody in a wheelchair could. It doesn't necessarily have to be singing for the brain sessions tailored for people with dementia. It needs to be opened up more. One other thing...

P10: Yeah. Yeah, supporting those services to be more accessible in the broadest sense, really. Some people will want to attend, carers will want to attend particular carers groups as a carer of someone living with dementia, some people with dementia who wants to attend particular dementia groups. Some people just want to know what's going on locally that they can access that might be something you they can try or might need their interests. It’s trying to have that mixture? Just like if you ask me what I wanted to do or any of you what you were interested or what you would like to do locally, it's the same. None of us would come up with the same things and we don't want a range of options.

P9: Before I dominate all the time because I'm aware [P11] hasn't had a speak, I was just gonna say 1 final thing as well about something that's accessible to everybody regardless of the stage, but including people with early to moderate is working with animals like animal therapy. Again, it's just so it's accessible and petting... I remember, a lady told me that give me tears in the eyes [P10] at Christmas time they brought a donkey in to a care home and some of the residents that weren't verbal one of the gentlemen actually spoke to the donkey ‘here boy’ or something, he hadn't spoken for many years so, I think like some of the activities that can be tailored to people with advanced dementia have a therapeutic value to all of those because I'd like to pet the donkey too.

**R1: Absolutely.**

**R2: Right, yeah, thank you.**

P11: And so obviously I have not been in this role too long, but most of the people that we that I seem to have contact with generally a more advanced in their diagnosis. The few people that we have that sort of early onset and have got mild or moderate symptoms they don't want to engage in most of the services because they’re kind of not suited to them. We did have a men's only club that was run by one of our colleagues, but that wasn't dementia related. It was for anyone over the age of fifty and so a lot of the men used to really enjoy that they enjoyed not having women around them.

P9: Yes, that's very important too - like men sheds type things, [P11].

P11: Yeah, so the people that had sort of mild - moderate symptoms, they would join that because that was open to anyone over the age of 50 regardless of what else you have going on.

P10: Sorry, I’m currently being interrupted by my support animal.

[THE GROUP DISCUSS THEIR OWN PETS FOR A COUPLE OF MINUTES]

P9: But coming back to what you said [P11], those gender specific things are also very important. I think regardless of the stage you're at living with dementia, them sessions where it can be men only, where people with early or moderate dementia can mix with other men and talk about football or go in the pub or anything else that men wanna talk about that doesn't involve dementia.

P10: I think the key thing really with setting up any kind of activities is you gotta have that coproduction, I’m not a carer of a person with dementia. I don't live with dementia. I have no first-hand experience of it, so the most important thing for me is that we've got those people with the lived experience involved every step of the way. So, we have a network of champions who range from Chief officers of dementia support organizations to people living with dementia and carers of those living with dementia and you need that community engagement and involvement. I would never set up a project or a service without that level of consultation and coproduction because they are the people who will continually be able to be involved in an informed way what services people actually want and need and get value from. And I think that's a really important thing. And to monitor them in a way in terms of, on the app, we can... for the Christmas show we got people to record their well-being a week before the event, the day before the event and then after the event to see to track that kind of well-being. And that's one of the things that we can do on there is if people were putting activities on there then you can do that kind of well-being measure and see if there is things that give a particular up turn to the people that are using the app and I think that's really important to mind and obviously to understand that there are lots of other things going on in people’s lives and just because they might be having a bad day that something else might have happened in might not be directly related to an activity, event or service, that community involvement is so important. I think whenever you're trying to put anything on and not being afraid to try new things and not being afraid to if something doesn't work, that doesn't mean that it’s not never going to work. It might just not be the right time something might not fit with people. Is it the right day is at the right venue is at the right time, was it promoted in the right way, in the right places? So yeah, there's so many different factors, something that might work well one week and might not the next, and it might not be for any particular reason or anything like that. That's one of the reasons I love working with communities because of the sometimes unpredictable and interesting nature of it.

P9: I think I'm what you also alluding to their [P10], is that we live in a culture where we're all very risk averse. And people get concerned about working with people living with dementia because... We don't really know what then the persons need are or they don't know that much about dementia or the image they've got of people living with dementia is that stereotype of someone sat in a chair in a care home. And then so I'll give you an example what you were saying about co-producing or Co designing services. It's so important so many years ago I was working doing a similar role to this where it was about involved in engaging the public, but with adults with substance misuse issues. We got some funding from the lottery and we set up this project in the community and then before they did that role, it didn't really know that much about drugs and I'll call myself or really about addiction. So, I just set about learning about addiction from the people that was working with and it tended to be people that weren't accessing services, so rough sleepers, people with very complex needs, lots of physical health problems, complex mental health problems, and they would often dependent on drugs or alcohol or both. I literally designed that service with them and we were ending up achieving better outcomes than drug and alcohol services. At its height we would attract in up to 50 people who were in active addiction to some of our sessions on a Thursday afternoon where we put on again things that they wanted. The people themselves were running a tea bar, they were making packed lunches for people to take away. We were having board games, badminton, pool. Alongside that we have some more coming in doing craft. We also had a nurse coming in like do triage and people for leg wounds and trying to prevent hospital admission. People thoroughly enjoyed it, I was working on my own and I was having up to 50 people were in active addiction turn up on a Thursday. It grew hugely, and that was all down to the fact that it was designed in partnership with the people who are going to use that service.

P10: And remembering that whilst people might have... everyones got specific needs and so that that's not condition dependent and it's remembering that they are person 1st and actually if you're not sure about something... I haven't chatted to any carers of people in the dementia or any people living with dementia have been bothered by me asking about them, their lives, how it acted on them, what they would like to see that isn't out there, and what they particularly enjoy and I think that's really key. This is just another person. And don't be afraid to ask questions and find out what life is like for them and what gaps they might be in terms of activities, events and services that they might want to see.

P9: Like and saying about being risk averse and that being a barrier. One of the things we did was a lot of the people I was working with on that project on addiction were living with a blood borne virus through injecting drugs such as hepatitis C. So, you would think that the idea of doing crafts using needlework would be a no-no. But we did a risk assessment in partnership with the nursing team and the people in the group were able to make a huge like memorial sort of thing like a like a collage where they all created like a square and do so in that their own needle kit and everything. And then it was all put together and it is fabulous. So, risk can be overcome, but it's having the courage to do it.

P10: And actually, you should be putting that in place for any group, because there might be people out there who've got a blood borne virus you don't know about it. So those people like… that's a known case and it's like people in any community you don't... People don't necessarily have a diagnosis, so if you're going to be thinking about service creation instead of its design, it's actually thinking about how do you remove, how do you understand and remove those barriers to access that might be in place for particular communities.

P9: Yeah, on the assumptions that people make because that was one of the arguments, I put forward that I could be hepatitis C positive and I could go to any needlework class, so why shouldn't people in that group be able to do it as a separate?

P10: I used to work in sexual health and HIV services and it's the same if you're doing anything like that, you should just make the assumption that everyone’s got a blood borne virus and then make your risk assessment based on that.

P9: Exactly.

**R2: Yeah, and so we are speaking a lot about community involvement and is it because... I really have to say it was where one of reasons when I'm very happy to be in the UK because you're really in advance in the involvement of people in research and these kinds of things. And for example, in Luxembourg, it was really difficult just to have a peer support group. It was very difficult to find people living with dementia. Happy to be part of this group, so do you have some tips or maybe things that are easier that help people to be engaged? So, for example? As a people with dementia and maybe carers are they happy to be, maybe you can say that, but to be part of that or maybe other afraid saying, oh, I don't know maybe, what I want is no things for everyone.**

P10: I think I think it depends. I think what we have got particularly in Greater Manchester is a really engaged involved in vibrant voluntary and Community sector services and I think in order for people to be engaged in consultation and coproduction, they need to have a level of trust. So, by what I've done is built relationships with those organizations and via them access to the people that access their services. And then there's kind of that level of trust instead of trying to go out and find individuals particularly... because cause most of those organizations have so many events and activities going on, they probably already got a group who's like a service user involvement group and I found the people in the kind of dementia community are very passionate. So, we were involved in kind of a Twitter chat with Diverse Alzheimer's. And it was huge amounts of engagement on Twitter. I mean, it was really difficult to manage because I think I have my laptop and my phone one and it was quite challenging, but those networks are already there. So, if you want to engage in a community level, it's building those relationships with those fantastic VCSE organizations that there are who are already working with those people and have that relationship or level of trust.

P9: I’d agree with you [P10]. And also, that's becoming even more important through in the context of Covid because whereas I used to do quite a lot of place-based outreach where I'd go out and I’d arrange to go and visit a project and then...

P10: Chat to people...

P9: Have a brew with people and get to know me because I’ve found if I just try to circulate a flyer, you'd got a low response rate because it all comes down to relationships and if people have met you and you can take away the fears and let them know that they're going to be supported if they get involved, that can make all the difference. So, like [P10] says, during lockdown, we've very much increasingly utilized relationships with the voluntary sector and others, many of whom have shifted some of that activity they've done the hard work of enabling people that were digitally, weren’t digitally literate or didn't even have equipment? Very often they've done that groundwork to make that happen so that they can continue to deliver their own services. So that's something that you can benefit from.

P11: Yeah, we currently have the Get Connected program here, so we have a loan system going on, so we've been loaning out iPads and we've been running courses on teaching people how to use and access zoom. So, our hub meetings have moved online so that people can still join them.

P9: Is that for over 50s [P11]?

P11: So, this is mainly for anyone that's got mild cognitive impairment or a diagnosis of dementia, and I imagine if somebody phoned like general inquiry, we may be able to help, but it's generally people that were sort of already aware of.

P9: It's just that I'm going to a meeting next week called ‘all around digital inclusion’. So, if you could send me the details, it just be good to know about that because a lot of our work has a digital focus now and as we know digital is not for everybody, so anything...

P11: No, we found we’d send some iPads out and they were back within the day there were people were just like no it's not happening because again, if you can sit next to someone and show them how to use the iPad and you show them how to swipe. But trying to describe that over the phone with somebody that's never used technology before can be quite challenging.

P10: Yeah, there's that fear of breaking or doing it wrong, so ideally, I would have been wanting to go out to Community groups with an iPad. This is how you log on. Do you want me to set you up an account, this is how you do this, I can do that and it breaks down any anxiety or fear? But how do you show someone? How do you build that confidence in someone if they're not feeling confident with technology without having that face-to-face rapport, it is an incredible massive challenge? But there is some fantastic work going out going on across Greater Manchester in terms of digital inclusion and providing equipment and Wi-Fi and training for people. But there are some people there are some people who just aren't going to... It's not for them. They're not going to want to use the internet, and, that's fine, that's their choice. So, we know that our app is not going to be for absolutely everyone that's diagnosed with dementia in Greater Manchester, but hopefully a cohort of people will find it useful.

P9: [P11], I'd like to know the details of that if you was able. If you can share me if [R2] or [R1] could share my email address with you for the work, you’re doing around digital for people with dementia because it's really interesting.

P11: It would only be for anyone within the Trafford area.

P9: That's fine, but there could be like... because we look for innovations to roll out more quickly and things that would benefit the NHS. It could be the approach that you were using might help... if what I mean, so it's just learning, understanding how you're managing to do that when there could be multiple barriers for people. How are you managing to empower them to get on to be able to use technology and devices may be interested to know more.

P10: Bolton CDS (?) I know we're doing something. They've got a digital inclusion network there because I went and chatted to them about the app and they're doing a similar thing in terms of I think they've got some funding to provide people with devices and Wi-Fi and training so that they can break down some of those barriers to people getting online.

P9: Could you send me the details of them [P10]? I know about digital buddies and because they do something where young people support older people to be able to become digitally literate and stuff.

P10: I think I think there's a lot of that going on informally as well, and we've had more carers registered for the app than people living with dementia, at least initially. That balance is tipping a bit now, because the carer tends to be younger than the person that they're caring for, and they tend to be slightly more digitally savvy.

P9: [R2], the things we’re talking about, is that the type of things you're looking for?

P10: Will be having our own network meeting, yeah?!

**R2: Yeah no, no, it's yeah, it's really interesting and you're bringing up topics that are very interesting no. It was really indeed how to involve people in this kind of things, because as you said, we have this the stereotype, but dementia and the image of dementia is quite related to severe stages of dementia, when the person has maybe less autonomy, so and it's very important to find a way to involve multiple with early stage is an example. Maybe until now a lot of activities were maybe quite passive and how can we tell other people to be more active and as human changes at the beginning, people created their own activities, their own things and all groups. So, it's really, really interesting. And regarding digital inclusion, we saw a lot of testimonies, about the fact some older adults had no ideas before COVID-19 how to use that, and we're not interested in. But now they're quite happy because they are able to manage that to contact their family, friends or having activities. Do you think it's also...? Have you heard of similar stories in people with early stages of dementia and they are now maybe quite proud because they think, OK, I'm able to...? Before that I thought I was not able to use Zoom, but now I can. I see I can do that...**

P10: I think, yeah, that definitely describes some people, and I think for other people they're just a bit like... They're scared of doing it and it's all, going into a group is quite scary anyway. If you've not done one on line before, I think that's additionally terrifying. And also, if the thing that you're really missing during lockdown is face to face contact with people then I think that people just think it's not going to be the same, so I'm not gonna bother. And I think some of that is about having... Where there's been a carer who might have been more confident with using Zoom or teams or whatever format is being used and then enabling the person providing they're within their household to be able to feel a little bit more confident with it, we found it a real kind of mixed bag, but a lot of the... I might go to a group where only they usually have 20 people, but only three people are on the zoom. Or I went to the Hayward Middleton Rochdale Circle Group last night and they were quite a really good core group of them on that meeting so I just think it's a really big mixed bag I found.

P9: The other thing is not just confined to his email or Microsoft Teams because one of the platforms, the ladies running a project in Rochdale where she's working with the South Asian Community including lots of older women. So that will include people living with dementia is what the WhatsApp platform.

P10: There's definitely been a massive growth in those in terms of the stuff that we've been promoting on the app. Obviously a lot of stuff happening virtually, and so some of it by services has been that they've got particular WhatsApp groups now where people use that as a mechanism for support and engaging.

**R2: Maybe in some cases it can be good, because maybe some people are quite shy, and going in the group they want to have some crucial social contacts, but it can be quite impressive to go in education building and meeting, a group of 15 people so maybe in this case having a zoom meeting or WhatsApp exchange can be helpful for some people.**

P10: I think it definitely works for some people, although most community services I know if someone was to say to them it's my first time coming and I'm a bit nervous about it. I think most of the services I know and I know I used to do it. I'd go and meet them somewhere they felt comfortable to meet nearby and walk in with them because that initial going into a service is pretty terrifying and I think that going on a zoom is. I do think there's potentially if you're savvy with the technology and happy using WhatsApp, I think it does... You can build that initial report a little bit where you might feel more comfortable going to face to face group when you're allowed to.

P9: The other benefit of working... what we were saying before about the value of these networks and connections with like the voluntary sector and stuff. Because those relationships that it also helps overcome or the barriers such as language barriers so. Like recently I was working on a project called Around Digital Tools. So basically, about access to GP services that have been moved online during the pandemic, and a lady who set up this service in Rochdale, she's managed to move her things online to WhatsApp. She was able to deliver that group in Punjabi.

P10: Brilliant

P9: So again, that's another benefit of engaging with utilizing the connections that that you've got, I don't know if you are both aware, but at Health innovation, Manchester, we've got a Greater Manchester forum and it's made up of professionals, but also members of the public that lead in public involvement engagement activity. Where we can share best practice and things like that and also work towards some what we call shared outputs. So, we recently did like a briefing paper about involvement and engagement that had been done during the pandemic and how people have gone about it so I could share that paper with you because it's in the it's with all four of you because it's in the in the public domain. So, it’ll give you some tips on what people have done, what approaches they used to involve and engage the public. I know it won't be specifically people living with dementia, but like we said before, if you're looking at early onset or people with early to moderate symptoms and some of those people might still be accessing some of the services that people are delivering. The forums attended as well by representation from the four universities including Manchester met and also the NHS trusts and also young people’s networks and things like that like 42nd St and Mental Health Network across Greater Manchester and we've got like 30 plus members now and we hold monthly forum meetings where you can come to learn more about what others are doing. So just thought I'd make you aware of that as well.

P10: Yep, yeah, that sounds like a fantastic network. Yeah, yeah, for me it always comes down to two things. Have you spoken to people about what might work and what they want and how it's going to work and are you trying lots of different methods? Because if you're trying to do a piece of consultation and you've only got one method for it, it's not going to work very well. It's like with other things, you need to have... Not everyone is going to want to do an online survey. Not everyone’s gonna want to go to a focus group. People will access things in different ways, so it's trying to... It's working with those people and asking what range of things that you can have as a as a suite of engagement tools that they're going to get you the best bang for your buck, I suppose.

P9: Exactly multiple methods, so even like with that online access to GP services, we did an online survey, but alongside that we did some virtual discussion groups. Then there was some community... A lady from Rochdale did and the WhatsApp group with the South Asian Ladies and then she did some telephone interviews for us with community and faith leaders as well. So, we have to like you've just said [P10], a mix of approaches.

One size doesn't fit all.

P10: And being I'm being kind of led by people. When I, when we did the first 2 phases of testing on the app, I set up an online survey for the testers, but said ‘if you've got feedback, you don't have to fill that in. I can arrange a phone call with you and you can send me an email like however you would like to give feedback on it. Just tell me that's absolutely fine, because your feedback really, really valuable’. And obviously it's great to have an online survey because you can collect those results really, really easily and run a report really quickly, but it wasn't vast numbers of people that we were getting to test so I was happy to take feedback anyway that it made it accessible for those people.

**R2: Speaking of accessibility and difficulties, so we mentioned the use of technologies that can be challenging, but I would like to ask, but potential difficulties you might have observed with we get to access to leisure activities and also potential difficulties during these activities, so what difficulties do people with early to mid-stage dementia experience in participating in leisure activities on offer? It can be... so we talked already, about IT, these kinds of things but it can be I don't know be transportation... all these kinds of things.**

P9: Access to transport can be something because if even if the symptoms if they’re at early to moderate they may have lost the driving license so those people may never have used public transport for years. Well so it can be quite daunting. And so, transport is definitely been an issue. But also, I think like [P10] said before about when somebody... how difficult it can be to access a new group or go to a new activity. That can be more so when you're newly diagnosed with dementia because one of the things that people have reported to me is that one of the things that happens is you totally lose your confidence. When you're diagnosed and also the mental health impacts are basically being given a terminal diagnosis is obviously huge, so just because somebody's in in the early stages doesn't mean to say that it's have a small impact. The impact could still be huge.

P10: Yeah, think about the things that might be potential barriers and what could be removed. So how accessible is the place on public transport actually, how affordable, is it for people to access and then once you get in there, I know that there's lots of one of our champions has been involved in projects where they've gone to football grounds and gone round and supported that football ground in terms of things that they could do to make it more dementia friendly and I think that's something that really resonated with me in terms of what is important to those groups? And actually, what can these services do that breaks down some of those barriers? So, getting people involved and thinking about what... What would stop someone from going somewhere? And is it fear of going there? Is it being able to get there? Is it the cost of going there or are there other things in terms of...? The flooring. Is the flooring really, really busy and it makes them feel like they're going to fall over or, they can't sense depth and perception? How is the signage and things like that? Other things that might make people feel a little bit more comfortable? I think there's a role, a partnership role for organizations across the patch to work with services to support them in that really.

P9: Definitely think the key here though is to be able to ask people who are in the early to moderate stages, what their values are. That's what I think was really help inform your work as a while ago we were doing a piece of work around creating these dementia friendly swimming sessions and people will always tell you things that you just wouldn't have thought of, which is the whole value really, so one of the barriers for people using the local swimming pool, is that in the changing rooms they used to have music playing in the background. Like when you go shopping and you can hear the music in the shops and that they found really difficult when they were living with dementia. They just heard noise and found multitasking difficult. So, we were trying to focus on one thing like getting dried and getting dressed. This music was really distracting for them.

P10: And yeah, just little things like how if someone is in that early stage and they still are being able to enjoy films. If they're going to the cinema, what's the lighting like in there? Are they going to be confused by a lot of trailers thinking that that's the film starting and then they forgotten about it like it so many just little tweaks like that that that can I'm really impact people? I know a lot of people at the beginning of the pandemic were saying to me, it's really, really difficult when the signage in terms of how you walk around the shops is on the floor. And for people with dementia to be focusing on the floor and trying to follow that round isn't great for some people in terms of perception and the way that they're looking at it, better to have things up at eye level that people could follow. But yeah again, it's about asking people, but there's often very small little tweaks that can be made that that make a massive positive impact on people's lives that would then... And if there's a lot of places were marked as dementia friendly. I do think there is some value in that kind of kite marking system if you will, and I want to work to LGBT foundation, they did their pride in practice around GPs being positive about LGBTQIA plus people and they had to go through a process to demonstrate how they were making people feel welcome, how they were making sure that they were inclusive, and I think that that there definitely is some merit in that in terms... Back in the day when I was working with young people, it was the ‘you're welcome’ and standards. And actually, those standards work across the board for making services accessible to lots of different groups of people, not just young people. So, I do think there's potentially some merit in something like that? There's some standard here. These are some key things that you can do to make your services more accessible for people living with dementia, but also by doing that you are generally making your services more accessible to a wider community as well.

**R2: So, it exists, for example, some initiative like Dementia United to really help services to have more knowledge about dementia or inclusiveness in general. And do you think, for example, we just talk about swimming pools or this kind of thing, do you think owners of these places are aware of that, and they're really willing to do efforts and proactive in having more information to other I don't know, swimming pool shops or things like that more inclusive. Or do you think it's still for an Association for example to educate or you action to go to see them and say OK, it would be great if you can do that and that.**

P10: I think some services will want to do it because it will improve their profile. It's something they can promote on social media. If it's a service that might be eligible for applying for different types of funding, that looks great on a funding. but also, a lot of people’s lives have been touched by dementia and so you'll find our Christmas show badgering(?) who are based in Media City are a video production company they filmed and edited that for us for free for the app because someone there, their lives have been touched by dementia and they thought it was a fantastic project and really wanted to help. So, I think that there is that that you can harness within the community and also, we've got a group of really passionate champions about our project and I think there's lots of different groups out there like that. Who, if you just speak to one of them, you'd be like, yeah, of course we want to do that? That's got a massive number of benefits, so there will be some people that want to be involved, but I think for lots of different types of organizations, whether they be a shop or a takeaway or a service, I think there's lots of positive motivation for people to work towards that sort of thing.

P9: I was only gonna say it could increase the revenue as well. If their premises is more dementia friendly, the more likely to attract people living with dementia to attend. So, in these times when people have been furloughed and the economies on its on its knees, to say the least, encouraging people to access their leisure facilities can only be a good thing.

P11: I was just gonna say that it's a service that we actually offer here at Age UK Trafford, so we offered dementia friendly training to local businesses. So, a lot of the local opticians and things nearby have been provided with that training and they found it really helpful.

P10: I think it's great. I also think there's that visibility of it. So, one of the things when I worked with LGBT communities was if they could see if they're in their GP practice and they could see a poster that was from our organization, they would feel safer coming out to their GP or feel better about the fact that it was their... It gives you that confidence. I am being represented here so. If that like the work you're doing, I couldn't remember whether it was Age UK that was doing that or not, so I don't wanna say case, I got it wrong, but I just think there's a lot of power. Even people displaying a sticker, it just in terms of people being able to recognize and go ‘Oh, that's the place I'm going to be safe and I'll be OK in there’. It’s that visibility thing as well but. Yeah, I think it's got a ton of multiple levels of benefits, not just for those who are accessing.

**R2: Speaking of minorities for example, so just talk about LGBT can be also some technical minorities. I think it's quite difficult to be aware of the specific difficulties they have so do you think it's something to improve in Greater Manchester?**

P10: At the moment, a lot of the stuff on the app, a lot of stuff is in writing and actually just translating stuff isn't necessarily very helpful for people whose first language isn't English, particularly older communities, because they might not actually even read in their own language. So actually, thinking about what images can use. If you see a sign for a toilet, that’s a sign for a toilet. You don't need to read the word toilet above it and you can see that in lots and lots of different countries with lots of different languages on. You can identify things like that, so it's actually what common images and things can we put on there and actually do people understand spoken English? It might not be able to read it, but actually can they pick up on spoken stuff? Then you have some voice stuff on there and it's just thinking about those little things like instead of a big chunk of writing, are there any images that you could use that would demonstrate the same thing?

P9: And also, people might lose the ability to read as their dementia moves...

P10: Do they struggle concentrating on long bits of text? One of the mobile champions gets really frustrated. They used to absolutely love reading books, but he can't now because he just gets halfway down the page and he's forgotten what is read.

And maintaining that. So, thinking about the level of text. But once again, that's one of those things that helps a broad range of communities actually having loads and loads of text isn't massively successful loads of people.

P9: Just to say as well [R2], involving people living with dementia research and I don't mean like in clinical research, but any type of research is something else and activity can be really well received because it means that devastating diagnosis has got some value that they can share, and so I've got an article that was written by one of the people that I've worked with who's living with dementia. It was published in like a Journal and but he did it in partnership with Lancaster, Lancaster University. I think again I can send you that to look up because he's talking about as someone living with dementia himself, how much it's enriched his life to be able to get involved in influencing research.

P10: I think as long as you've got that feedback loop in, what people hate to do is to be consulted about something, give loads of opinions, loads of advice, loads of information their own personal experience, and they don't know what happens with that. So, what's really important people is knowing that they've been listened to and valued, and that that's had some impact, and then that's fed back to them. Some of the people we've spoken to are like ‘it's just fantastic. You're listening to us’ and I'm like ‘I don't have the experience to further develop this app, I need you to suggest things, tell us stuff and have ideas and those are really useful and really valuable. And some of them I can do now, some of them need to go on a list for future development. But letting people know really, really goes a long way and it means that people will come back and continue to engage as well.

P9: It can really build peoples self-esteem because then I used to do a lot of public speaking with people living with dementia and delivering training and workshops to different audiences including at the Partnership, and the people living with dementia thoroughly enjoyed it and different people that I presented with have different needs and we tailor what we delivered to according to them. On [P10]'s point as well, I think it's really important to be honest about the scope. So, say like your research that you’re doing for this. Be honest about this piece of research might not lead to a huge change in how people...

P10: Your dream service.

P9: Just be honest about what your ambition is, but what might be realistic as well so that you don't over promise and under deliver. A bit like Boris! Oh, what a surprise and I have to say I was very shocked to learn that schools with opening before hairdressers looking at the state of him on that briefing.

P10: I think he likes look like that, so he disarms people and people just think he's silly and lovely and look at him with his unbrushed hair. When yeah, anyway I'm going off on a tangent. I don't think he's a very nice man.

P9: We need a comrade.

**R2: And speaking of environment, so [P11], you talk about this dementia friendly trainings for businesses. Do you have some people living with dementia involved in this training?**

P11: So, this is not something that we've actually done since I've been working here, we've not been doing it because of covid. I just know that it's something that we offer to local businesses. But like if you go on to the... so like we have a local optician that I know have had the training so it's actually on their website and they actually have reviews from people that have been like family members of people with dementia that have been and they've experienced the difference in the service sort of before and after they have the training. So, like they would only sort of test one eye and they would go on two separate occasions because doing both eyes on the same day just far too much for them. And so those reviews are on websites that just show like the difference in the service they received both before and after the training.

P9: [P11] that highlights the value of asking people because I would never have known that it is better to do one eye at one appointment on the other eye another. You just wouldn't know that unless you asked.

P10: It's not that it's not being afraid to ask those questions. Like in no service over the work with has anyone been bothered about me asking questions about them and I used to work in [HEALTHCARE] and you can always say to people, ‘if you don't feel comfortable answering any of these questions, you don't have to but it will help us improve services using the information that you give us and give.’ Give people that option, but I do find that people are very open to providing that information, discussing it, and they actually, if they know that it's gonna go towards something useful. And actually, improves their lives or it will be put forward in that way. I think there's a value level of it definitely. And also, sometimes it's just nice to them to offload a little bit about things that might be annoying.

P9: And people want to be included, don't we? Who wants to be left out? No one wants to be left out.

**R2: Yeah, and [P10]. I think in in greater moments it's possible for people to give some feedbacks about activities, is that right?**

P10: Yeah, so one of the...

**R2: Yeah, I think giving feedback about access ability and this kind of things.**

P10: Yeah, so at the moment it's just it's a five-star rating, kind of like a trip adviser so you can when you go into a service it tells you more information. You can click on it to attend and it'll put in your calendar. Or you can rate it. And there's other things that have come out of consultation since Covid that people would like to see on there in terms of kind of bulking up a bit in terms of what things were there that made it good or not so good and we didn't really want that on there so that we could be like, oh God, you're awful we wanted it on there so that we can showcase services that are consistently getting really good feedback and get them to support other services, so there's ones that consistently scoring low, actually why is that? And so, when we first set it up, it was, we thought the Five Star rating would be brilliant. And now there's so many other elements that we want to add, but we need to wait for confirmation of future funding before I continue to add more features. Those things like accessibility stuff, if someone is going somewhere, do they know that they're going to be able to park close by or is there public transport close by? Is there a toilet if they're feeling knackered? Is there somewhere they can sit comfortably? Is this where they can get refreshments? And actually though, whilst those things might be specific around certain people living with dementia, actually I wanna know that too If I'm going to park for a long walk, I want to know if there's a toilet or if I can get a brew there as well and how close can we drive up to it and or is there a bus nearby that I can get there so? I guess one of the things I want to pick a little bit more as under that five-star rating, what are the key things that people using the app? We want to add to that, once they give an overall five-star rating, but actually, what are the key things that sit under that that have contributed to that so we can understand that better?

P9: Be good to have a section where it's free stuff as well because like not everyone can afford to go in good things ...

P10: We always want to have a range of stuff on there so the apps free to use. We want to make sure as much of the stuff that we put on there is free. But obviously we want to promote and advertise the widest range of activities and events. Because it isn't just about finding things that are dementia specific to put on there, it is about activities and events that are going across Greater Manchester and then as users use the app it will start intuitively pushing relevant content towards them. So, if they are constantly adding sports themed events to the calendar it will push more of that content to them. I mean the apps only very knew, so it's not doing any of that particular jazzy stuff. Yeah, we only launched at the beginning of October, so it's still very much in its infancy. The kind of develop the real quick thing.

P9: It sounds really good. Like you say, will be for everybody, but it could be for quite a few people and it. As time goes on, as more people are introduced to the app when they're in the early to moderate stages, then hopefully it can support them right the way through. If using it while they're still quite well.

P11: Sorry. Can you just excuse me? One minute I'll be back in a minute, sorry.

P10: I think it's one of those that we wanted a social prescribing tool. So, whoever diagnosing or seeing someone for a review to just go, here's this flyer. There's this app. It might be really useful for you, and instead of having to be like oh God, I don't know what goes on their local area. I'll just Google something or not tell them at all. It empowers that person and/or their care to have a look at what's going on locally, what they'd be interested in, what they might like to try. And that sort of thing. So, it's about empowering people to be able to see what's going on locally.

**R1: I was going to ask [P10]. Weather is the app local or is the app national?**

P10: It's at the moment is funded for Greater Manchester.

**R1: Yeah, because I mean one of the issues is around updating to use AI for that, or how does it work.**

P10: At the moment, in terms of the services, events and activities we do that yeah, so we rely a lot on either finding those or the networks that we've got sending us that information. We are we are looking at licensing it elsewhere. We're exploring other options because we think we've got a really good product that could actually be used across a range of different long-term conditions, and it feels like we're piloting it a bit with dementia. So, we're speaking to a school that works with young people with autism, for example, and how they might want to use it. It's a challenging thing because we're not endorsing any of these activities that are available on there, but you still need to check, take that responsibility for yourself to check them out. But it's empowering people to use it as a place where information is gathered but they still need to take that level of checking. Yeah, if it was much bigger, we would have to think of a of a much better way of doing that and I will be in a network and I think if I've been able to go out and talk to people, we have many more champions and then we could give them access to put content on there and then we just kind of have to roughly, check it to make sure it fit in the format looked alright, and had pictures on it and things like that, but it still is people’s responsibility to check that that's happening. That sort of thing really because we just can't moderate it when you got like 80 services and loads of different activities on there, we can’t check all of those.

**R1: Absolutely.**

**R2: And my last question now. We talk about difficulties and also some strategies. So, network, formal and informal network, it seems can be very helpful for people to deal with potential difficulties. Have you other ideas or observed other things because today is our last focus group with experts in the field and we will begin soon some interviews with people living with dementia and carer, but it's also interesting to have your opinion, about what you observed and which kind of really active strategies and how they are able to deal with the situation.**

P9: Sorry [R2], I didn't understand that question.

**R2: Which kind of strategies people have to attend activities. So, for example, if they have no car anymore, they will take public transportation, but sometimes it can be difficult, but will they ask some help to their neighbours or friend.**

P9: So, some places have got voluntary drivers. So, like Rochdale, well obviously if it's still running now, but they used to have a voluntary driver scheme. But again, there's a cost associated with it, so not everybody can afford to do that. And I don't know if [P10] knows anymore or [P11]. How do people get to your services, [P11] when they're open?

P11: We run a day support service here at the moment and we provide transport, but that is a cost.

P10: I know Heywood, Middleton and Rochdale circle have a range of voluntary drivers that support older people living in that area to get to and from appointments. Or things that they need to do so that's a great service, but I'm assuming that they've applied for funding for that and they've got a pot of funding to cover that. And then they've got a network of volunteers who run that.

P11: I know with our Community hubs that we generally do it when it's in community because Trafford is quite a big area, will run them at different places. So, we actually run hubs at four different places so that it's generally closer a lot of people can generally walk. And so, having the same service and maybe a number of different venues.

P10: It so it's thinking about what those community venues are, how accessible they are. Where do people go? So, I live in Salford. It's quite a big borough. It's very diverse. It hasn't got a real discernible center. And if I was going to... I live in kind of the [SPECIFIC AREA OF SALFORD] area, so I wouldn't run a workshop here that was for all of Salford, because [THE AREA] like Liverpool really. To be fair, that's really, really far. So, it's thinking about can you break that up? And are there... It doesn't even have to be a neighborhood level, but are there particular? Where do people gather? Where do people regularly go? Salford precincts? That's a really good area around there to do some kind of community engagement because people gather there for all the different shops. All the buses stop outside. And so, thinking about where people go within the local area and how far that is and where those places might be accessible for them to get to because people don't necessarily want to travel far and wide to do things. So somewhere is around the corner you've immediately made you broken down some of those accessibility needs. And also thinking about.... It’s that balance for me. What's in it for them?

So, someone might say to me, oh, we want to consult with such and such a group. Can you do a survey? And it's great that you want that data, but actually what's in it for the people who are going to be filling in? What are they going to get out of it? What's in it for them to spend 10 minutes filling in your survey? For me personally, unless you tell me you're putting me in a prize draw, I'm not clicking on a link to fill in any survey! Even though I'm unlikely to win if you tell me, I might win a shopping voucher by filling in your survey I’m there, otherwise I'm like no. So, it is about asking people in about what's in it for that person. Carers don't have huge amounts of free time or time for themselves. If you want them to engage with something, it's gotta be really clear what the ask is and what they're going to get from it.

**R2: So Greater Manchester is quite big. Do you think there’s some disparities between Salford, Trafford...? Maybe so it's difficult to say that, but some disparities and some...**

P10: It's very different in different areas. Very different. Even in different parts of different boroughs, like Prestwich is only just up the road. But that's part of Bury, but it's very different to Bury or Radcliffe which are further afield and so it is very, very diverse and that can sometimes be down to quite a micro local level, but that's where your community organizations come in in terms of helping you. They've been out doing community engagement for years, so if you wanted to know where to do something, where to put information or how to engage with a particular community. Use them, they've got those skills, expertise and experience already, so it's not something I would ever start from scratch. I'll just be happy with those local experts.

**R2: And do you think sometimes you have some competition between services or at the contrary, it's something with some emulation. So, for example, if one council, I don't know, in Salford are creating a service, it will give an idea to... (inaudible)**

P10: There is a level of competition so if one borough is doing something particularly well. Another borough will probably want to do it, and so I think services do work a lot in partnership, but then there is the problem that all services need ongoing funding. They're probably not being funded for huge amounts of time. Five-year contracts are things of the past, and so particularly in voluntary community sector. Whilst you might want to work in partnership, actually you're going to be those people are also your competitors in a competitive tendering environment. And yeah, there's more competition for bids and grants and funding than there ever was. So, I always found that a really difficult balance to strike. It was great to have partners in partnership, working to be able to do that. Actually, unless there's money in it for everyone, is it a real partnership, and is there enough money to make that work. Is a great wonderful thing, but whilst everyone is kind of struggling for enough funds to deliver all of their services and we're probably going over and above what they should be doing and delivering anyway. Yeah, it does throw in an additional spanner into the works.

I do think that Greater Manchester probably is a little bit further along with kind of working in partnership and across boroughs than other areas are because of all the devo[lution] work that's been going on?

**R2: Yeah, it seems to me that funding is something quite difficult because it's services, it's a lot of charities and so I'm really impressed by all these initiatives and ideas, but very often people say OK, it's a five years funding or this kind of thing. So, for long term things, it's probably difficult, and also because you are involved with people who are offering something and it's probably difficult to say OK, but I don't know in two years if it will still be possible to have this service or...**

P10: And if you're starting something new, in my personal opinion the first year, not an awful lots gonna happen because people don't know about it and you gotta build that report and trust. Year two, you might start getting to momentum. Year three, you start actually really seeing some potential and some results and yes funding needs to be around five years. But 12-month funding, two-year funding with potential extension. There are really common. I spent most of my career in the voluntary community sector, and I’ve been made redundant four times; projects ending, funding uncertainty, restructures changing and I love it don’t get me wrong, I love that kind of work even though I'm working in limited company at the moment. It is quite difficult and if you're really passionate about what you do, it can be really upsetting to know that people have got so much benefit from a service and you're gonna have to stop.

P9: Yeah, that's the thing that's happened to me too.

P10: Is it really upsetting and you do have to be quite clear with people about the boundaries and the limitations of what you're able to do or not do? When you've got a really good service and it doesn't get funded again because people want innovation all of the time. But then you've also got to demonstrate sustainability, which are massively at odds with each other. So, it is very challenging.

P9: They certainly don't make it easy for us.

**R2: Thanks.**

P10: ‘We need you to have a new idea, but we want, yeah, but also demonstrate how you're going to make it sustainable. Even though we're gonna fund you for 12 months...’ It's a challenging environment working for sure.

**R2: Yeah, great. So, I don't know if you have some question or last things to say. Or maybe [R1] will question you.**

**R1: No, I think that was a really interesting discussion. As [R2] said earlier this, this was the third of three discussions, and each time we had a slightly different composition of people. organizations, dementia organizations and so on, so which is brought up really different aspects each time, so that's been fantastic. Thank you.**

P10: Yeah, it’s been great to meet everyone. Is everyone happy to have their email addresses circulated because it would be great to have both of your contact details if that's currently.

P9: Yes, definitely [P10]. I don't mind. Are you able to do that [R1] or [R2]?

**R2: Yeah, yeah.**

**R1: Yeah, yeah, if you're all happy with it. I will just send a general email to all of us. Yeah, yeah at the end to make sure you've got and then you can exchange things. The paper that you mentioned [P9] and other things yeah.**

**R2: No problem with that.**

**R1: Yeah, that that be great. Yes, we started matchmaking. It's good.**

P10: I think it just really miss networking opportunities. So, to come to something like this where there’s people I don't know, it's like, oh, fantastic.

**R1: I can also see there might be potential because for your app for example, if you're interested both in terms of what we're developing with the service, obviously that your app wasn't on the horizon when we make application two years ago, so. But we also develop something a digital platform as part of the Mind project, which we haven't yet kind of rolled out yet. But we're looking to develop which might provide some of the supporting aspects that your app doesn't yet have, and things like that. If we start on all these different fronts, but we might just be able to progress them together at some point.**

P10: I think anything like that where we can support each other, would be fantastic so that we're not paying twice for the same thing, really.

**R1: Well, exactly, it's silly to be in competition if we don't have to, if we can support each other so...**

P10: Absolutely, and I am 100% for that.

**R1: So, as you probably noticed, our approach is quite open. It was one of the things that we try tried out. With the Mind project originally, which was also European funded then for your project, which was quite large, 16 partners across Europe but one of the things that we started off with in terms of design is that people haven't had the idea say ‘we want to make a kettle, or we want to do this or that’ and we generally tend to take quite an open approach, so we said yes, we want to design a service to make things better, but we said, well, we actually don't know what that service needs to look like. So, we had some underpinning information from people with dementia from the Mind project who told us that they wanted to be more involved and have more opportunities to realize themselves. So not just being presented with and being the sort of passive participants, but they wanted to be active in... if they can knit something, they wanted to have an outlet or if they can cook, they want to share it and those kinds of things so they wanted to be really active. That was one of the really key outcomes that from the mind project. So that's what we're driving towards, but we don't know yet exactly what shape and format that will take. So, we've got these three focus groups to start with and then we follow this up with some further interviews. We then have the focus groups with people with dementia and carers. And once we've evaluated all that information, we’ll then try and follow this up with some co-design sessions with the community. So, nothing is decided yet. We haven't decided that we're going to make a kettle or a red or green button. Sorry, this is an inside joke from a design conference is you get a lot of specially from the Asian communities, PhD students doing this very, very focused projects. Whether a red button is better than a green button or... Just very specific, yeah.**

P10: Very specific, yeah.

**R1: So, we were having taken quite a different open-ended approach. Where we say we don't know what we're going to design. We think it's going to be a service, so this is what we're starting about. But again, so what you said earlier very much that we take the community to heart and all the stakeholders involved. To figure out what that service needs to be, we have a hunch what's missing and that there is something we think about kind of what's missing, but we don't necessarily know the solution, or we don't pretend to know the solution.**

P10: I think it's very refreshing.

**R1: So, I hope you'll all be involved along the journey with [R2] and I will be going through this project and see what happens.**

P10: Yeah definitely, definitely. That's that sounds great. All too often I'm complaining because a strategy or a service has been devised for our service for a group of people in that particular group of people have never been involved in it in any way, shape or form and a room full of people in suits have decided that's what's needed and yeah, so it's good to hear that there's not like we have got an idea, but we're actually going to wait and see what comes out...

**R1: It's a bit nerve wracking. It sometimes makes us look as if we don't know what we're doing. Which in a sense is true!**

P10: I don't think there's a problem with that. I wish more commissioning organisations would take that approach and then they have much more successful services with fewer barriers.

**R1: Certainly, with the MinD project it's proven very refreshing and very successful. I think we developed four things. One is now hopefully getting into production to a board game for people with early-stage dementia. Although it's not budged as such. So, it could be for anybody.**

P10: Which we could promote on the app.

**R1: It's a large storytelling game, yes. So, we, we are in progress to talk to company which we have with the Alzheimer’s Society. They made the contact for us or gave us a recommendation. So, and then we've got the Living Life booklet which we've made available online and we know it's already used by some people, but we want to do an actual evaluation still because we after the initial design, we completely redesigned it and so we still want to do an evaluation, and I've had some interest from people, sorry that’s to [P9] because she was helping us to find people to participate in just before covid, but we shelved it for now because of the covid situation. It got very difficult. But we have some potential interest from an NHS trust in Cornwall on this as well, so maybe we can run something across Cornwall and Greater Manchester over next year or something.**

P9: Brilliant. It’s been lovely meeting you all.

P10: Yes, and you.

P9: I'll send you these documents that it was the briefing paper from our forum and also the article that person living with Dementia wrote up for Lancaster Uni. I'll send those 2 to circulate. I'm happy to share my email, but I'm gonna have to go now because I've got another meeting shortly.

**R2: Yeah, so thanks a lot. I will contact you soon and to see if you are happy to take part in individual interviews. Short ones one just 30 minutes to add more details but in the meanwhile thanks. It was really interesting.**