**WORK PACKAGE 1 - FOCUS GROUP 1**

**Focus group session with P1, P2 and P3**

**Date: 09th February 2021**

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

P1: = Stakeholder

P2: = Stakeholder

P3: = Stakeholder

**R1: = Researcher**

**R2: = Researcher**

[Confirmation given that the session is being recorded]

**R2: Do you agree to take part in this focus group?**

P3: Yes.

P2: Yes.

P1: [thumbs up] yes

**R2: Yeah, ok perfect, so thank you very much. [[R1]], is it OK? Or maybe do you think I forgot something?**

**R1: No, I think we're good to go.**

**R2: So yeah, I will ask you some questions. I have 5 big questions. It's more discussion as I said, about activities - meaningful activities. And the first part is more about which kind of activities are interesting and relevant for people with mild dementia, and after maybe more discussion about the difficulties and also the potential support and strategies. But please don't hesitate to, if you have an idea just bring it in the discussion and I will arrange to ask the question in the end, so yeah, so I will just read my first question. So once again, it's we're more in the context of people with mild to moderate dementia, so they still have some autonomy and still living at home. So what leisure or social activities are people involved in and where do they go to attend or participate in them? So we had a short discussion, about activities you are maybe already offering but yeah, what is your idea? What do you observe? What are the favourite activities of people? What is meaningful for them?**

P3: Can I chip in?

**R2: Yeah, that's right.**

P3: I think I think if there was one theme to draw out of that question it will be there is no one activity. It's about individualization people.

P2: Uh huh.

P3: If you met one person with mild cognitive impairment or early dementia, you've met one person with mild cognitive impairment in early dementia and the range of socio economic groups, the range of life experiences and life trajectories that come across even in the world ranging from you know, military lifestyles to people who've never had a full-time job to people have looked after enormous families to, you know it's just it's mind boggling, it's part of why I do the work. Frankly, it's one of the most enjoyable aspects of it. So to my mind it’s this transition - how do you maintain what's meaningful that they're already involved in? And if there's diminishing ability to involve or gain value from the things that they used to get value from for whatever reason because of an aspect of cognitive impairment or perhaps South Asian communities, a feeling of stigma or something else... How do you introduce a new activity which might be less demanding but equally socially rewarding or equally rewarding in a way? So that that's my mental model of it. So I don't know that there's one kind of activity for everybody. You know, I I meet quite a lot of antisocial people who for whom the idea of a group makes them baulk, frankly, but they you know they love some cognitively stimulating things on their own in a quiet space that's not, you know, that's not overwhelming, so I'll have a think about if there's any emerging themes of things that I like or that they like but I think individualization is the key. I don't know what [P1] and [P2] think?

P2: OK yeah, I agree with you. I think the common denominator in this is music. They all seem to like music and singing. I still see that with this thing in the brain. The group I was referring to *[inaudible] t*wo guys theresit with the wives on the seatee when we have a zoom meeting on a Thursday and they're just like statues. When we get the story book group on the Wednesday morning, there's only a few people involved, they just light up. *[inaudible]* Its absolutely fantastic and rewarding to see that. You’re right in what you say there [P3], about your people with *[inaudible*] we notice that within our group 'cause when it gets a lot of people together you can see them in different stages. But one thing they do, people with dementia, they seem to click with one another and recognize one another as if it's a club and that’s indescribable. My wife was a different person. A nice person in the group activities and I used to think 'why can’t you be like that at home?! Why can’t you be like that in different settings?!’ It was just like walking into a magic place. *[inaudible]* I've discussed this with one or two people within our group, but yeah. We'll see if you get the same thing. There is one of our members who [PREVIOUSLY HAD A JOB WITH A LOT OF IMPORTANT DECISION MAKING RESPONSIBILITIES]......*[inaudible]*. He's now got Alzheimer's and it was around 2012 when we started this group, but he's still on the committee, he's still functioning. But I know his wife well and when he’s at home he’s completely dependent. But when we have our committee meetings, if someone is stepping out of line, he’ll bring the law into it saying you gotta read the rules and regulations about this. Its awesome. He knows our Charity Commission rules, what we can and can’t do. It’s absolutely fantastic. Regarding your comments on the BME front we've tried numerous ways to engage and unfortunately we’ve only got one non-white, if that's the right term, I apologise if I don’t say the right terms. We've only got a non white person in our group with dementia whose an ex-nurse from the local hospital and she's from the Caribbean. A very nice lady, well supported by her daughter and it's good to have her around. And we have tried to engage with the BME community. *[inaudible]* We got nothing. Absolutely nobody coming, we've been in the mosques, we’ve been in the temples. We've engaged with the local imams and people of that nature or then on one occasion a young couple came in. Not sure whether they were man and wife or just happen to be a couple. Saying they we're looking forward to running something. So we had a good chat for an hour then they haven’t *[inaudible]* and they went out and we never saw them again. So there's a lot of work to be done there and I know Penine Care Trust, they’re doing a lot of work on trying to, I don't think integrate is the right word but trying to work in that culture to show it is not a stigma to have dementia, you need to come forward and be treated by people like yourself [P3]. Get the medication and *[inaudible]*. It seems a big, long, uphill battle to me, but all battles can be won. If you put your back into it, but I think it's really unlikely that I will see it.

**R2: Ok thank you. And you [P1]?**

P1: I've got to agree, I've been I've been banging the drum about how we're going to meet the needs of people from the BAME backgrounds. And the LGBT in the future, because of culture changes. As BAME communities become more westernised. How we gonna meet, especially if they revert back to their language when they have dementia you know this is there's so many challenges around it, but because at the moment I think here all the engagement we've tried, and this is over 10 years for me, all the engagement we've tried over the years, the culture *[inaudible]*. And grandchildren, and you know, and just view it as a natural age thing that old people get. And even trying to raise awareness out in the community has been really, really difficult. So how we will get them involved in activities, I've got to say I'm the biggest thing I've seen around Salford around activities, has been around cooking. Having a social event and having people to cook their dishes that they're used to and getting the support to do that as we know it can be quite dangerous for people but cooking has been a big thing with the BAME community, yeah. In Salford, I think because we’ve been doing this, as soon as we got the Prime Minister's challenge in 2012. You know, my commissioner put me on it, and he just said, 'cause I was the older persons engagement officer, he said right, and I knew nothing about dementia. You know, so it was a really good challenge for me, because we already had the priorities outlined in the Prime Minister's Challenge. And so I just went to greater Manchester mental health and they run a community cafe for people with dementia and their carers and just said what I was hoping to do. I also said ‘can I come round to your house and have a chat with you about what your barriers are? What you find is really difficult in life? And what we can do in the future?’, and I couldn't believe that every single - I went to 10 couples, and this was in 2013 and every single carer cried because at that time all they got after a diagnosis of dementia was a letter from the psychiatrist to say get your affairs in order and get sorted with a power of attorney. That was the only support that was available at that time. So since then I've had a group that meets on a monthly basis, that I've advised commissioners what they need and one of them was a one stop shop, which instead of going to hospital and back again and tests and so they in Salford now, they have a service, which is in one building in Little Hulton, where they can get tested and support and it's next to the hospital. So people with dementia get used to that building and it's not so many changes. They run quite a lot of different things in the hospital for like singing with the brain like you said. And then well out in the community now we have singing with the dementia and dancing with dementia, which are two separate things run by our volunteers, they have a lot of people attending both. It’s taking a while to get off the ground - maybe a year but it ends up that we have a dementia community in Salford and they tend to pass messages onto each other - ‘I've been there. That was fantastic’ - word of mouth seems to be the only way of getting something together and having some really good basis of people that can get that word of mouth out and the Dementia Champions group that I ran did a great job of getting that those things off the ground and advertising it themselves and obviously I could do all the admin support for it which was very important to organise things and do all the admin behind it which will need with every activity. You can't always leave that to volunteers 'cause they don't understand policies and procedures. That you have to do with health and safety, Etcetera Etcetera. And yeah, so and then and then we commissioned Age UK, Salford Dementia Services. And having that one service that does the lifetime for a person with dementia and carer. So someone who is a bit worried about how one of their family members are can get onto them, they can support the carer and the person with dementia so that starts off there. Then they've got buddy clubs. They've got loads of activities within that service. I'm hoping [A MEMBER OF STAFF] will be coming on to *[inaudible]* to promote that somewhere along the line, because she’s the manager of that service at Age UK Salford. And they set up a younger person's dementia group, which before covid these socialised. They do zooms now. Because there was nothing for people under 65. So it evolved into a big social group. They even go on holidays together, days out and they organize an annual sports day. Which is very well attended and they do activities like walking football. They get concessions on the disability bikes 'cause people have shown a real love to do that, out in the fresh air on the disability bike and they go to different parts across Salford on safe surface that we can't go out of control on them, but they also have the bikes that the carers can go on and the person can pedal as well. You know and join in on that activity. Yeah, so music, singing and dancing like [P2] said that that is one of the big things and we just organised a dementia walk in December. Because there were people that weren't connecting at all online. They get phone calls all the time off Age UK dementia services. But they weren't actually getting out of the house for some fresh air or anything 'cause they were too scared. So it took a lot of arranging, for just maybe a 5 couples to attend, but it, but it was a trial run and we will be looking I'm doing the evaluation at the moment and will be looking hopefully to put those on a monthly basis on different parts in Salford supported by City of Trees. Now City of Trees, actually do dementia work well. They do Bolton and they do a couple more as well in Manchester. So we are going to use them to spearhead a funding bid and for them to take control of that with the support of the Salford Ranger team, and the Salford Ranger team look after all the parks. So is getting out and doing that physical activity until, obviously in line with COVID guidelines, until we can get back to normal and do, you know, social activities again, 'cause I think one of the big things is social activities. I hope that gives you food for thought!

P2: Can I just raise a question on that if you don't mind?

**R2: Yes**

P2: Can I just ask a question to [P1]? Is that OK? I'm interested in you Salford one stop shop. I don't want to knock it in any way, shape or form, but I'm assuming it's Monday to Friday in normal working hours. Is that right?

P1: No, well, It depends what for because it's part of Greater Manchester mental health but all it’s dementia services are in there. So if you going for a diagnosis, you go there. You also have can have your blood taken there and all your different tests that you have done at the same place.

P2: I was thinking more for the carer having an immediate problem, if you could go along there and you know get some help or assistance whatever it may be...

P1: If it is a carer they either would be advised to contact Age UK dementia services, 'cause they understand dementia really well or *[inaudible]*, who are Greater Manchester Carers service.

P2: OK yeah, I mean we have similar things in Oldham way, we're linked with the Age UK. We seem to be as a group to be somebody to be referred to, the local memory service refer everybody to us which is a good thing and it could be a bad thing, there's only one with...

P1: So you need to speak to [ ]your Commissioner.

P2: I'm with [YOUR COMMISSIONER ]. I mean [YOUR COMMISSIONER ]’s working group.

P1: Yeah, [ ], you just need to say can you not Commission Age UK to get as dementia service up the same as Salford?

P2: We're working on at the moment [P1], we gotta build it, we got some funding but it’s the management of it, which like everything else is passed between the Local Authority and the NHS and hopefully the two will meet and we get a thumbs up on it sooner rather than later.

P1: Yeah, well when I used to run with Dementia Champions Group, what we used to do is have speakers who could update on their services and answer questions. So we had people that were running the care homes and we'd have people from the community mental health teams, post diagnostic, we have all of them. So I've done a document which is called the steps document and I've done all the steps that someone needs to know for worrying about your memory, who to contact on each step until end of life care - I can share that with you and probably if I put my email in the in the chat. I have no problem if you ask me anything. I'm more than happy to help out 'cause I've been doing it for such a long time. You know, and I've got to say, I really think because people used to meet up on a physical basis and those meetings we used to have like 15-20 people coming to the meetings. And because there were professionals there who put it out in their diary every month to support that group because they knew that that group would then talk to other people in other groups around Salford and get that information out to people you know.

**R2: I'm little bit sorry we are running out of time, but yeah, if you want [P1] I can send you email address to [P2] and you can maybe exchange about this this week, if you want.**

P1: Oh, I did something wrong. Oops. I just put it in the chat.

**R1: Great**

**R2: And I can send it to [P2] later**

P1: Thank you very much.

P3: Just the emerging theme from five years of working in this space is that there are 10 boroughs in Greater Manchester and everybody has something different and approaches in a different way.

P1: Yeah

P3: And that is one of the biggest barriers to building meaningful activities. For example, if you wanted to build something or make something organize something for people with younger onset dementia, you may not hit a critical capacity of headcount within a particular borough, and actually, that's something that needs to be commissioned at a GM level in order to bring the expertise in order to bring the diversity of activities and that GM commissioning that doesn't yet exist, so, so that's one of the big barriers, you know, and lots of our meetings consist of people saying, well, we have this and why don't we have it? And that can be powerful. It can be a powerful message to take to your own commissioners to say, well, hang on, they have it over there, why don't we have it? And whether it's a carers meeting or it's an activity group, or it's an approach, as you were mentioning with one stop shop. But they're not as competitive with each other as you might want. They don't always care what's going over, and they're not always trying to keep you keep up with the Joneses. But it is about getting things commissioned, either at the local authority level or within the NHS, because otherwise groups struggle to fund themselves. I know what you think, [P2], but you know, you can do a lot on a shoestring, but there comes a point where you wanna do something a bit special in your need something in your back pocket to fork out for it.

P1: I think it always helps as well, working with your local volunteer centre, you know we work very closely with Salford CVS and we know when funding is coming in and we just disseminate that information to groups like the singing and dancing groups that are service user led. And then they get support either from the health improvement team or from Salford CVS to fill in those funding bids and help them manage it so it's spent in the right way that is outlined in the bid.

P3: The other thing that sometimes people found useful is the only thing that I think that the either of you haven't mentioned is University of the Third age who provide for people who are a bit more earlier on in their disease process, and perhaps that there appeals to be with the idea of further education and there's no barrier, cognative impairment or early dementia is not a barrier necessarily to engage in some of the activities there, if that's what you're, I mean, I would agree with the themes that have emerged singing whatever that means to you, dancing whatever that means to you and socialising, whatever that means to you are all you know core themes that we use throughout and in fact implement on the ward even in people with advanced disease. So I think I think there are reasonable themes to pull.

**R1: It yeah walking and exercise, I think [P2] you mentioned earlier as well. Was there anything else you mentioned in terms of special activities you did with their games, something as well, quizzes?**

P2: Uh, yeah, we do quizzes. So I'm a member of *[inaudible]* [P3]. It is a good organization. I joined after I lost me wife, it give me something to do and refocus me life and at the moment it still the link ive got apart from my family that’s not dementia related, so yeah, it's good. Yeah, so the activities we do we were trying to think activities as well. We had a burns night in the afternoon a few weeks ago. One of our colleagues, [IS SCOTTISH] and she organised this burns night, and we've done this for last few years, but when we could meet together, we got a piper in and did things like that. But it's surprising how many people will offer the services for next to nothing, and this piper that came along -we know it charges about 200 pounds to turn up at the funeral and walk in front of the coffin. But he did this on Burns day with us. We got the whiskey and the haggis and stuff and it were a good do. But this year we got to improvise - they got a water bottle out, stuck some knitting needles in it is it's a bagpipe and put some music on. So people get impressed with it and that’s what its about. It’s about creating relaxation, laughter. We've actually made a CD, four years ago, uh, eit were a one track CD – a carol, ‘while shepherds watched’, we did that. There's a lady who played the piano for singing for the brain, and we did that. She got it through professional friends. Through one guy who had a recording studio in South Manchester. We went to the studio one Thursday afternoon, the music was pre recorded, you know LinkedIn by, however these professions do it, but we did it in one take, about 90 people that were dementia.

P1: Wow. Impressive.

**R1: Yeah, yeah great, great thank you.**

P2: If you go on our website, you'll see three films on the produced by BBC Outreach, which was where people would say you're a cameraman or something like that. You could take a couple weeks off and do something else. Within the BBC, away from you profession or current paying employment. They made some films on dementia, but sadly the people on these films have all passed away is the main stars of it. But they’re still there with the approval of their loved ones obviously. Well, it is there to look up if you wanted to get a feel for our group sometime. If it raises any questions feel free to contact me.

P1: What is your website [P2]?

P2: Good question.

P1: Well, just Google it. What's the name of your group?

P2: [WEBSITE ADDRESS PROVIDED]. There is another one which we originally set up, but the guy who set it up for us we fell out with them and they won't disclose the passwords sadly. So its just lying there *[inaudible]*.

**R1: Great, thank you. That's been fantastic to get an overview of all the different activities and on the ins and outs, I think, but I think it is about you've got the next question, have you?**

**R2: I have a question about the collective aspect so and the social aspect of activities. And so we said it has to be personalised. But I get the feeling maybe people are looking for more social activities with the evolution of dementia or maybe less or other need to support each other, *[inaudible]* on the social support and looking for more or less social contact?**

P2: I think the problem, if I may, I think the problem is it's not really good questions to ask at this time with the COVID 'cause its stopping us from doing our basic activities. One of the major problems is when we do have meetings, is carers more than the cared for will ask us ‘When do you think we'll be able to get together again and do it?’ And that's an unknown answer. The nearest we're going to get is to be able to do the walks in the park again and that depends on the physical activities involved in the carer or the cared for. My major concern at the moment, and I may be going off question is reaching to the members we've got now. I mean, I still struggled getting in on this teams meeting this afternoon and we’re heavily reliant on zoom to see people face to face theres no doubt about that. And the age group we’re talking about I’d say you could probably just about do FaceTime. If you got distant relatives and things like that, we managed to get some money to buy some cheap tablets on we provided some very simple instructions on how to use them. We about about the 8 and three are in use. People are frightened of them. I've been making noises over recent weeks and I'm falling on deaf ears and you may have the ability to assist or takeover, is that when the latest lock down was underway the BBC took it upon themselves to provide tuition for primary schools every day, and secondary school, and I think that we need to do that is the age group of the over 60s or the over 70s who don't no computers, who are frightened of using it and if they did it on terrestrial telly it could be recorded.It’s there for everybody because at the moment that’s the only way we can come face to face with people and engage. The next question leading off from that is when we do get together, who will want to leave and what deterioration is taking place 'cause I can see my members deteriorating, I don’t know about you [P3], it depends how long you’ve had your patients, if it were before COVID. I know there is natural progression with dementia but to watch it progress this fast isn’t nice.

**R2: And I will continue on this topic of difficulties, so we are in special contact *[inaudible]* you might have observed with regard to access to leisure activities and potential difficulties also during this activity, so access and during the realization of activities. And what difficulties do people with mild to moderate dementia experience in participating in leisure activities on offer? And can you give some examples? So you just gave one and it can be, of course related to the COVID-19 situation, an order restriction, but also more difficulties in general.**

P2: I'm a member of a group. A national group who meet every Wednesday. There are people there, a mixture of people like myself. There's no professional medical based people. The other the providers of service like Age UK and making space or people like myself and there are one or two people who've got dementia at different degrees. And at the moment COVID it is stopping everybody from doing things. If I weren’t doing zoom, one or two people have done things which we shouldn't talk about because I think it wouldn't do us any good if the legislation was aware of what we've been doing. But sometimes you gotta think about other people and it's like these computers, if you could go in somebody's house and say look you press this button, you press that button and you're in, you know keep it simple you can't even do that. You know some people got these gazebos and put the front entrance to peoples doors and trying to show them how you do things. It's not like going in their front room and sitting having a cup of tea. It's a difficult one, although again with the dementia you can show somebody something how to do it this week, although when next week comes, they’ve completely forgot. One of my major priorities when we get back, when we get new members and also with some of our existing members, when we have to ask their name and address and next of kin, we will also be asking have you got IT equipment? Can you use it? And if you can't, we're going to make sure you can use it. And I know there's a great push through Oldham CCG to get some more laptops or tablets to put out in the dementia world and I keep saying it's not getting the tablet -that’s the easy bit. The hard bit is maintaining it. Are people with dementia or anybody for that matter, going to screw it up two or three times, are they going to pick it up the 4th time or just admit defeat and that seems to fall on deaf ears.

P3: So I don't want to think about this [P2], but one of the barriers that people feedback to me at the earliest stages, for example, about dementia cafes. The carers are delighted to meet up, but the person with an earlier stage of dementia is afraid of meeting people with later stages as they think, oh I'm going to end up like this or I'm going to end up with more serious problems and I have heard that maybe from a couple of more sensitive people and more anxious people. But I wonder what you think about, sort of matching people's ability. And matching people's stages. Of course, many of the people who are later on in the in the progress of dementia within care homes won't than not you will be living at home and be less able apps to socialize. But what do you think about that?

P2: I must plead guilty. I just said earlier we join the Post Diagnostic Group. It's about week 8 of a 12 week course. Purely because we've just been identified or diagnosed and the following week we're on the course. It was quick as that. So I remember taking my wife and I said it's not for us then we’re out. She agreed with me and I was very frightened seeing somebody there who was at a very serious stage of dementia and I thought this could upset us both. Anyway, obviously 'cause it was post diagnostic the other people were in similar positions to what we was so it was just like an over 60s Club. As time goes on, meeting every Thursday we're doing a lot. You know, seeing people with different types of dementia going in different directions *[inaudible]*. ...it seriously affected carers. Some were happy to go. Some were just happy to meet other people and release the tensions every week, but I think thats what our group provides. Everybody's equal nobodys *[inaudible],* we just all get on with it. I think we want lots of social exchange at both levels *[inaudible]* .We used to have three groups. Groups of people with dementia and carers which *[inaudible]* but the other two groups were groups of people with dementia, *[inaudible*] and another group for the carers ran by psychologists. We never found out what went in the room with people with dementia with a psychologist 'cause that was confidential to them. They always keep nodding and smiling. But I just said to the psychologist who were running it, I need to know in every meeting if anybody in your opinion is at risk, so we can deal with it. And they always said, yeah I’m alright with that. Now with the carers situation, the psychologist at times had to close their ears up 'cause they weren’t particularly happy because we're probably doing things which are not in the book. Yeah, but it saved the day. One example we do use that there are and I'm not being sexist here in any way, shape or form 'cause I know I'm outnumbered by ladies, but don't read it the wrong way please. Theres a guy there, hes about 70 . And apparently in his past he was *[inaudible]* he were a bit wild and one lady said, oh why *[inaudible]* One lady said, “ I know somebody in gentlemen's barbers, yeah, she’s quite attractive. Why don't you arrange it that she cuts his hair?” That happened. This guy now wants to go every week for this lady to cut his hair. So it's the simple things out there in life. Which regarding the professionals, you don't see that. You're probably not going to say that, but this is the real world, in the unprofessional circuit that's good news that. And that will work for that lady, and the words of outpour of how it changed her life and that, its smartly *[inaudible]* he was dressing better and you know he could go out once or twice he and see *[inaudible]* and catching up. It’s the small things. It doesn't have to cost much, it's just that care and attention to detail and more so to that individual at that time.

**R2: OK thanks.**

[P3: has to leave the meeting so everyone says goodbye]

**R2: We still have 25 minutes. If it's OK for you. And so yeah, [P1], you impression but special difficulties in COVID-19 of course. But before that did you have the feeling it was accessible, it was OK? Or maybe we talked earlier but people from minorities or from LGBT population. Do you think some part of the population are facing challenges? Specific challenges? Or...**

P1: I think the best person to... We have a post diagnostic person attached to JMAH(?) [STAFF NAME] and [STAFF NAME ] and they are probably the best people to talk to about that because they do say... When its early onset or mild the impacts of a diagnosis is very difficult for people to, you know... And for them to absorb, and they find that they want to carry on with what they're doing as long as possible. And it's only when behavior changes begin that they end up probably losing friends and family, who they normally socialize with.And then, that's the time when they start looking for support and help, and they don't tend to do it straight away. So we do tend to miss out on a lot of people that have early onset dementia or mild to moderate. Uhm, and it tends to be people whose behavior is changed and who are finding the small tasks difficult now, that we get them engaging more, and that's usually down to the carer. You know the care needs that support, the carer wants that information, I mean we provide or GMH provides a post diagnostic type group training where they will go through, I think it's the eight weeks and it's a different thing every week and they go through finances, housing, you know, any kind of Citizens Advice they might need welfare rights, you know, power of attorney. It goes through all those things in that eight weeks to try and help, but not a lot of people take them up on it and it is, you know... So there is barriers, we’re not actually getting to people about activities because they're not engaging at that stage.

P2: Well, I mean you right there [P1], that's how me and my wife came into it in the early stages and it’s a difficult thing to move forward. I think we were being nosy more than anything, 'cause, you know, we walked in as Mr & Mrs Normal despite the fact we’d had a diagnosis, because you know there was no outward signs of it.

P1: Well, that's very understanding, so you obviously both had a good conversation about what you might have to face in the future. So let's go and find out what help or support is out there. That's brilliant, but a lot of people deny that they’ve got it. Completely in denial.

P2: No, the moment they're not taking place are they?

P1: Well, the person with dementia while they're on early stages will just deny they've got it, and as it progresses will not recognize they've got it. So sometimes.. and trying to get some people to get a diagnosis in the first place, and especially if they’ve got Alzheimers, and can get some medical, you know, medication support, you know and they leave it too late sometimes, which is so frustrating, especially for the carer.

P2: Maybe not. I never recognized me wifes problems, but I took early retirements and only when you start living with somebody 24/7 it becomes a different world that I started noticing one or two bits and pieces but kept it to myself but my wife had ME which is its own disease in itself and I just kept thinking, oh, it's that going worse. And then me son who lives 120 miles away, he mentioned something. And that led to me saying why don't you have a word with your GP, you know? I think there may be something wrong. Anyway, this went on two or three times and I decided to go with her as I thought, there is a problem here, but he gave me a list of consultants I've just said I wanted a second opinion. So I'm based in Oldham, so we tried Oldham hospital. You know, like come back in 12 months and we’ll see. Hospitals are like that, but we ended up going to Wythenshawe Hospital which was a treck in itself. *[inaudible]*  . And we got on quite well with [THE DOCTOR ]because he had a motor home, we had the caravan we used to tour Europe in the summer time after I retired, so we used to talk about the caravan and Alzheimers. But the biggest thing for me was when it was at the point where he thought she probably need more hands-on care, we had to leave South Manchester and move to Oldham *[inaudible]* because he wasn’t allowed to prescribe certain things that she’d probably need so we had to leave them, which was a great shame for both of us...

P1: Yeah, lack of continuity.

P2: Yeah, it was a nice run out in the car. We used to go to Tatton Park *[inaudible]* Dunham Massey, we used to walk around Dunham Massey. We made a day of it. So she look forward to doing so. It was a continuation. I think it's still like that, but I'm not sure.

P1: Uhm, I can't say for Oldham and to be quite honest, but [THE COMMISSIONER] used to work with me at Salford. So, uhm, who's your Commissioner? So he knows 'cause it was rewriting the carers strategy with me, and so he knows the way dementia and carers work in Salford and without sounding as though I'm bragging but we were way ahead of a lot of Greater Manchester Council because the Commissioner jump straight on it, which was fantastic, which hasn't happened with a lot of other councils. Stockport is very good as well. Stockport’s very good round dementia and stuff, but yeah, I can see there's still barriers all over the place and we're not … what we're not doing, even though we have the banner of Dementia United, I can't see where we're sharing best practice. You know, and I think when you see a service that I did the evaluation on the Age UK Dementia Services where a talk to everybody that used that service and the carers. And it was just brilliant. But I notice gaps in it where they weren't singing their own praises and they weren’t marketing it as well as they should do etc etc, which is only positive. It's positive stuff 'cause everyone was singing the praises of the staff. So if you’ve got really good staff you can take anything forward you know. And if you're working with those people that say when you say, what would you like to do? And what do you think we should do about it? And it's like one of my ambassadors says “Do nothing about us without us.” Yeah, so with these stages that you're doing here is about you know it is important that you get people with lived experience like [P2]. You know to do it, to be part of this research, but I do think it's quite a difficult time because all people have been talking about is COVID and carers being cooped up and there's no respite. Etc etc. You know, and just and talking about activities will just make them long for “oh wheres me singing with dementia? Where's the dancing with dementia? I don't see anyone anymore”, you know? So you might get a bit of a negative backlash there.

R1: Yes.

P2: I mean, the problem is what constants will people have when they are allowed to play out again. Both the carers and the cared for. That’s gonna need some managing that.

P1: Well, that's what I'm thinking as well, 'cause one of the things I'm talking with the Ranger team now is 'cause of summer in the park that got café's in parks now? Yeah, they've got a gazebo thats put up right next to it so we can put tables and chairs and distance each other. They've got public toilets they can open and make sure it's COVID Guidelines that they and the Rangers will support this. We also have all the dementia services and city of trees staff supporting it, so it means if they can go, if they're given an appointment, what time to turn up, you can give it to two couples and one Ranger and have one support working from Age UK or one of the other service providers. They can sit down at 2 tables or three tables depending. Get them a drink before they setup. Go round on a 15-20 minute walk where they've been told about what is happening with that park in their history and everything, chat together, have a brew when they come back and whilst that walks going the other one can go with another set and that's what we're hoping to sort out so they can do that social thing in. Sit down and talk about it and talk about anything. And it's also a way for all the other service providers to provide leaflets. If they need to, to give people who don't connect online provide information in support.

P2: Yeah, we did a similar thing but what we found out that... its not officially CCG. Well I got a couple phone calls afterwards saying get on with it. What we found out, because we're a registered charity until the last lockdown, we could do a walk in the park providing there were no more than 15 in the group. So we did that, and uh...

P1: OK, we’re actually staggering it. So even though it's more staff needed, the staff are actually itching to come out 'cause they're stuck in the house, working from home and want to see people again. And they were more than willing, and because we've got such a good partnership going, because of all the work we've done round dementia. And it ticks everybody's boxes for every strategy that the Council of CCG has, it ticks all those strategies and living well, aging well, etc. And then you know, it just needs the right partnership in every Council, that can help do this. And if that's even on a monthly basis, that would work really well, you know. It's all around from what I can gather from the last one. Having a main provider like City of Trees to organize the funding and making sure all the procedures and guidelines are in place and manage the funding. And then you need the other providers who actually work closely with the person with dementia and their carer. Work closely with them to book them in on those timed walks to say you turn up here at that time we're going to do it this way. Do you need any support with chairs or anything like that because they carry around those little chairs? Fold up chairs - the Ranger carries those. You know, take a flask with you if you’re worried about germs or anything so we can sit down and have a natter and so make sure and that worker just moves them on "That's fantastic, but we have to go now because we're expecting other walkers to come in and we have to abide by the guidelines”. We did this kind of video, twice, looking at what can we support for people to engage and we came up with the only thing we could do because they buildings take that much to keep clean to COVID guidelines, you wouldn’t believe these vaccination programs that are going on at the moment they have to clean down after every single person, they have to do everything, and so it wasn't the right thing to do within, so we thought if we set up the walks now then we can keep those going during the year. You know, until hopefully we can, you know... it gets cold and we can meet in again. The autumn and things like that.

P2: Well, we're hoping we can start walking sometime next month. Well, I'm sure we'll get some dispensation to go and play out again in a limited way and that's what we're looking forward to.

P1: Do you have a ranger team? Do you have, uh, a team that looks after the environment in the park? And the money from them.

P2: Yeah, but it's like every is like every other local authority that sit down. Now we're doing other things. So what we've got, we've got a guy who's a local historian and he...

P1: There's also friends of parks. You'll find that there's a group called Friends of Parks in every park. Who support looking after it and they know they will have a main person on there that will know all the history about it.

P2: Yeah, we don't have...

P1: You just need you need somebody like city of trees to become the organizer. That'll write a funding bid for you and then organize so it's spaced and timed properly over guidelines. I'm sorry I'm having...

**R1: No, no, it's it's actually fascinating.**

**R2: Yeah, yeah exactly.And it's really in the topic of the last question about the potential solutions and support, so I suppose yeah, network, look in your council, but maybe with other organisations. So you mentioned city of trees and this kind of yeah, having a network is really something useful to support access to activities, if I assume imagine that.**

P1: Yeah, 'cause we have a providers meeting which is all dementia which is hospitals, all the different services, I am including Alzheimers Society and Age UK because they deliver different services. Alzheimers Society don't need to deliver as much in Salford 'cause we've got Age UK Salford. So they tend to use their funding to go Trafford and different places. Well, yeah, if you can get Age UK onboard and Alzheimer's Society, []the Commissioner or make sure... Well he's the carers Commissioner, find out if he’s also dementia Commissioner which I think he is, you know and as its funding it you'll know what funding is coming up through the CCG. Your volunteer organisers because they can get volunteers that can help on the days. Also, they all know what funding is coming in. And have you tried the airport fund as well? Manchester Airport has a fund.

P2: To be honest with you [P1] we don't have a problem in terms of funding that we see over the right people in the right places, I mean. We've been fortunate getting monies. Rochester? blew a couple of weeks ago, a guy heard about us and he just gives us £2500.

P1: Oh lovely!

R1: Terrific.

P2: Which is fantastic, so we’ve no problem with that. We've got a little.

P1: Well, I thought your email so I will forward you the contacts in city of trees if you would like.

P2: Yeah. Yeah alright, yeah we can have a look at it

**R2: Yeah, and so what is also very important as you said, it's involvement of people with live experience of dementia. Volunteers and yeah, do you think I don't know? We just talk about funding, but do you think some potential people living with dementia saying, oh, I'm sorry I can’t attend to this activities because I don't have a car or I'm not able to drive anymore or I don't have enough money or this kind of.**

P1: Yes, because that's the that's mainly what the funding is for, the transport.

**R2: OK yeah, OK, that's fine.**

P1: Because if you go to five different parks, you know, within the year it's going to be close to some people there and it’s going to be right across the city for somebody over there, but they'd like to go, but they just see the petrol money or taxi money, you know. And also encourages them to feel safe. The getting there type of thing, which Age UK sorted all that out because they were inviting them to this. They did a questionnaire “would you like to do this? What's the barriers? Will you need transport? Will you need support on the day? There is toilet facilities there that will be open.” Then it is just giving all that information out and collecting the information of what they need on the day. And then the costs at the bottom and then we use one particular taxi firm, which this CCG would normally pay for because it's engagement. So we have a a fund for engagement so we can, as a partner, contributes to that. But if they were... if city of trees who were paying staff to organise it and run it and things like that then they would apply on that funding bid. And then what we do then we put all our hours so say I earned, just as a round figure £10.00 an hour, then if I'm going to be administering it in everything and it's gonna take me 6 hours to do that, I would then say that I've got 60 pounds with the matched funding. Age UK may need 6 staff for the day, at £10.00 an hour, so and they're doing all day with the different shifts and everything. So we add all that up and say this is the match funding in kind through partnership working which funders love.

**R1: OK fantastic great.**

**R2: Yeah, it's really, really impressive, and it was really interesting. So sadly we are very close to the end of this session.**

P1: That's fine. You’re doing such a difficult project now because...

**R1: But now it has become extra difficult, but at the same time we thought if we can manage it now if you can master it now and I think you've already given us some fantastic clues. Everything from you know, an overview of how difficult it is to reach and to engage people with early stage dementia is, to things that going on at the moment in spite of COVID things that normally go on things that can go on over the Internet as well as other things like you know, how and where do we share best practice between the boroughs? I think [P3] both [P3] and [P1] have said that, so I think there's a lot that is already come out in this focus group and which we obviously have, I think three more focused groups and then and so we will analyze that and also have some follow up interviews. Isabel, do you want to say a little bit more about that?**

**R2: Yeah. So the focus group is really the first type of the project and just in some weeks in two weeks we will have some individual interview, so with people with lived experience, so people with mild dementia and carer but also with some expert so if you agree with that, I will contact you again to see if you have time for individual interview.**

P1: Fine.

**R2: It would be quicker. Don't worry, but it will allow me to maybe speak more in details about some information you give to me and so yeah, it would be very great so.**

P1: I'm happy to join any, but I find free not a problem.

**R2: Oh great.**

P1: I think it's a great thing and I'm hoping Dementia United are included in this, are they?

**R2: I contacted them but I had no answer so maybe maybe I can see with you if you have a better contact.**

P1: Is there is there a [STAFF NAME]. So if I sent you the details, yeah and theres also Tide, who are a national carer organization for people with dementia. They will be really good because they'll bring something of best practice nationally.

**R2: OK.**

P1: I'll send you those details.

**R1: Yeah, that would be great.**

P2: There's also the Deep organisation isn’t there. We were members of deep.

P1: Yeah, so am I. I've not heard from them for a long time.

P2: They have a meeting every Wednesday. The meeting I was referring to earlier on that that's a deep meeting.

P1: Right, but that's national, isn't it?

P2: Yes.

**R1: Yeah yeah, yeah at the moment because we're looking at the service in Greater Manchester. We've been focusing on Greater Manchester, but I think there's some plan to look at the more national picture as well a little bit later.**

P1: Yeah yeah, 'cause it will be good if you get an individual from an organization to say this is what's coming to our attention because they're doing news letters with really good news, stories and things like that. I mean I'm one for scanning everything. I don't know what can we do better, you know, because it always helps working with dementia Commissioners you know and carer commissioners to say “Have you got any plans in the future doing this?” And if not, what I used to do then is say what do you think about this? People with dementia and carers, they go “Oh my God would love to do that”. I evidence it in my notes and minutes and then give it the Commissioners and say, “can you think about this when the future you know?” Which is where those groups like yourself [P2] though your groups, if you come across things that are happening.... Do you include Healthwatch in your meetings as well [P2]?

P2: We do. Yeah, well one of our committee members is actually the chairman of the local Healthwatch

P1: That's brilliant, yeah, 'cause healthwatchs very much to take forward the issues and help for people.

P2: Healthwatches address is our registered addresses as a charity we...

P1: Well, thank you. Oh, I've really enjoyed speaking. It's great what you doing? I can really give you a whoo whoo whoo!

**R1: I know sounded so great.**

**R2: Thank you, thank you.**

P2: If I can do anymore for this project feel free to contact me.

**R2: Uh, yeah.**

P2: The director, I've committed to it.

**R1: We will yeah.**

P2: And I'd like to see more integration, more help and more acknowledgement from the government. It’s all promises and we haven't seen the promises. You know, like you say, the David Cameron commitment to dementia, and where is it?

P1: Well, it looks like they would it be interesting. I thought I had to look through a while but they did a revised dementia strategy. A National One up to 2020. And Hazel Blears was on the government parliament group that do that strategy. So she used to take quite a lot of issues to Parliament from Salford, which was good. But it will be interesting what the update of this strategy is from 2020 about moving forward.

P2: Me personally, I think everything like this will get hammered until COVIDs over with. Yet the cost of of COVID will be the reason, yeah.

P1: Yes, what it'll be is that they can't meet their priorities because of COVID. You know, especially round engagement. It's very difficult, yeah?

P2: Yeah. I think you two have got a very difficult task and you I don't think could affect your worst time for doing this.

**R1: I know, I know, but we were coming from design. Well at least I am. *[inaudible]* learn the ropes in design just coming from psychology so together hopefully will be strong and this...**

P1: If there is a list of people ask them what was there before last March? What did people want to want to do? How did they tell the funders they wanted to do it? You know, Are they all volunteers. Or are they funded through, you know statutory organisations? You know, because some areas I reckon will be all volunteers like you know the groups and things like that. What actually are the Commissioners is paying for. Are they just leaving it to these volunteers to set things up, you know?

**R1: Yeah, absolutely.**

P1: And if this leaving it up ti volunteers, are they signposting those organisations like CVS, Volunteer Services and Public Health and Healthwatch to support them to get their funding and put those activities on. Look at me talking with my hands again.

**R1: Now that's nice. That's what we used to, aren't we?**

P1: Yeah.

**R1: Yes, yes, it's lovely.**

P1: Well I hope I’ve been some use to everyone.

**R1: I think you've all been absolutely fantastic. It's been so great to talk to you today and I think it's what's really important to bring things together, and you know, if we can end up, equalizing the field across Greater Manchester boroughs in some way we can make a little inroads in helping with that. I think then we're very successful. So we'll see how we you know that this will be all the way along with stakeholders with people with dementia, it's only a two year project. The aim is to come up with a potential solution that we can maybe in a mini way try out with people. So that we can, then with an evidence base go and you know go to the Commissioners and say here's an idea. This is what we could do to make it better. Please, you know, take this into your program.**

P1: Yeah, well, I'm just putting my notes here to put a calendar together. Well not a calendar but a list of activities with contact details together you know, like the disability bikes, walking football all these things that those could be shared 'cause they might go into different areas or ready. So we could do, eventually when we come out of this, I could put something together to say, on a Wednesday we've got dancing with dementia, we've got singing with dementia, we've got this, we've got that. It's a calendar of activities which I have done in the past but it changes that much that we don't get them printed up. Because then we used to print them up and then they go out of sync because somebodys funding would stop or something would happen. Doing it doing it online would help.

**R1: Yes, we've been working on something like that for the previous project, and it's a sort of early stage prototype that we're looking for further money, and we were actually thinking that if. You know, if we create a program like this, we might be able to use this. Ideally it would be AI driven, so it feeds itself from these various websites so you don't have to update it all the time because it drives you crazy and it takes a lot of person power.So we have a few things on the burner that we're trying, hopefully. You know, but this service is one of the centerpieces to it, I think. So the technology can then be I mean, it's another thing.**

P1: But but this is where I think Age UK Salford Dementia Services would be brilliant to work in partnership with. Yeah, because if it's funded it be sold to CVS for our area. The volunteer service for the money. Uh, and they might even be able to put a bid in, so we actually do that for our area. Yeah, because they work really closely with Commissioners at the CCG. So it be worth getting ahold of somebody for it. It’ll be lesmond? From CVS. But see what's available in the same things in the other councils. See if they can get a bit of money. They get the information together and then you could just draw the whole lot together and go “this is what we’ve done”. So get them doing the work. Get them doing the funding bids because they want funding from the CCG's. Fix everything today with living well and aging well, which they're all underneath that umbrella. All the councils are underneath that I don't know if you want to Google it and have a look. And we're also on the dementia friendly cities. So these are all these strategies that are there nationally, that we've signed up to. So it's all that for the CCG and the Council to say thats a good idea. But you just put one thing together and cost it up. And then present it in each area and then pull up together at the end. And then you've got a whole thing of what's happening across Greater Manchester as part of your report, and then we all have that together.So we have the contact details and what activity. I wouldn’t put a date on, I wouldn't do a calendar, I just say what the activities are, who to contact. And that would be it. Then it's down to us then and we're back out and about to be able to share best practice by visiting those different areas and different places and things.

**R1: Yeah, that's already a fantastic. You've already done half a year's worth of work for us.**

P1: I got to say that is my skill that was part of the team. That's what I do. I network with everyone pulling together and say why you provide this activity now and I'll do the report. And yeah, I'll let you have a copy of the Dementia Walk report as well.

**R1: That would be brilliant. Thank you.**

P1: You yeah I need to do that and put contact details on that for you, but.

**R2: Thanks for that.**

**R1: So thank you so much.**

**R2: Yeah, thanks again.**

**R1: Well, is there any anything else that you needed, wanted or needed to say?**

**R2: Me, I will. So [P2] and [P1]. I will contact you again so to know if you are still happy to take part of the individual interviews. An also because you will have a 20 pounds voucher to say thank you so just to to talk with you about the details. But yeah, I don't know if you have some questions or...**

P2: Well. Yeah, I mean I'm not in if for the voucher, that will go in our raffel or something like that. So I'm just here to represent really a carers view point over the past rather than the present and Looking after people and engaging people around the current situation, but as I've said before, the difficulty now is forward planning. As far as keeping a good group running is forward planning. Well, good activities up to the end of April so far. We’ve got a lady coming on Thursday.[CELEBRITY NAME -] She's an actress in [TV SHOW]. Anyway, shes on the telly [OFTEN] and she's coming on Thursday, talking about her experiences by zoom. We get lots of people like that. Which is good and engaging really? Well, we don't get everybody 'cause everybody can't get zoom. I repeat myself.

P1: That's true, that's very true. I tend to put up a wall against new technology. I don't do it, I'm not doing it. I had to do it from my job, I totally understand how people go “Oh my God. I'm not doing that.”And it’s because of frustration and having to learn something that you think you can't do, and so trying to get my mom on... Well I have to go now and that's fantastic. It’s been great to meet you all today. Yeah, I'll send you those funds that details R2:.

**R2: Great, thanks for that.**

[people say their goodbyes]

**R1: I'm stopping the recording OK. [*Recording ended*]**