**Work PACKAGE 1 - FOCUS GROUP 2**

**Focus group session with P4, P5, P6, P7 and P8**

**18 February 2021**

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

P4: = Stakeholder

P5: = Stakeholder

P6: = Stakeholder

P7: = Stakeholder

P8: = Stakeholder

**R2: = Researcher**

**R2: “My first question is: what leisure and social activities are people involved in and where do they go to attend or participate in them? Which activities, or aspects of activities do people like best/are their favourites?**

P4: Is this pre-covid or during covid? Pre-covid, they were groups, groups for people to drop into and our service users probably have quite good social connections with each other’s – going to singing groups, going for coffees. Not anybody is technically minded as well, maybe one of them

So now people join together obviously on Zooms but then the people look harmed… We have been landed tablets to people so they can stay connected with other people, but some just don’t want to use that kind of technology. I find now that people are just trying to go for a little bit of a walk just to get exercise but we do an exercise group online, it’s very popular, but again you know it’s for people that can deal with technology. We did have a men’s group – not being sexist – the gentlemen come. Some of them have the diagnosis, the other ones didn’t, but obviously they have the early stage, they do indoor bowling – but it had to stop – everything is on Internet. It’s a massive change. The person I have spoken before covid and now during covid: their mental health declined, they declined so much, dramatically, it’s so difficult for people.

P6: Yeah, I think the Zoom stuff, we tried Zoom, just some people are not focused on that, their concentration, looking on a screen, we all know that feeling very well, that Zoom fatigue, but it’s 10 times worst for someone with dementia, who are isolated at home and everything. It’s this dementia walk we are organizing in partnership with Woodland Trust, in Bolton, we have been doing these walks for quite a while. In September last year we were able to resume them, obviously we a reduced number of people. Before Covid, we had around 20-25 participants, and with covid we had to cap that down to about 6 people. It was quite difficult for some of them because it was a social element, it was really important I think so. As a Charity, we have this exemption and we can increase to 15 people, but people would probably not feel comfortable if it was a group of fifteen, especially during these times now, so we had to cap it to 6 to 8 people. So we still are getting people on these walks, what is great, and now also with Manchester, we are slowly getting more and more people every time, what is fantastic, but we also have Zoom sessions for the people that are able too, so luckily we have the walks and the online craft sessions as well.

P5: Since Covid, I have not been involved in projects, but I know people who have been involved in projects. I know Memory skills groups and cognitive stimulation have moved online and it has been a main issue making sure that people were able and confident to access it. To work with technologies, they are confident, comfortable. So pre-training have been offered before that and apparently they have been very well attended and people remained quite engaged, and those sessions have been quite beneficial. I really loved the way of they came up with different conversations about things not addressed in direct questions – more about opinions, and I think it was very beneficial for people talking about something not taxing their memory but with something they can play in their head. So I think groups like that worked very well but again it dropped down in numbers. I think it can be confusing for some people to have so many faces on screen and to be able to attend to everything in a once so I think they are groups of 6 people with several facilitators to be sure everyone can get online. The thing I’ll like to raise, from conversations I had recently with people with mild cognitive impairment, I think it’s very important to find ways to encourage them, to support them, rather to move on more dementia focused groups. There is a lot of value in being able to maintain those same social contacts so it’s definitively something I’m quite interested in is training and working with community groups about what is dementia, what differences is that make, how can we interact, how can you maintain contact with people who were in your group previously. People would rather not attend the group specifically with that tag MCI, mild stages, not everyone, so I think it could be quite valuable for people.

P4: We actually got a lady that runs an MCI group here, so if people come to us, I can refer them to her. I think that more and more people get diagnosed with MCI

P5: Yeah, and I think Trafford runs one of a view services in Manchester that runs specific MCI groups. I think it’s another one in Oldham. I think it’s a kind of stage of it’s nice to have this camaraderie of people with the same diagnose but also people are terribly impaired, they are concerned, nervous about someone noticing it, that they are not really able to do that. Building the confidence of groups is important.

P8: Before COVID, our young onset group was just used to going out and that something now that is obviously, they are strongly missing. Anything to do with singing, music, it goes well face to face but also online, it’s one thing that still works very well in our Zoom groups sessions. Since lockdown, since we are doing the Zoom’s session, we still got some face to face groups, we are linking them up with our zoom’s sessions as well, so those could come back to the group, they are still seeing each other. We have a big screen at the venue, that going down very well, people just want to see each other again. Actually, it doesn’t really matter what the activity is, as long as they are together and seeing each other’s. It’s tricky. We had previously body club that runs 3 time a week and we rearrange activities, and you have some groups members that want a thing and the other another one. But the kind of courses that all the time going down well is things related to reminiscence, they actually like cooking, baking and stuff like that. During a Zoom session we had a vegan UK chef that came around – and after that some participants emailed each other with some pictures of what they cooked – it worked very well.

**R2: What is the content of craft activities? How is it organized? How was it before?**

P8: The thing that was easier before compare to now. Before, the staffs and volunteers were with the group, so if some them struggled with something, it was possible to assist straight away. Doing it now is a lot trickier. If somebody is struggling with something, it’s much harder to communicate how to arrange it or just show to somebody. If you need material, what we made, depending on what the activity is, we dropped some resource boxes at people houses. We do that as well with bingo – bingo tickets – so we do online bingo. So, you still have, depending on the activity, to have this connection to home, you’ve to drop resources. Obviously, it’s a lot easier with the group.

**R2: What are you doing with what they produced? Are you keeping it?**

P8: Yes, they keep what they have make. And sometimes, if they make more than once, it depends – example when you’re doing drawing with this powder you blow on your paper, and it makes lovely pictures, you can make trees and so on, some people can make a couple of them and we ask them if we can keep one and we will display them in our activity room or in our office. But mostly people will take them home to send them to family.

P6: So the craft sessions we do, the way we do it before covid: we had an hour were we had a little walk around anywhere we were and then we go inside, have a cup of tea and some biscuits, and they would do a little craft session. With us being an environmental charity, we are trying to do craft sessions with genuine things you may find in a house. For example, birds’ feeders, we do them with inner tubes of toilets paper or a milk carton. But with the fact now we have not really anywhere where we can sit down properly… Usually, they would have the tutorials during the café, we would usually saying them… but as we don’t have that now, we have to try work out as we can, doing a “wild” session without working around… It has been quite difficult honestly. The dexterity of some people is not great, and things like that. But we have managed, we bought some polaroid cameras, which have been really great. So, while we walk around, people can take pictures on their polaroid’ cameras, which have been fab. We try to have some craft elements. But City of Trees and the Wooden Element, we got a lot of resources online, we have printed things out for them so they can take them back at home. During the first lockdown, last year, when things stopped completely, we did a newsletter for our mailing list, we put in this craft resources and we asked people to take pictures of it so we can put them on our twitter page, or Facebook, or anything like that. That worked very well. It became very popular and we got a lot of pictures, people sending us the bird feeder they made, the butterfly feeders they made, and things like that, and it was absolutely fantastic. It was really good to have that engagement even without physical engagement.

P4: At our Day Support for dementia was stopped in March but we were able to reopen in July. So, from March to that time, people were at home. They came back, but obviously in smaller groups (from 30 to 12). So, we had in sort to “pick and choose”, allow people that can understand social distancing and so on. As a lot of them are early onset dementia so they understand. They can go for a walk around the room and what we did, we made activity packs when we first reopened, they all had their own packs with their name on it, to avoid cross contaminations, with pencils, pens. It was crosswords, words search, art therapy, so they could work on them when they came in. Then, during the afternoon session, we moved the tables away and we could do our on chair exercises, so they still get their exercise. The families had started to get the respite again… You know, it has been a hard process, but the difference in the people from when they came back to how there are now… They are back in the routine, being in the same room as people, being able to chat across the room, it was a massive thing for them. It has worked really really well

P5: The only thing I would like to add about crafts is that open the door to intergenerational plays at well… I have been in groups where very young and very old people had come together and crafted in a lovely way to kind teach each other and show each other creativity. I know in Ireland pre-covid, I think all the school children have to go in a care home, it’s like a part of their curriculum. Have some time there. I think craft is definitively a way for them to interact. I also used to do works around poetry and I think it something that could be done online… You know, poetry doesn’t have to rhyme, it’s just a way of getting creativity and interested in. You can do that in groups like this one, you show a picture online, you just get some comments and put them together in a kind of poetic way. People can be very proud of the output, it’s nice to see your words come together.

Again, in Ireland, they’re doing something called poem-athon where I think they get hundreds of older people, with or without kind of memory problems. They just contribute one line to a poem, it’s this kind of things that build up and then everyone just goes. I think the output can be great and it’s always fun when the output can be share and they can feel ownership and being proud having contributed in something like that. Even if it’s a quite small activity in a way, the noise around is big and it’s really empowering too.

**R2: Speaking about empowerment, is it possible for people with dementia to lead their own activities, to initiate them?**

P8: I think we are. Not necessarily with craft activities, although we have had somebody modelling with concrete and things like that who said she would like to have own session, ask us “give me some opportunity” so we have organised that. Now, obviously, everybody has got concrete at home and is moulding. For example, last week, during a music session, a couple attend it, he is the one who got dementia. His daughter [PLAYS AN INSTRUMENT]. He was telling everybody about, and he said, “why is she not joining at the next session” and she did, she played. It was lovely for him to see her playing for everybody in this group, online, it was brilliant and worked very well. So yes, everybody ideas are welcome. Because you really need ideas, it’s the hardiest bite I have to say…. Being creative, coming with something new to do… So yeah, we draw on everybody ideas, expertise

P7: Before Covid, in sort of day to day activities, they develop activities linked to annual events, obviously Christmas, but they also do… it’s quite a mix of carers and people with dementia… but we did a couple weekend breaks, in an hotel, -

P8: Yes, that was usually our young onset group, a very lively group, they love going out for lunches or trips. Salford Union, they are very good at supporting people who need additional support. A group supported by a colleague of mine, absolutely love […], they go twice a year, usually at Christmas and during the summer. They absolutely love it and it’s always packed. It’s always people wanted to go. Maybe 25 of them go.

P5: Did we mention gardening? It’s a big number of gardening groups, pre-covid, they kind of grown their own vegetables or just you know, plant plants. But also, during covid, I wrote a blog about what people are doing to keep themselves mentally active. I keep in memory a lovely lady that made a garden in her back garden and her granddaughter was doing the same in her own garden, and they were sharing pictures of how far they got, a little bit like a competition, so I imagine that during covid it's “what can you do on your own patch of land”, which is nice.

P6: Yeah, definitively. I know some of the care homes with whom we are working in Bolton, they got nice piece of land with them as well so they have been doing some fairy gardens, doing some walks with their residents and staff, what have been absolutely wonderful. In terms of gardening, I know there is this work with [A STAFF MEMBER]. It’s not specific to people with dementia, it’s more like a kind of mental health initiative. I would love having this gardening group coming to join the dementia walks. Before we had this covid pandemic, I was hoping… Obviously at city of trees [THEY] are focusing on planting trees, so kind of physical work, and had planned before covid to plant about 50 trees and that’s still on the cards. What I would love is being able to do it with our new dementia group we are forming. Until now we just had a couple of walks, but even if it’s just one tree they could do, you know it’s just a great idea. The place is accessible – the path, being flat, and everything, it’s just a great place to do these walks… Hopefully this time next year… It will be great if we can.

**R2: So we are speaking a lot about social activities, and especially with the current covid-19 situation we are aware it’s very important. But have you observed that some people are interested in groups activities and other one are not. Can you find them some individual activities, in a context where they are comfortable?**

P4: Yes. I have sent some kind of online activities to people by email, which they can print out, together as a couple. But again, it is really really limited what you can do. We were holding drop-in sessions so people could come and speak to us face to face, in the confidence as well, one to one base. That had to stop as well. So, it’s basically phone calls and just checking they are ok. Just being there, really.

P8: I agree with that. We were basically doing loads of phone calls for those who can’t access group activities or can’t access anything online. And even though we are proving this support, we encourage people to get online because it opens a whole new world. But some people, for whatever reason, a range of reasons, don’t access anything online. So, they are kind of prioritized regarding weekly calls. Some we send out information and advices, we still have our activity pack that we send out. The thing is in the activity pack they get a lot of different ideas. We just find that some people are kind of on their own. They are just happy with the phone calls, having conversation, they want to know what’s going in the carers’ life, there is creative good friendships there.

We do try to encourage physical activity at home, giving information advices about what we can do to stay physically fit. And again, with the “World through your window” … we got some people obviously living in flats, on second floor…. They shield in, they can’t go out. So, we were “how can we bring them outside” in? Just asking to people “open your windows? What can you smell? What can you hear?” That kind of things. That’s the focus of this group… some people not accessing anything, socially anyway.

**R2: We talked about involvement of people, individually or collectively. But have you notice a change in involvement with dementia?**

P8: I think people are less motivated… I think they probably need more activities. I think the more people now stay at home… Pre-covid, obviously, it was some people that find difficult to access things or didn’t want to. But then we did home visits so you could maybe do something with somebody while you’re there. Whatever in which activities or in what they are interested in. Post-covid, I think people will be less motivated, they will get use to stay at home although they were desperate for getting out…. When we first re-opened our group, carers were telling us all the time on the phone they were desperate to go out, to get somewhere, but when the opportunity arrived, it was… “oh, actually”. We had quite a few that became worried because they are so accustomed to be at home all the time. Obviously, it was still fear of infection and so on as well, but I think some people have become a little bit agoraphobic because they have been so used to be in their home now…. It’s very difficult for them then to actually take that next step and going back out.

P4: We also found in Salford as well that a lot of people that have been suffering of memory loss haven’t been going for assessment. Obviously, they were frightened, they shield in. So, it has been quite a drop in diagnosis rates in the moment. I have done of a sort of a big flyer drop around to say “if you are worry about memory loss, get in touch” because people thing they will not get an appointment so what is the point, they must wait, and now things are deteriorating. It has a massive effect as well.

P5: And I think research show at the moment that people who are disengaging, not able to go out, not able to connect, obviously their memory problems get worst due to the fact of it. And I definitively think that for all of us in a sense, the way we are interacting with the world is changing. I know from [A MAN I KNOW] was “I will go everywhere, I will do everything” and now he is very different, he doesn’t even go down the road. I think we are all changing in the way we are acting. Hopefully that will change, but otherwise I think we need to respond around it. We had some lovely stories at Global Brain Health. I worked with a lady who run “Singing for the Brain” sessions, so it’s full packed. But she said that first when they start them on Zoom, some people were not so sure, some of them were in their pyjamas. But she said by like a few weeks in, some of them become to put make up on and recognized it was one of their chances to actually engage with people, and she said that even so it’s online. I think… again, you know, a person living with dementia is a person first and foremost. We all respond differently, it will be the first and biggest difficulty for any project…you have this kind of iceberg where you know a few people who are interacting with services but there they is a huge variety of people with different needs. It’s going to get harder to get older… Maybe [P4] see more of these people with early-onset diagnosis… it’s kind “where are the people that don’t want activity groups, that are maybe shrinking to the background? What are their needs, what happen then?”. It’s interesting.

P4: Yeah, definitively. It’s why I think, even, just by… You know, I’ve got a gentleman, his wife just being diagnosed but he wants to do everything himself. He doesn’t want any help from anyone else. And his daughter got in touch with me. So, the way I worked that… I’ve made a weekly phone call to him, I built up a little bit of a relationship with him, a bit of trust, we were not talking about dementia at the start… just general chit-chat. He is now become to trust me, and he has now allowed me to set up carers going in. It has been a journey all the way through covid. It’s a nice sort of result in the end. But again, it’s all being done by telephone. But even pre-covid, I don’t think he would had allowed me to come for a home visit anyway because he didn’t want anyone else.

**R2: Potentially activities related to access to activities and performing them**

P6: I think it has already been mentioned, it’s about with these groups we do have, physical groups coming out, it’s the fact they don’t all understand in terms of social distancing. We got to take pictures, to tell them… You know we all do, don’t we? It’s still new to us too. But it is one of those things that is difficult sometimes, it’s the reason why we have put this cap on numbers of people that we have in our groups. Another one I find is… even if we are a charity… we still wear masks as well. I think it’s one thing that is really really difficult for some people… many of us wearing glasses, it’s just like “I know… the glasses fog. It’s always a pain, isn’t it?” It’s difficult to hear as well. Just having these masks on, it’s difficult to have a proper conversation ([P4] agrees). I think those are the two main issues we have in terms of engaging people in our walks.

P4: Yes, you know, even responding to somebody is a massive difficulty as well. You can’t see when he is smiling, the only thing you can see are crow’s feet, so it’s a massive barrier.

P8: I agree with everything you said in regard of the online stuff. Pre-covid, transport was a big one, I have to say. It’s a big barrier for people accessing stuff, especially when somebody has the license taken from them, you know, because obviously they have been not enough fit to drive anymore. But I think there is too…you know…people get worried about being sort of in public, when the person they are looking may display particular behaviours… people get embarrassed. There is always this problem that “other people won’t understand”…if the person they are caring for… you know… says things, inappropriate things, things like that… people get embarrassed and say “I would just rather not go” or “I can do it on my own”, that kind of things. I think it has always been a barrier.

**R2: Do you think this situation related to dementia-related stigma improved in the past years?**

P8: Yeah, I think it’s still an issue. You know, I don’t think we can pretend that everything is fine and that everybody fully understands, fully be aware… I tend to find this more when it’s a married couple rather than a daughter taking a parent. From my experience, I would say it’s really hard for a wife taking a husband out and the husband maybe missay something or suddenly swear whereas in never done it before. Then they get very embarrassed. But I think that where, like our group for instance, people relax quicker because… we all get it… nothing shocks us, we don’t worry… it doesn’t matter if someone says something inappropriate, that’s absolutely fine. So, I think that’s where… with other people who they know definitively have an understanding, it makes it easier, they relax more. Just going out and joining in, maybe like a local sport centre or something like that, for some it’s not a problem but for others it’s still too… they are too nervous about that, they are worried about what the other people will think.

P5: I think that so true. This confidence… this stigmatisation is one of the big things. It’s hard to change society as a whole, it’s not impossible but it’s hard. I think the most safe spaces they have, the more organisation know about this... I used to go to the aquatic centre, they used to organise dementia swimming sessions. I don’t know how well it was organised… But the more places they are aware, that they can accommodate and can create that safe space, the better.

I also think it is a lot of work to be done around kind of culturally appropriate sessions or places where people can go out, for south Asian or afro-Caribbean groups. Even the way they speak about dementia can be very different and it can be hard to go to a group where people don’t understand culturally where they are coming from with that. I think there is a huge leaps and bounds to be made in those communities because it can be so different and it can be so few resources.

P6: I think… we work in such a diverse area…so it’s one thing. When we first started this project at Manchester, we collected a lot of contacts basically, trying to gets the mosques involved, the Afro-Caribbean people involved, things like that… because it’s so diverse as well, so diverse people. If English is not their first language, that’s also obviously a barrier. But I know that [A COLLEGUE] that works with us, you know, diversity is such a big passion for her… Hopefully by working with them that will get easier… that we can actually have more diverse group coming up with us…

P8: I think physical disability is a problem as well…being unable to get out and enjoying things, making sure that place is accessible, it’s something else that needs to be considered. The same with sensory as well. Sensory impairments are a problem for using Zoom… for online activities, if there is a sensory impairment here, gosh it makes it so difficult.

P7: I think there is also some people that just don’t like being in a group situation, they don’t see themselves as a group person… it’s the nature of the lifestyle. They just don’t like to engage in this type of settings, I think.

P8: You saying that makes me think about [SOMEONE I KNOW]. [THEY DON’T] have dementia, but group activity wasn’t his thing. But saying that, where he made more of socialising was in Morrison’s in [SALFORD]. He had a fix time when he will go because he knew who would be there at that time, and I have seen this in quite a few people with whom I work as well… It’s like “oh, we go to shop at 2 pm… it’s when [A STAFF MEMBER] is here as well, when we could have a coffee”. This kind of things used to happen a lot. People might not go to groups, they might consider there are not taking part in activities… but actually, as long as they got back connection somewhere

P7: You only have to look the Wetherspoons… Prior Covid, it was packed… a lot of people socialise there… it’s so a social outlet… We just think that people should go to services that are provided for them, but they use resources in the community that are personal for them.

Coming back to people with sensory impairments, typically hearing difficulties, quite often they don’t like to sit in a group situation because they miss half the conversation, they can’t engage and that create quite a barrier for people as well.

P5: Many supermarkets, local amenities, many of them have like “sensory awareness hours” … I know some did this around autism… times where the lights are slightly lower… and even if they don’t do that specifically as a dementia friendly hours… you know, you could encourage local amenities or big supermarkets to have, I don’t know a Monday morning, or something like that… it would make such a difference. As you said, people interact with their own community and they are not necessarily going out to find a group for support… they are going to their local COOP, or their local church maybe

P7: Yeah, I know the Lowry in Salford [theatre and gallery complex] does that for people with dementia. It has been a lot of work done in [SALFORD] with businesses, raising awareness about dementia and certain like Morrissons, they got benches for people to sit on, to socialise…to encourage that. (three participants joke about the fact they are living in [SALFORD] and should met)

**R2: Strategies – potential support for people living with dementia and their carers**

P8: Pre-covid, probably also now, we have encouraged people to be in contact with families, we have encouraged families to have more contacts with parents… I’m focusing more on now I have to say… So, post covid. We have managed to link … because it’s easier now because more people are using online…a lot of people we support, now are using technologies, where they didn’t pre-covid. When we wanted to touch them, it was other ways to communicate. Now, it has really open doors, some opportunities to see families, to speak to families, you know they might live abroad and things like that. So, I think it worked very well. We have a carers’ group that encourage that. We encouraged people you know “get your daughter online” and we will send the link. That’s really works and hopefully the plan is that they accommodate that and will continue to support each other that way, with us stepping away, and that works well. More of some of them than the others of course.

P4: We got an IT specialist, so he is training people… you know, people with tablets that are at home. Just to keep them up and running. So, he is like the specialist IT support for them. People are getting more and more use to it, even so they were frightened at the start of it. They are engaging more, definitively.

P8: Pre-covid… I’m just trying to think about barriers that could stop people… Part of our team can do one-to-one support… so if we had… you know…a couple or somebody who was reluctant to access anything… what we do we report that to a member of this staff and this member says “well, just go, go for a coffee and next leave. You don’t have to stay, you don’t have to commit or becoming a member of that group”. Being done on a gradually basis… eventually then… you know, they become comfortable to go on their own... you know… they would become part of this group and…they build friendships that way. That’s something we did before.

Again, something we can do now, online, for those who can’t access online groups and stuffs…we are still doing that, we have a lot of phone calls where we have to do a lot of encouraging, they are on their own but say “oh, actually, it was great, for an hour. It was easier than what I thought” … you know…so that’s work well.

P5: If you’re looking for some specific details of groups that have been adapted to be more dementia friendly, a colleague of mine, who works in Leeds in a theatre company, she said before she noticed for a while that some of the older members of the theatre group were developing dementia and she actually think she was one of the first people who recognise their memory problems and she has now adapted the group so those members could continue to come because they were starting to feel less comfortable and some of them were dropping off, but it was one of the things they really enjoyed, so she was highly aware of that, and kind made sure the group could accommodate that. So, if you want I could put her in contact with you and she can say you more because I don’t know the details, but I found it great.

**R2: Dementia-friendly – characteristics – venues (examples of dementia-friendly characteristics)**

P6: So, I guess one thing we do with the walks… we try to have some different levels. Before Christmas, we had different walks we could have done depending on the ability of the people who were attending these walks. That’s one thing we always try to do, it’s to have those different options. Pre-covid, it was a group of 20-25 people with about 4 or 5 staff with us as well. So that means that we could have split the group into different smaller groups and then one could have gone for a much longer walk, where someone was a bit more active or wanted to know a little bit more about the area and this kind of thing. We would had split the walk maybe in 2 or 3 groups, something like that, for people to have their own level of abilities. And, in a way, it’s just giving people that choice as well of what to do…. Instead of saying “this is a more accessible route”, you could say in terms of “this route has got stairs”, you know, “would you be comfortable using these stairs?”. Because if you just say it’s more accessible, it’s more accessible for some people but still not accessible for others, depending on what your abilities are.

I think it’s just… I know we are trying… sometime you overthink some aspects of the activities… we always do that… you know, “maybe this person can’t do that”… just maybe give them that try, just let them try it, you know, it’s up to them if they want try it. I think it’s something that need to be focused on as well… you know we are always all about self-isolation and independence, but sometime, you can “spoon-feed” a little bit too much as well. Just keeping their independence and keeping them making their own decisions of what they can or can’t do.

P5: I think it’s a perfect example of a group facilitator and a group that is very aware of this. I think it’s something that needs to be told more and even, at the communication level, someone might have word finding difficulties, but you don’t prompt them on those words, you know… you maybe don’t correct them neither… you make this environment as comfortable for them as possible. I think that kind of awareness of community and activity groups would be really really valuable, and more people would feel confident to actually go out and interact if that was there… I think it’s probably much harder to have the whole group like that if it’s a group that is not oriented dementia-friendly… but at least the facilitators are aware and… you know… it would be really valuable.

P4: Yeah. It’s like in our day support… because people are at different stages, so you got… you know… early onset and you got further communication issues… So, we give activities adapted to their capabilities, but not something easy. We will give them a little bit of a challenge…” Come on, do you want to try this? – Nooo – Yes, come one, have a go”, so they will (big smile). And most time they will attend, and they are absolutely over the moon because they managed to do it whereas they thought they couldn’t.

And then, you’ve got the other end, where people have lost the communication skills, that are unable to talk… We put some music on in the background, and they are singing every single words of that songs! …You know… everyone else is enjoying the music, but that persons, it’s making the most of themselves as well. They might not be able to the activities in front of them, but they can sing. (inaudible)

P5: I was just going to give a little bit of a plug… And I have too as I was used to work in the research area… clinical research… and I actually think that’s a really interesting way of involving people in their own care… kind of empowering them to be involved in elders care as well, to think “I’m doing something beyond myself”. People that get involved, either as participants or in public involvement kind of planning research, and even in activities like this, they really felt like their voice has been heard. They had that support they didn’t have otherwise, someone people found communities around that, they stay in contact with… you know…with the other families, and often those individuals, not only they are helping within the system, but they are gaining so much of it as well, and I think that’s not spoken about as much… because it always sounds really scary, like “do you want to be involved in research? – Oh, you will give me drugs”. But in reality, a lot of it is being involved in focus groups or taking a few memory tests, and the memory nurses are utterly lovely and they understand everything, and that’s a new contact for you to… you know… to chat to, and to get a little bit more information from. I think it’s an untapped resource and there is a lot going on in Manchester… a little bit like this… you know (laugh)… we are all doing stuffs, so yeah

P8: I was gonna say… same as [P4] really… some of our groups are for both the carer and the cared-for, but we have also groups only for people with dementia. The purpose of those groups is to give them some independence away from the carer, to kind of see of what they are capable of. Because, you know, you can over care, doing so much… you know… and the carer thinks that he has been a very good carer because he has do everything for him… and actually he is capable doing such a lot himself.

And we do an assessment sometime before somebody comes to a group… the carer says “oh, nooo, she can’t do that, she won’t be able to do that” or “he won’t be able to do that”, we say “that’s fine, that’s fine”. And actually when they are in a group… “just have a go, it’s ok”, you would be surprised of what people are still capable of… People have maybe this assumption they can’t….

But another thing I didn’t have the chance to say before…. For me, when talking about dementia friendly, it’s not always the environment, because you can’t change everything like that. It is really around people, and people attitudes, and people understanding. I think that makes a bigger difference than the floor in or the lights… you know, this kind of things…For me, I was thinking “dementia-friendly hour Morrison’s” would be when you know the staff have a really good understanding… so it doesn’t matter if anybody does something that seems a bit strange…. That’s the biggest thing for me, that would have the biggest positive impact.

P4:

And a lot of the shops in [SALFORD] have got the sticker in their window “dementia-friendly” … I’m obviously based in [TRAFFORD] and I don’t really see it in [TRAFFORD]…

P8: Oh no, it has been a lot of work done at [SALFORD] with the local shops and local businesses

P4: Yeah, and I think that’s a massive thing if people are working past and seeing that… they could feel like the barriers are open… you know people could be more understanding with them… it could promote their independence as well.

P8: Just, sorry, another little thing we haven’t touch down before… We… Some people attend a group on Wednesday, and we have… there is this snooker table there, and we got a couple of guys who used to love play snooker but now their ability to play isn’t quite what it was… but how the other group members support them, their support with that, their patience “no, no, it’s alright… don’t hit that one”. You know… that is lovely to see, that peer support, that happens a lot… which I think is really good for those providing this support. You know what I mean, it’s not often that somebody with dementia is the one providing that support… and I think that’s really good to see it… and that happening.

P6: Yeah, I think when you mention that peer-support… the fact is… obviously I’m not from a health background or dementia. So, my knowledge, in terms of…the care, and things that people need, is … very very little compared to all of view on the call right now. And I think, in a way, it helps a lot of people… I think it was mentioned before about not specific… I think it was [P5]… about not specifically being targeted as a dementia group, and I think that can help some people in terms of getting that access.

As I said, my knowledge about dementia is very little but it’s the fact… we are still doing these walks, we do get carers whether they are the carers from the resident home or either a husband, a wife or a daughter, or anything like that. So we do have that help from the carers coming with them and they support our work. But I think the fact, you know, I don’t know anything really about dementia or anything like that, I think that kind of help certain conversations as they… as I said, I’m not in the ability to…as [P8: ] said… over-care… I don’t know anything about these specific people that come to this group. So, I’m just there to have a chat, teach them about nature-based things…just have some fun with them basically! It’s another thing that is important in some aspects.

**R2: Yes, looking the person as a person, not as a person living with dementia, I think it’s really important.**

**R2: Role of carers – caregivers – what are their expectations regarding activities?**

P6: I think, at City of Trees, as we are not, we don’t have that caring element, with the walks. So, the carers, whoever they are, they come on the walks with us. But what we have found in the past with these walks is the carer will chat with the other carers… you know, they form friendships and things like that. I think those understanding of what people are living out is very important for them… and again, they introduce people to new groups… there was one couple, coming to the Bolton walks with us, and there was another mum and daughter there, and they introduced them in another gardening group that was happening… and it kind of escalated into a new friendship… which is absolutely fantastic… So you know, the people with dementia, the carers, they just are all forming these relationships, or friendships… even though we don’t offer any sort of direct respite to the carers… but I think they do also have that… we do also have that element…you know, just in terms of offering different things to the carers as well.

P4: Yes, I spoke to a lady the other week. Her husband has just recently been diagnosed with dementia and she was kind of … “oh, he is repeating himself, I looked forward this programme but I can’t watch this programme anymore, he used to love fishing, he used to go on the internet. But he doesn’t bother it now… he just wants to sit down and snooze all day…” I just suggested to write the instructions down, next to the computer… how to switch it on, how to log on, and others…, so he can research his fishing and look at pictures… and he is doing it now! So she gets now that respite time at home, just to watch a rubbish programme… you know… she was embarrassed to say she watches, but that was her time. In the same time, he is doing something he enjoys, he is keeping his independence even though the instructions are written there for him… He can just say “I’m going on the computer” … and you know that’s work for them at home, being stuck together…

P8: I think… not everybody wants the same thing…you know…you have some couples that want stay together, want to do activities together, the others where… who are together but…you know… the carer would be desperate for a break, but unfortunately the person they are caring for wouldn’t go anywhere without that person. If it’s a way to…get in that sort of variety… I think carers need that break so I think if you could find an activity to the cared for to do to give the carer a break off… where there are “together” but both have an activity but separate, if think that’s really good… but them also doing activities together can reinforce the relationship…that is often very strained… you know, it can be quite strained, because you know carers get tired, and so on. So I just think if there is things they could do together, and it’s positive, and it just gives them something else to focus on, give them something to talk about, something they can do together again because often… it’s sort of go down in that dementia journey…if you like… you know, their ability to do things together often starts to separate… Yeah, I think doing things together is definitively a positive in their relationship but I think also, the ability to do things separate… I think it’s healthy too…

P4: Especially with lockdown as well, sometimes you do need… I need that break from my husband (laugh)...

P5: Yeah, I think, being aware, in a way, it’s really important because, I guess, they are also in quite a vulnerable situation in many ways, their mental health, the fact they have to deal with so much, and the fact there is probably not enough support for a lot people to feel… you know… they are supported. So being aware of what they need… as like [P8: ] said… some of them might want to have an activity they can do together and they can connect with, but others might want a little bit of respite, they might want… you know…

I had this story, of my group again in Ireland … saying they put together an activity for people living with dementia…not a lot of people were coming…and then they decided to put a carers’ group that runs simultaneously, and what happened is actually that the number of people turned up because the people living with dementia were relying on the carers but the carers couldn’t attend the group, so they didn’t really want to bring them and hang around… so sometimes it’s really beneficial just think of both sides than either run the activity with both or have separated activities. And again, as you said, when carers get together, they can share their stories, feel less isolated too…

**R2: Yes, we attended some groups like that, south-Birmingham.**

P4: Yeah… we would normally run a group as well where both… you know, both of the couple come, and everyone would get together, and they build friendship up…but now we’re doing that on Zoom, so we do that once a month. It’s nice because there are more and more people I’m speaking to after… a diagnosis, and they want, they are actually wanting to join the Hub… and we got a little WhatsApp group, so they all chat between each other… even though they have not met physically, they are seeing each other on the Zoom Hub and they send each other little jocks on this WhatsApp group, so it’s keeping them up as well…

P6: One little story that has been nice with us… The Woodland Trust has been running Zoom sessions and then we have been doing the physical walks and things over Bolton and, with these Zoom sessions, we had some people that sort of attend these sessions…during the interruption, and it kind of increase their confidence to come on the walk… I think it was last week or the week before, we had a walk, and this new couple came along… we hadn’t met before because we have not be really involved in the Zoom sessions that much, but they were on the some sessions and they recognised someone else who was on the Zoom session and who was on the walk as well…Now, because they have been on the Zoom, and they have been on physical walks as well, you can just see as you said that element of friendship and socialization increasing.

And I think, even though at the beginning of the all lockdown process, our workload, our mindset had changed drastically, and now, we will probably, no matter what happens with this pandemic, we will probably still gonna have to do these Zoom sessions, along with these physical activities. So that might be kind a downside for us because we think now it will double the work to do, but it’s just so important, isn’t it? That people can access all these things for whatever reasons they want. Like, sometimes they might not be able to come on the walk but then they could do the Zoom sessions instead or something like that… no, yeah, so that was really great to see they recognized each other from the cameras to real life now so that was really great to hear.