**WORK PACKAGE 1 – SESSION 9**

**Individual interview with stakeholder P9**

**21st April 2021**

Audio File Name: S11 - IDoService - Individualinterview - Other stakeholders - 21 apr

Duration: 00:37:00

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

P9: = Stakeholder

**R2: – to wait ten seconds because I will have to ask again if you consent to take part in this study so are you –?**

P9: Of course, that’s fine. I give –

**R2: Okay.**

P9: – consent to take part in the interview and for it –

**R2: Great.**

P9: – to be recorded.

**R2: Perfect. Thanks a lot. So, yes I have some questions maybe more related to your job at Health Innovation Manchester. I'm sorry I forgot for how long are you in Health Innovation Manchester?**

P9: It’ll be three years in September.

**R2: Okay. And I'm sure last year or at least… Yes, so last ten months were really [laughter] new and with a lot of things to adapt and –**

P9: Yes, definitely.

**R2: – lots of things to learn.**

P9: Definitely. We’ve had to adapt our ways of working during the pandemic. We’ve moved a lot of our activity online.

**R2: Yes. What is the proportion of action related to aging and people living with dementia in I would say the global activity of your organisation?**

P9: Prior to the pandemic, we had two or three dementia specific projects and when the pandemic hit our portfolio was reviewed and some projects were paused, some projects were halted completely –

**R2: Okay.**

P9: – and some were accelerated.

**R2: Okay.**

P9: Unfortunately, one of the projects in particular that I was working on on dementia that we were making really good progress with was halted. I don’t know if or when it will be restarted because it wasn’t seen as a priority in the context of Covid, which is a real pity because I thought it was an important project. It was focusing on the public’s understanding of dementia. What the general populations’ knowledge was around dementia and how they could improve people’s understanding but also how they could communicate health messages around prevention and lifestyle changes. We were actually going to… It was a project that was being delivered in partnership with big pharma, big pharma –

**R2: Okay.**

P9: – companies and also a consultant of dementia as well and obviously Health Innovation Manchester and the public. One of the pharma companies had recruited… I can't remember his name now, someone who’s from Greater Manchester because one of the questions we explored when we held some discussion groups was people’s attitudes towards being tested for dementia at an early stage because if there are going to be treatments that are effective they're more likely to be effective the earlier dementia is diagnosed. What we found was that there was great reluctance to undertake things such as lumber puncture at first –

**R2: Okay.**

P9: – but when… In the discussion group, I think we had eight or ten members of the public and we co-delivered it in partnership with the pharma company and also this consultant and after being able to hear directly from the consultant and ask questions there was a huge shift around testing

**R2: So, yes having this direct contact and the possibility to ask question was really helpful for people and reduce their fear about some examinations.**

P9: Yes. It was the fear of the actual procedure, which is invasive obviously, you're taking spinal fluid.

**R2: Yes.**

P9: It was also fear of do I need to know if there’s nothing anyone can do for me?

**R2: Yes. Exactly.**

P9: And it was about people understanding that the earlier you're diagnosed you’ve got a better chance of living well because you can get the right support and even if it was Alzheimer’s, you know for Alzheimer’s there is some medication that can be effective in some people in the early stages for a short time. So, it can be helpful to get people on to that or if it's vascular dementia, obviously Alzheimer’s and vascular are the most common forms of dementia. You’ll get people on the appropriate medication for the vascular system for the heart and blood pressure and things like that.

**R2: Yes. Indeed.**

P9: So, when that was explained there seemed to be a real shift in people’s understanding.

**R2: Yes. Yes, I know it was really great. So, for a moment due to Covid-19 it stopped.**

P9: It did, which I was really disappointed about because dementia’s always been the poor relation compared to cancer.

**R2: Yes.**

P9: We’ve got 30,000 plus people living in Greater Manchester with dementia and 850,000 across the country and that figure’s set to rise with the aging population even though dementia isn't obviously an ordinary part of aging; it's a disease or a set of symptoms. My concern is that the pandemic may have set that research into dementia many many years.

**R2: Yes. Yes.**

P9: Although Covid, I heard on the news that there are concerns that Covid can impact the brain.

**R2: Yes.**

P9: Actually, trigger dementia so it might as time moves forward shift again, where emphasis is very much on understanding the impact of Covid on dementia but you know… or may be a trigger or a cause for dementia. I don’t know whether we’re at that stage yet because we’re still, in terms of understanding Covid, probably still at a really early stage.

**R2: Yes, it's really, this illness is reallly intriguing and it's quite crazy because between symptoms and contamination we are probably just at the beginning of our understanding of that. It's really really weird but as you say it’s probably a lot of impact on the cognitive functions so, yes probably in the future something we’ll have to take into consideration. As you said, it's really less money and also quite some less public interest for dementia compared to cancer for example, do you know –?**

P9: Another interesting thing about the discussion group was I didn’t… When I was recruiting for it, I didn’t mention the word dementia –

**R2: Okay.**

P9: – because I thought there would be a lack of interest.

**R2: Yes.**

P9: So, I just… I can't think how I worded it now but I didn’t use the word dementia. What we found was once we actually got people in the room and we started talking… I think we’d set the group up for an hour and a half because we were concerned that people might lose interest, they said they would have stayed for the whole day. They found it that interesting.

**R2: Okay.**

P9: They learnt that much about dementia that they didn’t know. Having said that that cohort were people that had an interest in getting involved in public and community involvement engagement activities. Some of them had done stuff like this before. So, although I’d tried to refute the general public if you like that can be difficult can't it, to just… You often get people who’ve had an experience of healthcare themselves in some way that they want to make a difference that they put themselves forward for that type of work. But certainly, I think [pause] what the feedback was was that an hour and a half wasn’t actually long enough and if we’d have –

**R2: Okay.**

P9: – had (unclear 00:08:37) group they would have been more than willing to take part. I think there was one person in the room that had a family member that had been diagnosed with dementia but apart from that, most people’s experience of it was just from the stereotypes really. You know, an older person sat in an armchair in a care home.

**R2: Yes. Yes. If you didn’t choose the word dementia, how have you advertised that? It was healthy aging or condition or memory or…?**

P9: Because I'm working from home now I don’t know if my emails will go back that far but I’ll look it… I would have created like a plain language summary. So, I’ll see if I can find it and [pause] get it over to you. I’ll have a look back through my emails and through my files and see –

**R2: Great.**

P9: – if… Because I specifically avoided the use of the word dementia because what I didn’t want people to do was any research. I wanted them to come cold so that I could find out what they knew about dementia and we could maybe find out what were some of the myths.

**R2: Yes. No, it's really an interesting approach because indeed people have some stereotypes about dementia and in worse case just saying the word dementia they would say oh, no, it's to for me. I will not go to this meeting. So, yes I'm really interested… If you have time if you can find… send me some more information.**

P9: I’ll have a look for you. I’ll have a look and see if I can find it. I'm sure I've got it.

**R2: Right. That’s nice. I have quite a related question because we talk about diagnosis and the need of early diagnosis so it's quite related to something you mentioned during this focus group the fact that for people with early dementia or at least early onset MCI or even early symptoms it's… A lot of services and activities for people for dementia are not very relevant for them so they’re not really interested in that or… How do you think we can increase attractivity of activities or even community based activities in Greater Manchester for them?**

P9: Sorry, I was just trying to find that form for you. Could you just repeat that little bit again for me, [R2]? Sorry.

**R2: Sorry, no problem. You mentioned during focus group that people with early symptoms some mild dementia for example they're sometime not very interested in activities in Age UK Trafford for example or Age UK or Alzheimer’s Society or these kinds of things because it's not really interesting and I think maybe it's for people with severe dementia –**

P9: Yes, a lot of –

**R2: – severe symptoms –**

P9: A lot of the community provision targeting people living with dementia tends to be activities that if I was diagnosed tomorrow would not engage me at all. Such as armchair aerobics or you know, stuff like that. From working with people living with dementia what they want to do is carry on doing the things that they enjoy. Not suddenly pigeon holed into doing activities that are… have no interest to them and might not actually help keep the brain active.

**R2: Yes. So, are they looking to just keeping the usual activities and adapt to possible changes, are they looking maybe for different kinds of activities? So, maybe not just dementia related but inclusive for all or for new (unclear 00:12:34) learning new things?**

P9: Well one of the gentlemen I work with called [NAME] didn’t have a history of doing woodwork and joined a community group that wasn’t dementia specific but it was working with people who were marginalised or socially excluded in some way. It was people with mental health issues. People with physical disability a range of age groups, you know. Some people who had a history of being homeless –

**R2: Okay.**

P9: – and the focus was on woodwork and it brought people with all different backgrounds but they were vulnerable in some way together. Although that project ended up closing down this gentleman’s continued with his woodwork. He’s even had a huge shed built in his garden and he’s now selling, although he’s six years into his diagnosis, you want to see the woodwork… the things he makes and he sells. People put orders in for them and it's not people who are just doing it to be nice to him it's because what he’s creating is wonderful.

**R2: Right.**

P9: So, there are a lot of myths that you can't learn new skills or even use… continue to use existing ones and things like that need to be challenged. I think there’s a place for peer support for one person who’s being diagnosed supporting another to show how you can live well. I think that’s really important but it's also important to be inclusive so you're not just palmed off into a group of people living with dementia and not offered anything else.

**R2: Yes. Yes, yes so it's more for as you say people with some vulnerabilities but quite an open group with good access.**

P9: I think ask the people with dementia what they want to do.

**R2: Yes. Yes, exactly.**

P9: (Over-peaking 00:14:50) services or support that’s able to respond to that. Someone might just be able to want to still go shopping and browsing clothes shops, you know and use public transport or go to a museum or an art gallery or the theatre or the cinema. You know, it doesn’t necessarily have to be craft based activities –

**R2: Yes.**

P9: – and woodwork and things like that. It's like all of us, we’re all unique and that doesn’t change with a diagnosis of dementia but it's about making reasonable adjustments like you would in the workplace. Because I've thought myself if I was diagnosed with dementia tomorrow what impact would it have on my job because I could have dementia now and not know. Would that mean that there would be an expectation that I’d resign?

**R2: Yes.**

P9: Whereas if reasonable adjustments were made, I might be able to continue with my job for a long time with the right support.

**R2: Yes. Exactly. It's also one of my questions for people, for example, with early onset they can still have a job so… Are you aware of some things in Greater Manchester maybe in Great Britain to help people to adapt their job or maybe they will leave that job but they will say okay I still have skills and I can help so I would like to be a volunteer. Are there some volunteering opportunities for people with dementia?**

P9: I don’t think there’s enough if there are any because they're not –

**R2: Okay.**

P9: – widely publicised. I think one of the biggest projects I was aware of was the one that was on Channel 4 –

**R2: Okay.**

P9: – where they made the programme and that involved some people from Greater Manchester. I can't remember what it was called but it was a café.

**R2: Okay.**

P9: They employed people living with dementia –

**R2: Great.**

P9: – and a restaurant and it was run like a proper restaurant and people were given roles to do and supported to do them. What they found was that the people’s symptoms of dementia reduced –

**R2: Oh, great.**

P9: – through the experience of getting involved. It was an amazing fly on the wall documentary.

**R2: Yes. Okay I will try to have a look if I can find that on internet or find more information. That’s great. Yes, because I think in the Netherlands they really try to facilitate volunteering for people living with dementia with kind of agencies, helping them to find a place where they could volunteer, is that something (unclear 00:17:35) in the UK or maybe a project in the future? You don’t know?**

P9: I don’t know about that but I think there's definitely a place for people who have been diagnosed who have in their world have come to terms in some way with their diagnosis and feel able to support others who are newly diagnosed.

**R2: Yes.**

P9: Give them hope that their life isn't over. You know and that you can live well with the right support. I often really worry about people who are single who haven't got a support network and how they cope with the diagnosis. I would imagine many end up in care homes before their time –

**R2: Yes. Yes.**

P9: – because there’s a lack of hope and because they don’t get the support they need.

**R2: Yes. Yes, indeed. It's basically a minority true. You mentioned during the focus groups some dementia champions…**

P9: Yes, that’s the Alzheimer’s Society and dementia –

**R2: Okay.**

P9: – champions were people who delivered awareness sessions, I think, around… you know, dementia friends becoming… to encourage people to be dementia friends. So if you put in dementia friends or dementia champions into the internet it might bring up –

**R2: Okay.**

P9: – some options for you to do some further reading.

**R2: Great.**

P9: I can't remember what context I mentioned the dementia champions, can you remember what I said?

**R2: Yes, because I think it was quite… It was not a long time ago dementia was a priority from the UK government it said from David Cameron maybe (over-speaking 00:19:40) –**

P9: Yes, that's right.

**R2: – plan – Okay. Do you think it will change mentalities and options and services for people with dementia? It will help to improve?**

P9: I still don’t think enough has been done. It continues to be the poor relation compared to cancer. That’s my opinion and I think there’s very much a postcode lottery, depending on where you live.

**R2: Yes.**

P9: And that’s including Greater Manchester. You know, Greater Manchester is a huge area with ten boroughs and depending on where you live will depend what support you get. Although because of devolution Greater Manchester has got a whole programme of work called Dementia United that’s been delivered by the partnership the Greater Manchester Health & Social Care Partnership. But it will be worth exploring with them what impact the pandemic’s had on that on the work of Dementia United and whether or not it's still continuing at pace to make Greater Manchester the best place to live if you're diagnosed with dementia.

**R2: Yes. Yes, I have to say I tried to contact someone at Dementia United but it was not possible. I had no answer so I will try again because I think it's really something very relevant but I think I heard… I [s.l enquired 00:21:13] finishing the first [s.l funding 00:21:14] and going in maybe a different format so maybe that’s why it was difficult for them to give me an interview.**

P9: Can you remember the name of the person you spoke to? Can you remember who it was you tried to email or whatever?

**R2: I think it was quite a complex family name but [laughter] –**

P9: Oh, it's okay. I can make enquires to see if there's anybody… Some of my colleagues in Health Innovation Manchester might be able to suggest some contacts for you.

**R2: Yes, it would be nice just to have a short interview 30 minutes just to… Because it's really interesting what they are doing so it would be great for me to learn from them. So, yes if you can do that it would be great.**

P9: I'm just making some notes of what I need to follow up.

**R2: Yes, just a contact of someone maybe for having some information about the programme.**

P9: Okay.

**R2: Great. I also have a question… Last time you sent to us a document about Greater Manchester forum, something you –**

P9: Yes, the Greater Manchester –

**R2: – were organising.**

P9: – forum. If you go onto Health Innovation Manchester website there’s a whole section now.

**R2: Okay.**

P9: If you go under the tab called Our Work at the top on the main page and scroll down you’ll see Public and Community Involvement and Engagement tab. If you click on that, you’ll see at the bottom two pictures; one is for Health Innovation Manchester’s Public and Community panel, which is a panel of people from all different walks of life, which now includes a gentleman who’s got a diagnosis of dementia.

**R2: Okay.**

P9: (Over-speaking 00:23:14) but he’s actually in hospital at the moment just having had major surgery. But the other tab is all about the forum and you’ll be able to see whether or not it will be of interest to you to join that forum.

**R2: Yes. Yes.**

P9: Because the forum is all about people who are leading public and community involvement work across Greater Manchester. From the universities. From the NHS Trust. From the voluntary sector and community groups. What we found during the pandemic is obviously we can't go out into the trenches and do place based research so we’re dependant or we’ve been utilising the relationships networks and contacts that other people have got, which includes members of our panel and members of the forum. In fact, although if you go on the website you’ll see a list of some of the members of that group, it's grown a lot since that website was updated. We’ve got over 60 members now.

**R2: Great. Yes, I will have a look. I will see what's possible to try and… It's really… yes, really interesting and as you say we really need to ask people what they need and what they want but sometimes the difficulty is to have access to them so…**

P9: Yes.

**R2: It's really –**

P9: (Over-speaking 00:24:40) would be another organisation that’s for carers –

**R2: Yes.**

P9: – together in dementia every day.

**R2: Yes, I have to contact them too for more info. Great. What I heard from [R1] and other people is Greater Manchester or Manchester and Greater Manchester is really a great place with quite innovative people and motivated people to do new things, what do you think is a place of innovation in Greater Manchester? Do you think it's really something people are looking for or is it a good place to deliver up new services for people with dementia?**

P9: Definitely, because you’ve got that whole programme of work, Dementia United.

**R2: Yes.**

P9: Devolution creates the right environment for that kind of thing but also Health Innovation Manchester, we’ve got an innovation pipeline –

**R2: Okay.**

P9: – and also like a portal called the Nexus where people with innovations can apply for additional support from us and even in some cases funding.

**R2: Right. Yes, so you are really supporting people.**

P9: Yes. If the innovations meet local needs then it could be something that we take up to support. It doesn’t have to be a medical device or a new medicine it can be a new way of working.

**R2: Yes. Great. You also talked about sharing best practices, so it's something the forum tried to do and is it…? Also, because what I heard during focus groups and it's indeed some disparities between boroughs. Some of them have a lot of services and others less services, do you think sharing best practice is something quite common or we can still try to improve that?**

P9: Definitely still try to improve it. Do you mean best practice in terms of involving people with dementia or –?

**R2: Yes.**

P9: Yes?

**R2: Yes.**

P9: Most definitely. I think it should be… I don’t think we can ever say that we’re doing enough. We should always be striving to improve and also include people whose voices are not heard. I think there’ll be pockets of really good work across Greater Manchester in terms of involving people living with dementia but the left hand might not know what the right hand’s doing –

**R2: Yes.**

P9: – and there’ll also be a lot of people living with a diagnosis and their carers who don’t have a voice at all.

**R2: Yes, exactly. Asking two people is a thing but sometimes we are in contact with the same kind of people with a similar background and… Yes. Finding and being in touch with minorities it’s more difficult so it's also quite a big challenge. Yes, that’s great. I have a last question.**

P9: Okay.

**R2: In a perfect world if you have a lot of money and you can do what you want to do, do you have a project or something that you saw in the UK or maybe abroad a project something you would like to have in Greater Manchester?**

P9: I don’t think there’s a one size fits all.

**R2: Yes.**

P9: I think it's about having choice and it's about finding out from people living with dementia what they would like and trying to create different options. That includes the people who are single. I know that people have said communities for people, like housing estates, little communities for people living with dementia might not work well so well because people with dementia might need support from their neighbours and they don’t want to be separated off from the rest of society. They might want to live next to families with young children and be able to interact with people of different ages and not just be defined by their dementia.

**R2: Yes.**

P9: On the other hand I think there’s a place for peer support, you know, for people to come to terms with the diagnosis and give them hope that you can live well. I also think you need enablers to help people who haven't got support or whose dementia is starting to progress to continue to do the things that they love and enjoy. It's not just the family or the carer taking the burden all the time. Not that I'm saying the person is a burden but carers often get burnt out in trying to meet the needs of people living with dementia.

**R2: Yes.**

P9: Holidays, so that people can go away to dementia friendly places where they’re supported to have a holiday and do the things that we take for granted.

**R2: Yes.**

P9: One of the things I was going to do but the gentleman actually ended up being diagnosed with a serious heart condition so he couldn’t do it but we were talking about going potholing, you know, with proper trained people. Like I was frightened myself –

**R2: Okay.**

P9: – but this was a gentleman who used to lead groups of young people potholing and he was diagnosed with dementia and it was like because he was diagnosed there was a perception that he wasn’t able to do that anymore, well why not? With reasonable –

**R2: Yes.**

P9: – (over-speaking 00:30:37) and the right support why couldn’t he have done that?

**R2: Yes. Yes. Exactly. It's not because I have a diagnosis of dementia I'm not able to continue to do things and new things and maybe some (unclear 00:30:52) I don’t know but… Yes.**

P9: Also, the biggest thing that I think needs to happen is more awareness.

**R2: Yes.**

P9: One of my friends is living with dementia and my partner, we’ve been together [MANY] years but he’d never met my friend and before the pandemic, I’d said we were going into Manchester to meet him. Go for a few drinks and watch a band and my fella never said anything but I thought he might have been a bit apprehensive. They are the best of friends now. They never stopped laughing all day –

**R2: Great.**

P9: – because [MY FRIEND]’s just so funny and we just had a ball. It was like such a fabulous afternoon and I don’t think people get to see that. They just see the label of dementia and that conjures up the stereotype and we need to challenge… If anything’s going to change that needs to change. We need to change –

**R2: Yes.**

P9: – society’s perceptions of people living with a diagnosis.

**R2: Yes. Exactly. We have this stereotype link to people at the severe stage and so… Yes.**

P9: And the fear as well because people are frightened to say the wrong thing.

**R2: Yes.**

P9: Sometimes it comes from a good place. People don’t mean to exclude someone but they’re terrified of saying the wrong thing.

**R2: Yes. Yes. And that’s why it's also important to have more possibilities to meet people living with dementia and be aware of that in the community just to be aware if there are people like others and we don’t have to be worried to say bad things. We can adapt as we have to adapt with everyone.**

P9: I think it helps when we see some famous people who’ve been diagnosed speaking out about it. I think that does help to raise awareness but then of course coupled with that is the person’s demise such as with Barbara Windsor and it frightens people.

**R2: Yes. Yes, and it's also... I think maybe a few months ago it was maybe a famous football player say okay I have dementia and it was a lot of very sad commentaries on the internet so it's really still showing that… he may have dementia, okay, it’s a death sentence –**

P9: Yes.

**R2: – and this kind of thing.**

P9: What it's not showing is the live well bit.

**R2: No. We still have… Yes, I totally agree.**

P9: My friends yesterday, they’ve been stuck in throughout the pandemic but they’ve had their vaccinations now and they went to a pub beer garden for the first time and they sent me a picture. It was just… It was brilliant. You know, to see my friend who’s got a diagnosis sat with a pint.

**R2: Yes. Exactly.**

P9: You know people don’t think of that. What? People with dementia go to the pub?

**R2: Yes. Yes. Exactly. It's really a bit different between what people want and what we think they want.**

P9: Yes.

**R2: Great. Thanks a lot. It's a lot of very interesting information. Maybe if I still have some questions I will just send you a short email to have a look or something like that.**

P9: No problem at all, [R2], and I'm glad to have been some help.

**R2: Great. I will let you know and [R1] and I will stay in touch with you to let you know about future steps and how the project is going. Before ending this call, you have the right to have a £40 voucher or you can make a donation if you prefer. I don’t know what you prefer.**

P9: Well, what I was thinking is my friend who does the woodwork obviously he can't work now because of his dementia but he dedicates his time to building things out of wood so if you send the voucher to me I can send… Where are they for?

**R2: It depends. It can be Amazon or something else I don’t know if you have an idea or…**

P9: If you send them to me and I’ll forward them to him –

**R2: Great.**

P9: – to get some stuff for his woodwork. Would that be okay?

**R2: Yes. Yes, no problem. So, for which kind of shops? I don’t know. You want for Amazon or something else?**

P9: If you let me know, even B&Q.

**R2: Okay.**

P9: If you let me know what you can get I’ll find out from him which works best.

**R2: Okay.**

P9: Because then I know that someone’s benefiting directly.

**R2: Yes, exactly.**

P9: Because I know charities do some fantastic work but I also am aware that sometimes a lot of the money gets syphoned off. The staff on the front line are paid really low money and the people higher up are on huge salaries and it… So, I’d rather it benefits someone living with dementia directly.

**R2: Great. Yes, no problem. It’s a very good idea. Yes.**

P9: Even if –

**R2: I will –**

P9: If you did it in two £20 vouchers I've got two… I could send them... I've got two or three people I could send two of them a £20 voucher each and just explain that I got involved in this research and I wanted to… I was entitled to this voucher but I want them to have it.

**R2: Yes. Great. So, I will ask for two of £20, it's not a problem. I will ask for which kind of voucher Amazon or other things we can have and –**

P9: Yes, and then I’ll come back to you and let you know. That’s brilliant

**R2: Great.**

P9: Thank you so much.

**R2: Perfect.**

P9: Thank you.

**R2: Thanks to you. Yes, thanks a lot. Have a nice day.**

P9: And you, [R2], Bye now.

**R2: Thank you.**

P9: Bye bye.

**R2: Bye bye**

**[End of Recording]**