**WORK PACKAGE 2 – SESSION 4**

**Focus group with stakeholders**

**11th January 2022**

Audio File Name: Workshop 1 – Group 3

Duration: 00:56:00

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

**I1: = Interviewer 1 (Interviewer 1 in bold)**

***I2: = Interviewer 2 (Interviewer 2 in bold + italics)***

P12: = Stakeholder

P5: = Stakeholder

P9: = Stakeholder

P47: = Stakeholder

P8: = Stakeholder

(Started at 00:00:10)

**I1: …people are able to access and what people would like to do more. Based on that, the idea of the skills exchange service has emerged. So the session today, in fact this is the fourth in the series, [P8] knows, we’ve done the first one with Age UK Salford, with people with dementia, to now figure out what skills would people like to see in those services from the dementia side. Then we’ve had sessions with, like today, service providers, with people who work with people with dementia and provide services for them, to think about, from that side, what could that service look like, what should it deliver, what skills, volunteering, how can that fit in what’s already existing and help support, bring something in to being that draws on existing and helps extend that. So we’re hoping that this will become, or planning that this will become an iterative process after the workshop today.**

**We will gather all the information again and look through what picture emerges in terms of what might be the most useful forward and we might put together two or three proposals of what this skills exchange service might look like and then arrange some more workshops in February, or from February onwards, to discuss those ideas and see which ones might be the most sensible or suitable to take forward and how might they be implemented so that in the last phase of the project we can then try and run a simulation with a small number of people where we, very hands on, organise things as if the service was in place. So we call that simulation in order to see does it work, where could it be better so that in the end we have a proof of concept that we can then try and take forward for serious implementation. So that’s the idea of the project in general. So from the early session with people with dementia for example, we had a lot of fantastic input about what kind of things people like doing or what they have in terms of skills and what they potentially could work, also help others with, whether it’s supporting people to travel or cooking, cake making, swimming, ballroom dancing, even parachuting came up.**

**It turned out that as the discussion emerged, people with dementia mentioned a lot of skills they had that they didn’t really think about anymore but actually really were happy to talk about and thought, “Oh yes, I could still do this or that.” For example, we’ve had a couple of examples, one about swimming. Two of the carers said that they couldn’t actually swim whereas some of the people with dementia had been swimming instructors. The carers would really like to learn to swim. They’d even taught their children and grandchildren to swim but were anxious to do so themselves. So for example volunteering, those people who’d been coaches could volunteer to help them get over that anxiety, not necessarily with the physical support but certainly with the mental support and encouragement to do so. Similar with dancing. There were lots of other activities such as cake making and so on. So that was a really great start. So these were examples that came from people with dementia.**

**So today is really about from the provider side to think about how can we enable people with dementia to participate or to offer these kind of opportunities for active involvement. So we’ve got lots of little virtual post-its here that we can put things in but I’ll unshare now so we can see each other. I’d like to hand over to you really to see what your thoughts might be. Sorry, let me try and get out of this. Here we go. I can see you again now.**

P12: Could I speak please, [I1]? Just going on from [I2] did mention that we had supported a person with dementia to run a marathon. With Age UK Salford, we’ve been able to support people living with dementia with certainly a lot of the activities that you’ve mentioned there. So we’ve already done a lot of that in the past. Obviously the barrier is resources but we’ve had craft classes for people but that was a project that we were involved with, I can’t remember who it was now but it was someone paid for the artist basically. So we find the people, the people attend our groups and when we’ve been able to get people from outside to come and provide these different classes, one of them being crafts, etc. So we are able to facilitate things like that. Sometimes resources obviously can be a problem because an artist can be expensive so we’ve only been able to do that once or twice. But other things, for example sports and things that don’t really cost anything, it’s basically staff time. We do usually support a group of people doing the same activity.

Obviously that is a lot easier, we can manage that within current resources but when you do come across clients who, like running a marathon for example, well obviously that was done in my own time with the client. So that’s where we struggle currently with activities if they were individual where staff may not be available to do that. But we’ve certainly got a lot of ideas. If we’re working in collaboration with other organisations, the possibilities are endless.

**I1: Absolutely. So one of the things that might also be something to think about is how connecting with volunteering organisations for example, people with dementia can be supported through volunteers to enable those things but also of course the other way round, how people with dementia can become volunteers. But yes, we recognise that there is a huge amount of fantastic work already out there and fantastic opportunities but some of the things that people we interviewed, people with dementia told us were around being able to access these straight off as well as the diversity in the different boroughs of Manchester. Anyway, I’ll hand on. [P5], I think you had your hand up.**

P5: I think [P9] had her hand up first so I’m going to let her jump in.

**I1: Okay, [P9] then. Sorry.**

P9: I don’t mind, [P5], if you want to go first.

P5: We’re too polite, way too polite. Yes, okay. I was just going to raise, so I think I’ve already spoken to [I2] about this a little bit. I’d love there to be some kind of linkage between these projects. So myself and [P47] and [A MEMBER OF STAFF] from Greater Sports and a few localities, so Wigan and Trafford, have put together to develop a training platform or a training programme for community groups which aren’t necessarily immediately dementia focused, so not dementia cafes but maybe knit and natter groups, sports groups, so a bit like you say, like swimming and leisure providers. So the idea is we’re developing a piece of training that can help them feel more confident supporting people living with dementia in their communities to access these non-dementia focus groups. Now, the training is being developed by two partners that we’ve brought on board, an organisation called Made By Mortals and another called Together Dementia Support. I think you’ve spoken to Sally Ferris from this group. As time goes on, once the resource is developed, we’re really interested in making sure that this is spread across the whole of Greater Manchester and can be repeatedly used but we still haven’t quite got a model yet for train the trainers or encouraging people to bring this together.

So just joining dots that probably aren’t there but just think it’s something that would be wonderful to train someone living with dementia and their care partner maybe to deliver this to their local organisations or if there was something like this. So that’s happening. It’s not going to be complete until March, the training package. We’re going to start piloting it then. But I just wonder whether there’s some crossover on that point. I don’t know if there’s anything you want to add, [P47], sorry, I don’t know if I’ve missed anything.

P47: No. I suppose that’s an offer to include within the service as a thing that can be exchanged and promoted.

**I1: Yes, that sounds great. I mean fabulous work of course. Sorry, [P9], you were…**

P9: Mine was just a brief point really, [I1]. When you were describing that you were speaking to people living with dementia and after having a conversation people started recalling things that they used to enjoy and that they could probably still do, I thought really if you’re designing a service or co-designing a service, one of the starting points really should be somebody who can, or more than one person that can have those conversations with someone living with dementia so that they can talk through, tell them about their life and find out what they’re actually interested in. You hit the nail on the head, there might be things that they used to do that they can still do, that they might not have thought about and would enjoy and remind them that dementia hasn’t taken everything away from them.

**I1: Yes, absolutely. In fact, that’s one of the things that also came up in the previous group so I think that is definitely something we’ll need to look into, how can we provide this forum or this opportunity for people to actually talk about what they like doing or liked doing and see can that still help them to look forward as well. [P47]?**

P47: I think [P8] was first. I’ll let [P8] go.

**I1: Okay. I’ll not try and call anybody out. I’ll just say next next time.**

P8: No worries. Thank you. Mine was a question really. I was just curious, did anybody say that they’d actually applied to be a volunteer, gone through the usual volunteer channels, maybe at CBS or anything like that? I was just curious to see that if somebody had applied and they’d not been able to find a volunteer opportunity or do people not just have that confidence in the first place to make that initial application?

**I1: We have heard from both sides. Well we haven’t heard from people with dementia that they have tried to volunteer so I think there probably is confidence lacking although I’m not saying that there aren’t any because we’ve spoken to the volunteer organisations and they said they were including people with dementia in their services. But they didn’t tell us how many there were amongst the volunteers that they have so we don’t know if that’s one or two or rather more than that.**

P8: I’m just thinking maybe they could do with a little work around that as well to say that those volunteer opportunities are open to everybody. Do you know what I mean? I’m just thinking, we have a volunteer coordinator and her name is [NAME] and I’m just thinking we’re probably the same. We probably don’t get that many applications from those with disabilities generally so I’d just be curious to see if maybe we should be working a bit harder to be a bit more inclusive. Just a thought.

P9: Sorry, I think [P47] was next but I just wanted to say, following on from [P8]’s point, that one of the issues, particularly for people with young onset dementia is if they’re in receipt of benefits and they’re able to volunteer, that could also be used to say that they’re fit for work and that could be a real barrier for people living with dementia to actually take on volunteering opportunities.

**I1: Okay, that’s an interesting point. That hasn’t come up yet so we’ll keep that in mind. Who’s next?**

P47: Well my reflection on this, so maybe to go back a couple of steps is from what I have experienced in this job in terms of trying to engage more people with dementia into our workstreams is that it takes a long time and you need to appropriately resource the relationship building and building of trust, whether that be between the service you’re doing and directly the person living with dementia or, in most cases, you’re talking to someone else who knows someone living with dementia and you need that person to trust your service or what you’re offering is what it is and is good enough and all of the relationships around that need to be in place for it to work. So I’m just thinking for this service that’s around exchanging skills, the service itself to facilitate the exchanging of skills needs to have appropriately resourced and have time for the soft relationship building, trust building stuff that I think a lot of the time gets underestimated for how long it can take but is key to make it work and to make more people engage with it. So I think that was just my reflection on this.

**I1: That’s really important, really valid point, yes, absolutely. [P8]?**

P8: Sorry, that’s an old hand.

**I1: I think the time that it takes to facilitate those kind of relationships I think is really key in that trust in people being willing to and also to instil that confidence around that training programme, I think that sounds some really good thoughts there.**

P9: I agree, [I1], with what [P47] has said about relationships and trust and about it taking time. I was also going to say that when I was working closely with people living with dementia, what they told me was that after being diagnosed, one of the first things they lost was the confidence. That was one of the main things that happened on diagnosis, they totally lost their confidence. So what [P47] was saying about having to feel confident that they’ll be safe and support wherever they go, I think is important but also, the other thing that came out which was included in your presentation, is people don’t always want dementia specific activities. They want to feel normal just like everybody else. A lot of the time, dementia activities that are stuff that’s on for people living with a diagnosis, tend to be for people who are much older, much frailer and their dementia is far more progressed. That can actually be quite upsetting for somebody who’s been recently diagnosed thinking, “Is that going to be in x months or years?” So it’s a tricky area.

**I1: It certainly is to both target the people with dementia, with the diagnosis and at the same time avoid putting them into a category and stigmatising them or them feeling stigmatised by saying, “This is for you because you have a diagnosis of dementia.” That might already put them off. So there is a bit of a conundrum here which we’ll have to clearly work out how could that work, how could we capture those people at diagnosis. Absolutely, we’ve had that experience too with people with dementia lacking that confidence both in some of the interviews that we did in our previous project, in the Mind project where people said, “Now that I have a diagnosis, I don’t think I can do anything anymore,” that kind of (unclear 00:29:14). But also when we spoke even to very confident people from the European working group, who are ambassadors, when we probed a little bit, it actually came out that most of them had experienced depression between one and three years following diagnosis.**

**So there’s a real issue there as well to address and seeing how we can perhaps… one of the ideas was that if we can link it more closely to the diagnosis as a service, that connects between the diagnosis to accompany somebody I suppose, to build that relationship and support to enable them to realise that they do have skills and abilities, that they are not defined by their condition or illness and that they can figure out what they can and want to do. [P5]?**

P5: It’s fine. Sorry, I’m just formulating this thought in my brain so it’s probably totally incoherent so I apologise. But I don’t know what other organisations you’ve linked in with or you’re able to crosspollinate with because it feels like it would be really interesting to have a coworking between somewhere larger, maybe like Alzheimer’s Society but also maybe some of the smaller groups which have people living with dementia, to develop a dementia volunteering platform, so an organisation that people maybe soon after diagnosis might want to join. The idea is that there’s a lot of discussion over what skills do you have, how can we facilitate you to step out and help other people learn something new and then whether providers can join in on that. So obviously there are groups like the Camerata and the Hallé who are performing concerts for people living with dementia. Now I’m assuming there are probably a lot of people living with dementia who are amazing musicians who might equally want to join one of those groups to perform themselves.

It feels like if there’s some form of platform to bring those two providers together and that’s probably the kind of thing you’re already looking into but it’s just who would need to be involved in that and who would share the ownership because it feels like it needs to be a platform where people will be able to find it and have access. There’s enough, I don’t know, weight around it for people to be able to know it’s there but yes, just a thought.

**I1: Absolutely. I think that’s a key point of who needs to be involved and how we can connect. That will be one of the design challenges to really address. It’s one of the reasons why we’ll do this iterative process. So we find out who’s already involved in what might potentially be an interesting aspect and then to see what are the things that we need to look at in the trust building, the health and safety aspects and all these other kinds of things that then underpin how, in principle, it could work and how it could sit between and connect existing services.**

P9: [I1], I was just going to say that like you found when you’ve spoken to people with dementia, even people who come across as really confident and still able to utilise the skills such as the ambassadors, one of the key gaps seems to be that on diagnosis they might be given a load of leaflets and sent away and very little else, hence people sink into depression. That’s not to say that even if there was the right support in place, if someone’s delivered that news to you, the chances are that it’s going to have a dramatic impact on your mental health. But the severity of that and the length of that will probably be reduced greatly if there was something immediately after diagnosis and that could include encouraging people to consider what they can still do and have links from whatever that support is into what you’re creating so that the first steps of people on diagnosis thinking, “Well that’s it, my life is over,” “Well actually it’s not because you can still do this and you can still do that. This is how we can make that possible for you,” rather than being told, which I’ve heard said, “Go away and get your affairs in order.”

**I1: I know. When we started, I mean this is a few years ago now and I think things have vastly improved since then but I think there were three or four dementia apps available when we started the original project in 2015 and all of them were about negative behaviours. They were really bad. I still have one of them on my phone just as a demonstrator. They were so awful. I think that’s really useful saying that. So thinking about something that is directly after diagnosis and how it connects to the people who deliver the diagnosis.**

P9: I think there’s (unclear 00:35:16) between being diagnosed and then wanting to start doing activities because in the middle is this black hole and some people never get out of that because of the way they’ve been diagnosed, the way the news has been delivered and then the fact that very often there’s nothing that can be offered in terms of treatment unless you’ve got Alzheimer’s or if it’s vascular dementia, they may give you blood thinners or things for your heart but just sent away. Then what we rely on really then is for people, if they come out of that dark cloud, to think, “Oh well actually maybe I could still do things. I want to have a go at something,” whereas we need to introduce that idea much sooner if we’re going to improve people’s quality of life and enable them to live well.

**I1: Yes, I think so. I think that’s a really good point and it’s something that we really need to figure out, how can we introduce that earlier, so working with the people perhaps who deliver the diagnosis to then see what could we do at this point to provide that input. Sorry, I’m just looking, [P5] is putting something. Do you just want to say that? I can’t so quickly read all of that.**

P5: Oh yes, that’s fine. Again, it’s a case study I’m looking at writing up soon and sharing and probably [P12] and [P8], you might know about this. So in Trafford, there’s kind of an opt out system where everyone going through the memory assessment service is triaged through Age UK and offered that very quick support and signposting and guidance. I think the key to the success of that is the buy in of the mass service and this opt out model that everyone gets through that. I think that’s a really nice model and it takes people at that very early stage and gives them something extra, some kind of support that otherwise they wouldn’t have had. But we’re going to hopefully write a case study up on how that’s working, not necessarily going to be possible in all localities but it’s an interesting way of doing things.

P9: There’s another example of a volunteering opportunity where you could have people who are diagnosed, who are living well, at memory clinic to give people hope that their life’s not over. They could be promoting whatever it is, the service that you would create as well.

**I1: Yes, absolutely. I mean we have still something, if you remember, [P9], we were developing or we have developed as part of the previous project, something called Living The Life. It’s a little reflective booklet which is looking at some of these things as well. Because of COVID, we still haven’t evaluated that so that may be something we want to do over the next year, to pick that up again, to get it evaluated and see whether that can also be part of that package to help people figure out what they might want to do, so having both the people but also the potential tools by which we can help people to do that. Absolutely. No, that seems a really model that you’re mentioning there, [P5].**

P8: I just wanted to say in Salford, obviously when people receive their diagnosis, they’re automatically given the information around Age UK Salford but you can imagine somebody has just received that diagnosis, they’ve got a little bundle of leaflets there that I’m sure are really useful but they’re still reeling, aren’t they, from that diagnosis because we’ve had so many people who, when they finally contacted us or we’ve ended up receiving the referral through another professional, they say to us, “Actually we did get that leaflet at the time but we just couldn’t face looking at anything,” or, “We came across it again and we thought, “Oh God,” we’d forgotten we’d been given this.” So it’s all about timing, isn’t it? Unfortunately there is different timing for everybody so it’s going to be difficult to get a one size fits all but it is giving them that opportunity early and just say, “Take that away with you. Remember this is available. Put it somewhere safe and then contact us when you’re ready.” Obviously I’m saying the same for any volunteering opportunities. They just need time to absorb that bombshell that’s just been dropped on them and going from there.

**I1: Yes. I think clearly people do need that time to absorb it. There is the typical model of how people process this kind of negative information in terms of aggression, apathy, to slowly moving towards acceptance so seeing how can we make that earlier stage shorter, how can we support people to get over that and getting to acceptance and understand that acceptance doesn’t mean that their life is over. I think acceptance is made more difficult if people don’t understand that they’re still the same person that they were yesterday before they got their diagnosis.**

P9: Exactly. We could all have it now. We could all have it now, couldn’t we, and not know. That’s the way I always think of it. If I found out today that I had it and then suddenly if you tell people, they’re going to change towards you compared to how they were yesterday. Imagine that, how difficult that must feel. I was also going to say, and I know obviously it’s all about creating this service so that people have got access to opportunities to continue to have a life basically and do things they enjoy but I do think, like I’ve pointed out, that it’s closely linked as well to the moment someone’s diagnosed and how they’re diagnosed and what support… like [P8] said, they’re given a bundle of leaflets and it probably is the last thing they want to do at that time is look at it. But what doesn’t seem to happen is a follow up in four weeks or two weeks to see how someone is doing. Their world could have fell apart and even those follow up calls, “Would you like us to send you some leaflets?” finding out, it could be a month later or six weeks later, allowing people a bit of time to process it but what does seem to happen is people are diagnosed and sent away and nothing then happens, they don’t hear from anybody.

**I1: Yes. So that’s clearly somewhere that making an intervention at that point would be a really good thing to do, wouldn’t it, but it would obviously need to closely work with the health services in order to enable that follow up, whether that’s through the health service themselves or through a volunteer or through Age UK or through whoever. So that will be a key point to consider, how will they receive that kind of follow up. How can that follow up be provided and how can the stage be set for that follow up from the point of the diagnosis discussion I suppose. So I mean [P8], maybe you can enlighten us a little bit there or [P12]. You said that you very quickly offer support after the diagnosis. Obviously I haven’t gone through the services so I haven’t got experience of my own. How do people get referred to Age UK?**

P12: Different methods, [I1]. Quite a lot of referrals come through the memory assessment team at Woodlands. We have self-referrals, quite a few self-referrals. The majority are Woodlands. Then there’s other organisations, carer centres, social workers, hospitals, etc. So anywhere and everywhere basically. But like [P9] was saying, the problem is we get unstuck where we have to wait for people to contact us, either the individual or Woodlands. Unfortunately, we’ve had this conversation many times, haven’t we, [P8], where Woodlands will give the leaflets, ours included so you’ve got all this here, ours is in the middle of it unfortunately. People don’t look through it straight away because they’re in shock, etc., but if we were able to access, if Woodlands were able to tell us straight away and make a referral, we would be able to support those… we can even support people pre-diagnosis. I mean that’s going to be impossible probably, we can’t even get to know when they’re diagnosed. But we can start supporting people even before they have a diagnosis.

We would be able to attend GP visits and things like that with them but we don’t get to know unfortunately. Sometimes, a lot of the clients that actually do end up coming to us eventually, they always say that they wished they’d been able to access us sooner but because they’re just given a leaflet on the day of diagnosis and then like [P8] was saying, or somebody was saying before, it may have been [P9], that they don’t always see the leaflets until whenever. We’ve asked Woodlands in the past. I mean we’ll probably keep trying but if they were able to refer but they say they can’t at the moment. I don’t know why but they don’t do it at the moment. They can’t do it at the moment because, I don’t know actually. I don’t know the reason.

**I1: GDPR probably.**

P12: Well it’s part of it because they do say that the individual has to give their consent. Well fair enough, that’s fine. Well ask them instead of giving them a leaflet. I mean I know it’s our service and I probably may be biased and I know there’s a lot of other organisations that can provide support but if we were able to get the referrals from the people ASAP, we’d be able to support and then refer them to the other organisations as well anyway.

P8: I think like what you were saying then, [P12], one of the biggest things I think we provide all these services and obviously we do a range of activities for people but one of the biggest things that people need is that emotional support, especially in those early stages. It’s to help navigate through services and support that’s on offer. So actually I’m dead interested in what you were saying before [P5] about what they do in Trafford. They’ve got an opt out. I’m not sure how that works regarding GDPR, do you know what I mean, but ideally that would be great if we would be, as a service, if we were then able to contact that person instead of waiting for them to be able to find the leaflet amongst the bunch of leaflets or wait for a referral, if we were then able to make that contact, the soft contact or whatever. But the emotional support would start straight away. It’s an opportunity for them, if nothing else, to just offload. Or what we find a lot is they have lots of questions that they didn’t think to ask at the time. They came away thinking, “Oh God, I wish I’d have asked this and I wish I’d have asked that. What did they say about this? I can’t remember what they said about this.”

So again, that’s something we could support with. So I’d be interested to see what comes out of the work you’re doing there, [P5], regarding that. That would be very interesting. So if you can share that at some point, that will be lovely.

P9: I totally agree because I think most of the time them leaflets get shoved in a drawer or go in the bin because people can’t face looking at them. Then they won’t necessarily… if you’ve got young onset for example, it wouldn’t even be in your head to ring Age UK because the image could be that people think that it’s for much older people. Do you know what I mean? Whereas if colleagues in the memory clinics were able to say, “Listen…” and that also goes for what you were saying, [P12], before, you could support people pre-diagnosis. Well there’s going to be a whole cohort of people that have got cognitive decline that may or may not develop into dementia, that may be seen at the memory clinic but discharged because they haven’t got dementia. At the moment there is nothing for those people. Again, I think there’s a bit of awareness around Age UK to make people aware of what you can offer because they might not know. But I think the staff in the memory clinic, if there could be some kind of agreement where every person who is diagnosed, when they’re going out the door they’re told would they like to receive a call off Age UK because they can offer you this, this and this. Surely that would be better than giving people loads of leaflets that they’re not going to be able to use and process.

P12: Sorry. I’m not sure, [P9], if would it seem that we were being favourites over other organisations or something? I don’t know the reason but I’m thinking maybe they would seem like they were favouring Age UK above anybody else but I don’t know.

P5: I wonder if it depends what the offer is though, [P12], whether it comes from Age UK or whether it comes from say a social prescriber, that the offer in that first instance isn’t necessarily you want to become part of our organisation or join our groups, it’s that we are in a position to signpost you to places that you might want to be. As everyone said, I think people get so many leaflets from a doctor and it’s not always the right time and things get hidden. I used to work in research recruitment before this and it was really interesting that you could give people leaflets about really interesting research projects and you’d either not read them or they’re not good enough but you talk to the same person and they’d actually be really interesting. They’d turn round… so I used to sit in a memory clinic and after people had their appointments, they’d come and sit with me if they were interested. It was such a different process. It just feels like that’s the point of the pathway that we’re missing. It’s being taken up by all these leaflets and instead it should be a person. You do get dementia advisers, depending what they’re called, in different memory assessment teams so there will be someone who takes that up but I don’t think it’s standardised. I think there’s so much more.

The same as what you say about brain health, [P9]. I think we’re entering a time where there’s so much that can be done around brain health and mild cognitive impairment that that requires its own signposting. Again, I’m working on a leaflet for that at the moment which after everything we’ve said isn’t necessarily the best thing but it’s something because people don’t tend to get much information about that yet.

P9: It’s better than nothing, isn’t it, [P5]. It’s a start. I’m going to have to go now but I just want to say, I was just tying away then and I realised I wasn’t muted so sorry if that interrupted you talking [P5]. But I just wanted to say I’ve really enjoyed the discussion and hearing everyone’s points of view. I suppose in my mind, it has cemented this sort of idea that if we’re serious about improving wellbeing and inclusion for people living with dementia, it needs to start from those memory clinics and build from there.

**I1: Yes. That seems a key point that’s come up in the discussion today as well as some of the earlier ones. Thank you for that. Thank you for joining us today, [P9].**

P9: Lovely talking to you all and nice to meet you [P5]. Bye [P8], bye [P12], bye [I2]. Bye, bye.

***I2: Bye.***

**I1: Yes. Just picking up from where we left off before [P9] left, was that [I2] actually worked in (unclear 00:53:12) in Luxembourg. It just made me think. Do you want to say something from your experience [I2]?**

***I2: Yes. Luxembourg I think is really, really different. It’s really more I think an open discussion in Greater Manchester, in Manchester and a lot of services. But I think the main problem for us, it’s really a lot of different people in Luxembourg but in the end it was just Luxembourg people coming so we were missing maybe… in Luxembourg I think it’s 25% of the population or maybe 35% not being from Luxembourg. I think it’s really from minorities, I think it’s really difficult to access this for minorities. I think it’s also an important point of our previous discussion, how we can try to reach people, ones living on their own or maybe for minorities because I think it’s also… I don’t know if [P8] or [P12], you have a proportion in Salford, the number of people approximately with dementia and in the end with how many people are you in contact. So I suppose you are certainly just in contact with maybe, I don’t know, 20% of people living with dementia or something like that.***

P8: I couldn’t tell you the figures to be honest but I know the people we’re in contact with, compared to how many people actually are living with dementia in Salford is so small. There still are so many people out there. I think there’s a huge chunk of people with dementia in BAME communities that we just do not come across. We’ve tried so hard in the past, haven’t we, [P12]. We’ve been involved in projects and thought, “Right okay, let’s really try and do something about this. Let’s try and make those connections.” I’ve got to be honest with you, we’re just not very successful at it. I couldn’t tell you what the numbers are but I just know the people that we’re actually supporting are very low compared to the amount of people who are actually living with dementia in Salford.

**I1: Yes.**

***I2: I think it’s really something that we’ve found in interviews, people having access to your service are very happy with that and now it’s just (unclear 00:55:49) we had a lot of positive feedback about Educate Salford and Salford in general because it really applies to a lot of things, really to be a really great place to have dementia. But it’s really not the case I suppose in other places in Manchester. I think [I1], doing all the interviews and focus groups, we had a discussion about the fact it’s very difficult to have access to people from BAME communities. It’s really a big thing to do. Also, I don’t know, last time, [P5], you mentioned social prescribing or social prescriber. Do you think it’s something working nicely, social prescribing in Greater Manchester?***

P5: Yes and no. I think it’s the same feedback that [P8] just gave that they see a certain percentage of the people within that area who maybe have dementia, that often they’re probably more targeted around people without a dementia diagnosis but that’s not everyone. So I work with a small group of social prescribers who come from various different boroughs. They have a specific interest around dementia. Some of them are doing really exemplary work. So there’s a lovely chap who has set up his own support group in the GP practice that he works in, so it’s like a gardening group and he invites people with a diagnosis to come and join him one day a week on that group. He’s a social prescriber. But again, I think there’s a lack of knowledge within the system. I think there’s not… I think if you really want to make the biggest difference at this point, it would be targeting the pathway and bringing people together so as there’s some kind of designated route for people who have received a diagnosis to access support and services because it’s what you get all the time.

You get people with a diagnosis coming back and saying, “There’s just not enough available,” or, “I don’t know where to find it.” But then you also get people running the groups which are offering amazing support, like Age UK, coming back and saying, “Well we just don’t know how to get hold of these people. We don’t know how to bring them in to our service.” So I think finding a way to develop a pathway and the way I’ve been looking at that, and I’ve been failing, not failing but it’s not an easy thing to do, you put together case vignettes and small pockets of where this has worked and where things have worked. Then if you just get the right people round the table with the capacity to start something like that, but it’s having a model ready for people to jump into I think and then getting the right voices around the table. But I think clinicians, I keep saying this mass in clinicians need to be aware and be referring into this because people don’t just disappear when they leave the clinic. They are then in the community, they need that support so it needs to be continuous.

**I1: Absolutely. It’s one of the key things I think in terms of what we found in our previous project where we had clinicians involved and their feedback was that it helped them to really see differently how they even just talk to people with dementia. My husband needs attention every so often, not for dementia but medical attention and when I’m there, people tend to talk to me rather than to him. He’s perfectly capable of talking. It’s really funny. I have to say, “Please talk to my husband.” So I think just a bit of re-education there might be helpful as well.**

P5: If we weren’t living in a pandemic, I would definitely say it’s really useful to bring the GPs in for extra training and to have, I think [P9] was suggesting having a champion within GP practice or even within memory assessment teams who lives with dementia and who can provide that positive role model. I know from my experience, having known very little other than the very academic side of dementia from being at the university to moving into public involvement, it really changed my perspective on it. It made me feel a lot more positive in some ways because I would interact with such amazing people who were recognising that they had challenges but moving forward in so many other ways. It’s just you don’t get to see that all that often. I think it’s something that should be shown.

**I1: Yes.**

P8: I know Age UK a while ago, you probably remember, [P12], we actually did quite a lot of work with GP practices delivering dementia awareness training and then they were appointing a dementia lead, weren’t they, or a dementia champion within the practice. I think that generated some referrals initially and then it slowed up again. The thing is really, which is why it’s such a shame, is that if the GPs could make those referrals, and we’ve just recently updated it actually, they have their own systems and their own referral forms, they have their own format and they contacted us and said, “Can we change your referral form to this format?” and they sent it to us and we were like, “Yes great, whatever works for you.” I still think the numbers are miniscule for the referrals that we receive from GPs but I suppose what I’m trying to say is if they just realised that if they made those referrals, that would lighten the pressure on them in the long run because obviously, I know I’m talking from Age UK Salford point of view but we can refer in to so many other services as well as our known.

We all know that you improve somebody’s wellbeing, then they have fewer GP appointments, don’t they, and fewer ailments and so on. I just think if they could just see a bit further down the line, it would be more helpful. But we’ve been trying to crack the GP scene for a long time so good luck with that.

P5: Do you guys deliver care planning because that’s another thing. We have so many various strings that we’re pulling together at Dementia United and one of the things is we put together a wellbeing plan we call it but it’s a care plan. A GP who works with us is implementing that in his practice but he’s doing it alongside social prescribers. So the idea being, it’s really holistic so it covers the health side of it but it also covers the physical and psychological wellbeing side of things as well. The idea is that a GP isn’t going to know all the answers, a social prescriber isn’t going to know all the answers but they work together to bring that to the fore. It just feels like that has to be done. I think it’s QOF. Is it QOF?

P8: Is it QOF, yes.

P5: I think it has to be done so it feels like it’s another way to bring services together because a wellbeing plan or care plan could include both the psychological and the physical and be that linking part.

P8: Yes. Because we were involved actually. I know Dementia United were pulling that together. So I know we trialled the dementia care plan so we did that trial and it worked really well. There was a lot of similarities to our assessment form and our support plan. I think there’s a lot of services have their own version of a care plan. I remember at the time actually, I hope I’m not speaking out of school, but the memory assessment team weren’t very happy that we were doing that. It was like, “Why have you not asked us when we…?” so there’s always politics in there as well, let’s face it but yes, we were involved in that. I know Dementia United were looking at adding that to the dementia pathway and rolling that out across Greater Manchester if commissioners were buying into that. I’m not sure where it’s up to, what came of that.

P5: It’s still happening, it is.

P8: Is it?

P5: So it’s being altered a little bit at the moment with the help of our GP colleagues so it’s now being called a wellbeing plan rather than a care plan. The pathway is being digitised at the moment and we’re starting to build all of these recommendations and documentations into it. But it’s happening, it’s just a bit of a slow lumbering beast but it will get there.

P8: Oh that’s good because I think that will make a big difference, especially for GM really because I think like you said before, [I2], it’s so different in each borough of Manchester. Services are really quite different, and pathways are quite different. So yes, we are lucky that Salford does pretty well to be fair. But yes, that would be really good when that’s rounded up and good to go.

**I1: Yes, excellent. I mean that sounds a fantastic approach there, [P5]. It would be good to know…**

P5: Yes. There’s a lot that I can… it’s one of those things where we’re holding a lot of strings and there’s a lot going on and it is hopefully going to be real at some point soon but definitely this pathway that [P8] was talking about, it’s very in-depth and it goes through all the different stages and it has the what has to be done so the requirements but also the ambitions and the shoulds. We’re pulling together evidence and case studies around all of these so people can jump in and use them. But at the moment we’re just digitising it and we’re only at the start of that journey with our partner organisation who’s helping us do that. But I mean we’re really hoping that the summer probably that’s going to be up, hopefully before that but I’m always cynical so I say a later date but hopefully the summer. But yes, I don’t know if you, do you want to drop your email in the chat as well, [P8], because there’s a lot that I’ve said I’ll keep you updated on.

**I1: I think that would be great to perhaps also follow up and hear more of the details of that, so we know what’s existing. We either can support or deal with something that’s complementary or help migrate what you’re already doing or something, so we don’t get into competition but are mutually supportive. I think that might be a useful thing to do.**

P5: I’m not the project manager working on that project specifically, but I’ll clear it and I might be able to share because we’re still collecting comments on it. But I think even it highlights that I don’t think there’s a straight structure between diagnosis and being referred into post diagnostic support. As I said, that’s one of the things I’m working with Trafford on just to talk about their model, but no model is going to be perfect. I still don’t know exactly how they’re getting round the GDPR and what that relationship looks like but if there is something that can be learnt from that, that will be useful.

**I1: Yes, that would be great.**

P8: Sorry. I was just going to say it would be interesting to see in Trafford if that model works and so therefore more people with a diagnosis are engaging. I’d just be interested. Or whether it isn’t making a difference.

P5: I know it’s making a difference with MCI in Trafford so I think it sparked with the work they did around MCI and they have an MCI support group. I think as a borough they give the most MCI diagnoses. The question is whether that’s a good or a bad thing, whether it becomes a bit of a placeholder diagnosis when someone doesn’t want to give… so there is some questions. But I think that system works quite well, that everyone within MCI goes through Age UK and they have a very active support group there. But as I said, I don’t know enough. Once the case study is out and I’ve got all the information, I can share.

P8: That would be great.

**I1: Absolutely. Excellent. Is there anything else, any other comments? That was a really rich discussion around lots and lots of things but I think the key really is this pathway and to try and offer that support, that personal and personalised support to people early on, isn’t it, to help them not to slump too deep into depression and allow them to see where the way forward is.**

P12: Yes, that’s very important, [I1]. I mean I know we have difficulty accessing people as soon as we would like but when we do finally get referrals for people, we work with them then throughout the journey so they say. They all have an individual dementia worker working with them from our team for as long as it takes. So obviously that can be quite a long time, years. Then their needs will change along the way. But there’s one thing that they can actually rely on is our staff staying in contact with them, regular contact with them and helping them wherever they can. So it is so important, isn’t it.

**I1: Absolutely. It’s that personal connection, I think that helps people as well.**

P8: I’m just thinking when you were talking about the skills exchange and volunteering opportunities and so on. I mean we have asked people, haven’t we, in the past if we’ve been doing presentations, particularly to students and things like that, that’s something we used to do every year in October. We always asked those with lived experience to join us and do their bit. That was the bit that everybody always came up and went, “That was brilliant.” It wasn’t our boring PowerPoint presentation, it was the lived experience. We could always use more of that really for training or even just general awareness raising. We have actually in the past, we employed somebody, didn’t we, who was living with dementia. We had to adapt even our recruitment process. It took such a lot of planning and a lot of work adapting to make sure they were comfortable and confident enough and then obviously they stayed employed with us for a couple of years until obviously funding runs out, as it does. So yes, I’m just thinking for us as a service, it would be good if we could possibly look at those skills that people have and maybe draw on that ourselves a little bit more. We’re all so busy providing, aren’t we.

P12: Well [P8], if you remember before COVID, pre-COVID, when I used to run the young onset group and there were certain people living with dementia in the group who had certain skills with the planting for example and the craft, so we had [A GROUP MEMBER], we had different clients living with dementia and they had their skills. So they actually ran an activity alongside me using those skills, didn’t they? We have done that sort of thing in the past. If you remember, when we’ve had our groups, [P8], and we’ve had people living with dementia attending the groups, they also actually undertook a role as a volunteer whilst they were at the groups, setting tables. So it’s not alien to us, is it?

P8: Yes, I know. They won’t necessarily be in a formal volunteering role but they do take part. Everybody helps chip in, don’t they, when there’s jobs to be done.

**I1: Yes. I mean it could be from quite a formal thing to something that’s quite informal, just doing something within a group setting, as you say. But yes, I mean from this session I think the key message I’m taking away or messages that I’m taking away is having that skills audit in some way as part of following on from the diagnosis that then could feed into the different services available. Does that sound like something… okay, you’re all nodding so we’ll work on this and see what potential ideas around that we can develop, how it might work, not necessarily practical things but conceptually where it could sit, how does it link. Then we can present that to you in February and talk about some of the more tangible things that need to be observed in order to make that happen because obviously all of you have much more experience in that, really hands on experience. So that sounds really fantastic. Thank you for today. I think we are pretty much in time. Is there any final thoughts, any comments you have?**

P5: No. Just to say thank you. It’s been really interesting and lovely to chat to you [P8] and [P12] as well.

P12: Thank you.

P8: You too. Thank you.

P12: Nice to meet you all.

**I1: It’s been fantastic. Thank you so much.**

P5: Ys. Thanks, [I2].

P8: So we’ll see you in February if not before.

P12: Best wishes for Christmas and the New Year.

P8: Have a lovely Christmas everyone.

***I2: Yes, you too.***

**I1: Absolutely. Have a lovely Christmas too.**

**[End of Recording]**