**WORK PACKAGE 2 – SESSION 5**

**Focus group with stakeholders**

**18th February 2022**

Audio File Name: IDoService – Workshop 2 – group A

Duration: 01:21:13

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

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

P5: = Stakeholder

P2: = Stakeholder

P44: = Stakeholder

P56: = Stakeholder

P40: = Stakeholder

P8: = Stakeholder

P45: = Stakeholder

**I1: That seems great. So I am going to ask questions about that now we are recording. So just before we start, a brief reminder that your participation in the study is voluntary so you can withdraw from it at any time. Can you just confirm that you have read the information sheet I sent you, that you agree with the points in the consent forms and that you consent to participate in this research? Great. Perfect, thanks. Again, now we are recording, I have to ask if you agree with this recording because it will help us for the transcription and things like that. Is it okay for you? Great, perfect. Thanks a lot. So I will now share the PowerPoint if I’m able to do that. I’m not really good with technology. It’s crazy. After one year and a half I should be better to share my screen. Okay, it’s there. Okay, now it’s fine. So just to give you a very short overview about the project. So the IDoService project aims to develop a service to support people to plan, connect with and participate in activities they enjoy. It focuses on meaningful activities, so as you probably know now, daily living activities and leisure activities. What was really important for us in this project was to focus on the person’s needs and preferences because these activities provide emotional, creative and intellectual stimulation.**

**So some of you are involved in the project since the beginning. We began that I think one year and a half approximately. It’s in three steps. The first step was interview where interviews and focus groups with people living with dementia, with care givers and also a lot with people like you, I would say professional stakeholders working in charities and organisations. It was really during lockdown, so it was very complicated but hopefully we (unclear 00:02:47) so we met some participants living with dementia. These interviews were really about preferences, barriers and facilitators to participation in activities. A main outcome was maybe the possibility to develop a skill exchange service. So, this outcome from the interviews so we decided it could be nice to work on that during these co-design workshops so we are now currently working together to design potential tools and services. Our first workshops, so we had in total four workshops, were in November and December last year. So, we had the one with Dementia Café in Salford. The next step coming soon will be the evaluation of the service so it will be a pilot I would say, evaluation to have some feedback about prototypes.**

**So now just some insight from our workshop with the Dementia Café. So, we asked people for which activities they think could help and for which activities, things they would be happy to have some help or support maybe to do them again. We really had a lot of different activities and answers. So for example, one participant, one person was really interested in sharing memories with children or maybe veterans. For another one, he had a passion for ballroom dancing so he said, “I could maybe teach ballroom dancing.” For the other one it was supervising or teaching swimming, maybe also cooking, to support someone or even teach someone to cook or to improve how this person is cooking. Visiting people. We had one participant I think, and she was already a volunteer for an organisation and she said she would do that maybe more or with different organisations and gardening of course and also some people said they were aware of some difficulties, lack of awareness about dementia-friendliness in shops for example so they would be happy to go into shops to inform about dementia-friendliness. We had the same (unclear 00:05:37) when we asked for which activities, they would like to have some support. For one participant it was maybe help to organise some social activities.**

**So he was a caregiver and doing the activity with his wife was really not a problem but it was more the organisation of everything being a difficulty. For another participant it was quite original, parachuting but this person had a history I think in the past he did training to try to do some parachuting. I’m sorry, I don’t know (unclear 00:06:17). For other ones it was learning swimming because they said, “Okay, I’m going with my grandchildren to the swimming pool even though I don’t know, I’ve forgotten more or less how to swim so it would be nice to learn swimming again.” For other participants it was some support for short journey or travel, cooking again, maybe to learn or to do some mosaics and craft activities and also some support for more long-term activities, maybe not a good term but something like organising holidays or package deals or something, maybe going outside of Manchester. So three main aspects was really again of course that needs and preferences are very individual so services need to be individualised too and really participants said it was really very (unclear 00:07:27) big support for them was this friendship they develop for example with this Dementia Café but also with local organisations, with these local groups because it really offers them a lot of social support and it’s really something important to participate in activities and to develop new interests and also trying new things.**

**But sometimes they are not very aware of this skills or maybe they are not confident enough about what they can do and how they can maybe help other people so it could be nice to help them to have a better knowledge about how they could support their friends, neighbours, etc., community. So now we discussed the same topic with people from charities and voluntary sector. We are aware of course that it’s already a part of them so organisations offering variety of activities, very well-tailored and adapted to people’s needs but indeed we are aware that there’s some disparities in Greater Manchester and also some people are not really into group activities so for them it would be more for at home activities so as [P44] said, it’s important also to think about how we can support them at home. Participation in activities will be more opportunities if it’s possible to include them in a better way in existing activities. So dementia tailored activities are very important with (unclear 00:09:14) but it’s also very important to develop this dementia-friendliness and also that organisations are making things… advertise more about the fact they are open to everyone including people living with dementia.**

**So in this case I’m of course speaking about organisations not officially related to dementia or ageing. COVID-19 was a challenge but in a way, for some people it allowed them to develop their skills to use Zoom and these kind of online tools so maybe it can also be an opportunity for some people to invest in some distance volunteering so it can open them new opportunities. We also discussed a variety of topics, for example of course risk management and how is it possible to take a reasonable level of risk and how to manage that reasonably. We discussed about the volunteering centre and how it’s important to have a strength-based conversation to learn more about what people like and what they want and what they are looking for. The fact that having also partners, so a person living with dementia, having the possibility to be with his partner doing normal activities, it’s really something important to having some normal event for them, something quite usual. In the end, so just a very short overview of some topics but it was really across all workshops this idea that maybe it could be nice to have an independent skills audit. So it was the idea for today to discuss that, if I’m able to go to the next slide.**

**So maybe today to discuss the interests and possibility to have some skills and preferences inventory. So it could help to define opportunities for people, active participation in activities as well as volunteering. So it could be quite broad. So for example helping someone or being helped. By helping people and orienting them to the good organisation charity or service. So it’s our idea we would like to discuss with you today. Sorry, I hope it was clear and not too complicated to follow. [I2], if you want to…**

***I2: Thank you, [I1]. Yes, I think the workshops that we had in November and December were really fantastic. They gave us so much material but they’re also really interestingly converged on this idea that there was a gap between the (unclear 00:12:23) services and the voluntary services delivery. That’s where this idea of participants came up with this idea of the skills audit, albeit slightly rephrased to make it a bit friendly, skills inventory. So what we wanted to do today then is to explore what that might be and how that might be, where and how that might be situated and delivered. So we’ve got three questions that we want to explore with you or you to help us explore rather. So where and at which point should it be delivered? We’ve got some visuals but I’ll just go through the questions first but we’ll have some visuals to support those questions. [TECHNICAL SUPPORT] has also prepared an interactive board where she can, in real time, add your ideas if you’re happy for us to do that. So I’ll just give you an overview of where we’re going and then [TECHNICAL SUPPORT] can take over the screen and bring up the board.***

***So the question is where exactly in the journey that the person goes through from the diagnosis further on, where should it be situated in order to be most helpful and at what point. In the previous discussion it came up it should be maybe not directly at the diagnosis because people are too strongly involved and perhaps shocked from the result but perhaps a couple of weeks after and if so, how would it be approached? How would it be delivered? Then also what should the content be and how should it be delivered? So we’ve come up with a loose set of suggestions just as discussion points but we can completely veer off those if they’re not the right ones. So this is really about, even though we’re still not doing it in person, which would have been much nicer but much more difficult for everybody to get together. It’s really about the playful, trying to figure out which of these bits are the most viable, where do we want to go, how do we want to build this because in the end, we are hoping to, following these sessions, to then try and start putting some tangibles together to create a simulation that we can try out, offer to a handful of people to try out to see how it works and whether it will be beneficial.***

***Okay, next slide. Okay, so here our first question with a little diagram which [TECHNICAL SUPPORT] has kindly put together of the patient journey or the person’s journey. So usually, they go to the GP first or possibly to a dementia organisation but in any case, they then get referred to the MA(T)S services and there are differences of that in and across Greater Manchester. We won’t go too much into detail about this across the different boroughs but they are kind of reflected in the follow-on journey and that’s mostly taken from what we’ve already heard from within interviews as well as from the NHS website. So after MA(T)S, people get either referred back to their GP or to specialist NHS staff, for example specialist nurse or consultants or non-NHS organisations like Age UK. Of course, that’s a big one here in Manchester. Alzheimer’s Society and possibly various others, City of Trees and I’m sure you all have experience with that. I don’t know, Dementia Together support perhaps as well. From there people then get further referred to various aspects, sometimes medication, sometimes occupational therapy, speech therapy, physiotherapy and then also social prescriptions.***

***So there’s the therapy aspect and then there’s the social aspect, social prescription memory café, memory skills group, memory dining club, etc., etc. I suppose Alzheimer café, dementia café and things. So there’s quite a number of things that people then get referred to but it’s not entirely, as you can see, it’s quite a complex picture and it’s not quite clear how they necessarily get referred to these things. So [TECHNICAL SUPPORT], maybe you can take over and bring up the board so that we can move things around. It would be good to hear whether your experience of this journey is reflected in that diagram or whether you think it should be different. If so, we can move things around. Also, where you think we should position this potential skills audit or skills inventory if we’re thinking of this as a consultation of some sort, whether that might be individually or with a group, where that might sit. Does that make sense? Please do come in.***

P5: I’ll jump in if no one else wants to.

***I2: Yes, please.***

P5: I guess a broad suggestion, and this probably depends on what services are going to be on offer and how that information is going to be used afterwards but at points in the journey an individual will have a dementia care plan or a wellbeing plan. So Dementia United are developing one at the moment which the idea of it is it’s very holistic so it’s very similar to what you’re speaking about but it's beyond just health. It covers all aspects of wellbeing. One thing that’s working quite well is this sits within… to be honest, we’re piloting it in different services. We’ve piloted it… Age UK have used this document but also we have a GP who’s working with it at the moment. What’s interesting in the GP practice is they’re working with both their nurses but also social prescribers at the same time because the idea, because the plan covers health and medication but also more social and wellbeing, it needs a number of people to come in together to make it work. It feels like that stage might be when you want to be asking these broader questions, getting that idea of what people’s skills and experiences and passions are and where they could then utilise those. I mean I absolutely, and this is what you were saying, I love that idea of that skill sharing platform.

I feel like if something like that were developed in a smaller context, this would be the right time to collect that information and then maybe move those people on towards something like that. I’m going to pop a link in the chat just to the wellbeing plan that we’re putting together. We’re developing some videos around this at the moment and it’s going to be uploaded on to EMIS I think so it’s going to be electronically available in GP practices but it’s not quite yet. So that’s one suggestion.

***I2: Brilliant. Thank you, [P5]. That’s really, really interesting to hear that that’s already available. I was wondering what the wellbeing plan focuses on in terms of the social aspect. Can you elaborate some more on that?***

P5: Oh goodness. It’s very large really. It’s a document that you’re expected to sit down and have a relatively broad conversation on. The links I’ve popped in the chat have links to the paper version of this and it’s very much asking people to fill in the gaps in a sense, to give people that space to comment on what they’ve enjoyed but also their experiences. There’s also a separate section for carers as well to ensure that there’s support there too. I’m filibustering here, sorry, because I can’t tell you exactly what’s in there because I don’t remember off hand but I have put it in the chat. It’s quite broad though.

***I2: Excellent. Brilliant, thank you. So that presumably is done after the people had their diagnosis and they get referred back to either the GP or what we’ve called non-NHS organisations.***

P2: Can I just pick up a point that’s just been said? Sorry, I’ve forgotten your name.

***I2: Yes.***

P2: You made reference to all GPs, being available to all GPs. Can you be more specific about all GPs because Greater Manchester has very different trusts and things, they all seem to have their own ideas. Would it be available throughout Greater Manchester or is it localised?

***I2: [P5], I think that was for you, the question.***

P5: Oh, sorry. Can you repeat that, sorry.

P2: You made reference to the programme being available to GP practices, are you talking about local GP practices to yourselves or Greater Manchester wide because that many different trusts have their own different ideas.

P5: So at the moment we’re only piloting it. So there’s a single GP practice piloting it at the moment. It’s also been piloted in an Age UK branch but we are hoping that once it’s available on EMIS which is the online platform that a lot of GPs use, I don’t think every single GP uses it. I think there’s a little bit of variability between what online platform they use but the idea is that it would be across the whole of Greater Manchester. It’s just there’s various steps to take before it’s embedded across the system. But we’re definitely making inroads to make sure that’s going to happen.

P2: Have you got a timeframe around that please?

P5: I wish I could tell you. I think the digitisation is going to be happening towards the end of this summer, we’re hoping but we’re just waiting to get some funding through and to make sure that all the Ts are crossed and the Is are dotted.

P2: Thank you.

P5: But if you want more information, I can put my email in the chat. It’s actually not my project. I’m not one of the project managers on this but a colleague of mine is so she’ll be able to give you more details on that.

P2: I think it will crop up over time, won’t it? Thank you.

P44: [I2], I was going to say, I mean I think this topic should be brought up at various stages and I honestly believe, I’m fascinated as to how diagnoses are given and whether there’s anything strength based about giving a diagnosis. I just believe that people take very seriously what their consultant says to them or probably their GP as well. If the consultant says to them, “What do you enjoy doing? What have you always been good at?” and then says to them, “I’d really encourage you to try and keep doing that if you possibly can.” That’s a powerful message and is something to counter the very negative messages which otherwise I think are… I might be wrong but I’d love to hear from a consultant psychiatrist about what they say. I just think the idea of strength based or encouraging people and giving them hope should be a constant throughout from the point of diagnosis even if the longer conversation, which needs to be a longer one, how is it going to be possible for you to pursue your interest in swimming or walking? Well take more time. But I would think that still needs to be done soon after diagnosis because again, people need to be given some encouragement and some hope.

I think sometimes we see people further down the line, and I appreciate the dementia itself, the creeping dementia can make people apathetic but I think we need to really work hard to counter that. So by tapping into strengths and encouraging them to pursue things, that might counter a bit of the negativity from both the individual and the family that quickly develops I think. Just leave him in his armchair, he’s fine sitting staring at the walls. He’s not causing us any trouble. But we know that’s not good for people.

***I2: Exactly, yes. I’ve just very quickly clicked through those links. I think there’s something that I think we can think about in different ways of how we can bring that strength based aspect into this. I think the wellbeing plan is a really good thing but I think it’s that connection, allowing the realisation of that plan, that support, that mutual support and that strength based working of people actually thinking that they’re not necessarily, now that they are labelled as a patient or a person with dementia, that it does mean that they cannot help others and only can receive help but to turn it around and say, “Actually what are you good at? What would you like to contribute? What would you like to do?” and getting people really to think in that way again and feel that confidence that they can do that because that’s certainly one of our experiences from speaking to people with dementia is that they felt that especially after diagnosis it was like, “Oh God, what do I do now? I can’t take any responsibility any more. It’s the end of the road,” which it may not be for many people.***

***So possibly various points where people can access this and they can repeatedly go there or can be approached so perhaps it could be integrated as part of that wellbeing plan as an access point. Are there any other suggestions, comments on this because otherwise I think it might be useful to go to our next slide which is thinking about who delivers it, possibly actually to the last one, thinking about what would it be and what form it would be delivered in.***

P2: Just to jump in really quickly before you swap. I think there was a real big push to bring social prescription much earlier in the food chain if you will rather than being a delivered part to so they were more involved in the distribution of what would be the best service for people to be involved in. So they would, hypothetically, they’re aware of a memory café and they would then make that connection but they would do multiple connections rather than just one specific, if you take my drift. So they wouldn’t just say, “You’ve got some transport issues,” so they may get involved in like our volunteer driver service. You’ve got some stuff around the memory café. So they would make multiple referrals if you will rather than you’re not just a one-off down the line stop if you will.

***I2: So they’re offering already something of the kind. Are they connected to that wellbeing plan, [P5]? I’m really interested in these different aspects that are clearly there but are they… I’m trying to find out how closely are they or will they be connected?***

P5: Yes and so. So social prescribing is managed very differently in the different boroughs across Manchester. We have a small group of social prescribers who are currently working with us and looking at the wellbeing plan and definitely the ones who work in the GP practice where it’s currently being piloted but I think we have a little bit of work to do still to make sure that that’s embedded in the way it should be. I think there’s still some confusion on my part, and maybe on the social prescribers part, as to who takes that responsibility of signposting and looking at that more holistic side of wellbeing for people living with dementia, whether that’s a social prescriber or whether that’s a dementia adviser or someone else. Again, dementia advisers, I assume, are doing a very similar job to social prescribers but just very specifically around dementia. I think there’s pros and cons for both of them. I think definitely people in the earlier stages of that journey with maybe an MCI or an early stage dementia might feel more confident with a more social prescribing approach because the dementia itself isn’t something that they really want to focus on. Like you say, there’s a lot of skills there and things that they want to be able to do and they’ll want to get into community groups which aren’t necessarily dementia focused.

So I think there’s a piece of work to be done around bringing the social prescribers in and making sure that they feel confident to work with people living with dementia as well. It is a project that we’re working on at the moment and [P44]’s been nodding and there’s some training that [P44]’s working on to bring into community groups but also to work with social prescribers to help them understand dementia a bit better. I’m also doing a bit of broader Manchester wide partnership work just looking at how social prescribing is going forward in the ICS and what changes might happen with that. We’re quite interested in how dementia, definitely dementia and the arts and creativity fits into all that process. So there’s various strands but I feel a bit silly talking about it at the moment because it’s all just conversations right now because things are on shifting sand but yes is my answer. I also gave you a lot of other words but yes.

P2: Can I just ask before you move away from this slide? I can’t see it properly on my screen but from the non-NHS point, there’s five triangles there. Unfortunately, one of my information bars is going right through the bottom two. Would it be useful to have something like independent voluntary groups like my group or the other groups like Age UK and things like that are doing a fantastic job but we’re completely independent and managed by people, well my committee for example are either carers or past carers and I’ve seen and still see the dementia journey right from the beginning and, like in my case, from beginning to the end. We create a lot of peer support both for carers and cared for and we can see the cared for is referred to people with dementia as they interact and exchange with one another. If you leave them on their own collectively in some form of discussion group or a creative group, they really, really get on with one another. When the exchanges communicate with people, even to the extent that one lady once said, “I never heard my husband speak for two years.” He went in this group and he was away with it. I’m not knocking in any way what other organisations are doing. It’s a valid service. But I sometimes think that the voluntary independent groups need a bit more recognition than what they get.

P5: Can I add to that quickly and I’ve said this before and I’ll say it again, is that we’re signposting and if we’re working with an independent voluntary groups and groups that are doing this, supporting the community, they need to be provisioned for as well. So the more people who are being signposted to these services, the more work that’s on them. There needs to be that infrastructure so that they’re supported as well. I think that’s often a conversation that’s missed sometimes to the detriment.

***I2: Yes, quite. Great. So I have a question and that’s probably me as a designer being slightly ignorant even though I probably, by now should know that. You mentioned the social prescribers and the dementia advisers. How are they trained? How are they qualified?***

P5: Does anyone else have a good answer to that because I feel like I haven’t got the best answer to that.

P44: Well I mean dementia advisers can sit within the voluntary sector, can’t they? [P8], yours are called something different but they can be employed by the mental health trust or by Alzheimer’s Society. I mean that would depend on what the training is within the voluntary sector or the mental health trust. The social prescribers I think even more, I know even less about how they’re trained actually. I just don’t know. I suspect they’re very well aware of things in the community but I’m not at all sure of any training they might have around dementia.

***I2: So would there be generally… yes, [P56]?***

P56: I was only going to say in Stockport we have a dementia training programme that’s run by our local Pennine trust so people go along and there’s like three or four sessions of training that people go to so we offer that for our staff but it’s offered also for social workers, for anyone. But for some of the groups, like that was a good point you mentioned about the independent groups, they encourage the volunteer lead to go along to those. They’re really informative as well.

***I2: (unclear 00:36:09)?***

P40: From a Rochdale perspective, the social prescribers are linked to clusters of GP surgeries, normally based around geography. It’s more around the closest surgeries to each other so you might get on a technical level they’re not exactly in the same area of the town, if you’re familiar with Rochdale, say one is in Loughborough, one’s in Millwall but physically they’re relatively close and they cluster them around that. I think the individual social prescribers get training around different needs because obviously they just don’t cover people with dementia. They’ll come across pretty much all of life and everybody and everybody.

P2: From my experience, and this is a true story and I’ve got to be really careful what I say because I don’t want to identify anybody but I am well aware, there’s somebody who is employed as an admin person with no dementia background at all, I can guarantee that, and within ten days that person, without any training, suddenly became a dementia adviser. So from that I’m assuming, rightly or wrongly, is there a requirement to have some training before you call yourself a dementia adviser or like in my case, I’ve had no formal training although I went on some awareness training by the Alzheimer’s Society ten years ago, can I now call myself a dementia adviser? I personally feel no. I think I’ve got experience of it but I’m not an adviser.

***I2: [P8]? Very good point.***

P8: I just want to reiterate what everybody is saying really is that it does depend on the actual employer of the organisation on how they train their staff and I always think you need to be very wary of the word adviser. Do you know what I mean? I think you can give people information, share information and support but you have to be very careful but you have to be very careful with advising I think. I have no idea, as [P44] said, I don’t really know what training the dementia advisers have. I just know from our service, people have to have level two or level three depending on what role they’re in and general health and social care and dementia skills. But I couldn’t tell you about the other services.

***I2: Great. So presumably… I think that’s quite interesting also, that it’s not a coherent system of getting them recognised.***

P2: Is it something you need to focus on, [I2], not necessarily now?

***I2: No, it’s not necessarily something that we want to focus on but it’s obviously something that is of interest to us because if we’re thinking of offering this kind of service, we also need to think about, and that will be the last slide, no, actually the next slide, who would deliver this? Would it be within one of the existing organisations? [TECHNICAL SUPPORT], do you want to move our slide on to the next one? We’ve just randomly, well not quite randomly but put on all the major organisations. So we’ve got not necessarily voluntary but other local dementia related organisations so we can include the voluntary organisations in that perhaps, the major ones, Age UK, Alzheimer’s Society, Dementia UK. So we’ve got the NHS side of it and then we’ve got family and friends, private, voluntary, etc. But then we’ve also got the professional background of where people might come from as a psychologist, social worker, social science nurse, neurologist, etc., so who then become perhaps have the background to become dementia advisers, social prescribers and then of course we’ve got carers and others. So we’ll be thinking about if we want to develop a strength based service, how would we do that and who would do it?***

***[P8], is that a new hand? Perhaps just, [TECHNICAL SUPPORT], if you can just move on from that because we had a little bit of discussion around that, the next one. Then we were thinking about that comes back to the wellbeing plan that you’ve mentioned, [P5], is how would we develop it. Would it be through a questionnaire? Would it be individually? Would it be in a group session? Where would it fit? If people have that wellbeing plan, would it be part of the sessions of the wellbeing plan? Would that move them back to a social prescriber, so would it be a special thing that we do that the social prescriber can deliver, either an online platform or maybe we can do it through a game, well perhaps not a questionnaire, something mor friendly than a questionnaire, an interactive tool of some sort, whether digital or analogue. So there are many, many choices that we could make. So I think I’d find it really helpful to have a little bit of a discussion around that.***

P5: So can I clarify, when you’re talking about a service, are you saying that the output of this is going to be a physical service within the community which platforms this voluntary approach and this idea that people can join it and they can share their skills so there’s actually going to be an active service? Is it going to be online? Is it going to be IRL? What do you see that looking like because I think how that looks will influence how you signpost people to it and what people you work with.

***I2: Yes. So all of that is open so we have to try and hypothesise some of it, a bit like a chess game, start one move and then think about what would the rest look like. So we’ve had, I think, two or three different potential avenues that have come up in the conversations and that we’ve been thinking around. One has been that it sits within somewhere following very shortly after the diagnosis discussion or perhaps signposted through to diagnosis discussion to somebody, whether that be a social prescriber or perhaps somebody who’s delivering the wellbeing plan who is then also trained to deliver, or as part of that could deliver the strengths-based skills audit. So that could be part of what we now have with the wellbeing plan or the social prescribing or it could be separate to or as a consequence of those. So I think that’s still a little bit open but I think what the discussions, the previous co-design groups have brought out is that there would be that it’s a discussion around people’s skills and experiences in order to find out what people feel that they can and want to do.***

***Then to use that to help link to some of the voluntary organisations which have also been in touch, where there are quite a few who already provide voluntary services and they are open to people with dementia but they’re not necessarily connected to this chain. So we’re trying to design that little link between the diagnosis, potentially the wellbeing plan and the voluntary organisations that allow people to either gain help in doing something or to provide help to others or input to others.***

P5: Okay. I’d say very broadly you’re going to need to be flexible with who and depending on what part of Manchester you’re doing this in. A useful anecdote is working with a social prescriber recently who is very interested in dementia, not only does he work with people… so he works attached to a GP surgery so not only does he help people find things in the community that they might want to get involved in, he’s also set up his own gardening group within that GP practice because a lot of feedback came back to him that people were wanting that. So in a way, that’s a small idea, similar to your model I assume, that he’s been talking to people about what they need, what they’re interested in and from that he’s then, off his own back, set up something within that community. That won’t be possible in all circumstances but there will be individuals who are able to do that and probably within organisations. Sorry, I’ll let someone else jump in though.

***I2: That’s really helpful. Yes, [P8].***

P8: I think [P44] was before me, weren’t you, [P44]?

***I2: [P44] then, sorry.***

P44: Yes, sorry. Having a conversation, I would suggest it’s good to prioritise the person with dementia, ask them the questions first but then check back with the relative, the family member or friend because you sometimes need a reality check because the person might not have an awareness of what they can and can’t do. I’m just going to say that much. Keep it simple in terms of a conversation.

***I2: Yes, of course. That will be one of the things, is obviously risk management, yes. Sorry, [P8].***

P8: I think like [P44] said, obviously keep it simple when it comes to actually asking the questions, but I think it’s something that you’ll probably keep going back to. I’m just thinking. So you’d have, whether your wellbeing plan or some form of assessment and you’ll look at what people’s skills are and so on and then how they can develop those or volunteering and volunteer somewhere else. I think it is something that you’d keep going back to because people, as they get more confident, will want to do more so it’s going to change as time goes on so there will be a lot of dipping in and out. But I was just wondering, because I can’t see how it’s going to fit at the end. Like you were saying, is it going to be a service, we don’t really know. Would we or should it be linking into the volunteer bureau? I’m thinking in Salford you’ve got Salford CDS so they’ve got a volunteer bureau. So if we’re looking at… are you thinking that people will, at some point, be in a position to be volunteering and so then they could potentially sit in something like a volunteer bureau, put themselves forward so services could then draw on those skills? Is that an avenue that you’re thinking or not?

Am I just throwing something out there? I’m trying to picture something, a pathway and what will happen because I can see it as an individual. I’m just thinking for our service for instance, when we do an assessment, I can see we’ll talk about people’s abilities, what they’re capable of doing or things that they can do, more skills that they could learn and then how we would work with them and possibly refer them on to other services and so on. But I’m thinking if this is going to be a service, I know you haven’t decided on that, I’m just curious as to what it will do. Does that make me sound a bit silly? Do you know what I mean?

***I2: No, absolutely. This is designed as an open-ended thing. So we’re trying to find out some of these things and it’s good to ask the searching questions because they make it clear where things already exist, we don’t want to duplicate things but where we need to connect things. So yes, I think the question is what we’ve identified through the previous co-design sessions was that there is a disconnect between the diagnosis part and the volunteer service basically and we’re trying to provide that missing link. Obviously it’s a moving field and some things are already there but perhaps also not quite connected. So we’re looking at what can we provide that enables us to do that service. So we’re not designing the service from scratch, we’re trying to provide the missing link. I think that’s what I’m trying to say. That could be a web platform that a social prescriber uses or it could be a questionnaire toolkit of some sort that could be part of the wellbeing plan or it could be a separate session altogether that sits with the voluntary bureau but connects into the MA(T)S services. So I think we have a choice of where we… as you say, we may need to be flexible and it may need to have different permutations for different settings. Does that…?***

P8: So can I ask then, when you did the consultations and you’ve been talking to people who we mentioned there, carers, did they give any inclination on what they would want or what would work for them or did you not go as far as this?

***I2: No, we haven’t gone as far so that’s what we’re going to ask also in the session in March.***

P45: Can I just come in quickly? It’s really problematic, isn’t it, because everybody’s journey is different through the services and that’s dictated by where you live and your postcode and what services are available in that area. So you’ve got to find a link that everybody has, haven’t you, and social prescribing does look, to me, as a possible link because it’s becoming quite a frequently commissioned service, albeit an unregulated one. So we do have very different skills within that field of social prescribers because I think originally it was thought that they would be nurses and have a nursing background but that isn’t how it’s panned out. So to me, it’s finding that familial link within all of the different, if we’re just talking about GM, within all of the different boroughs perhaps. It is that one familial link with them. Everybody will see a GP, maybe a memory service. Then they will be passed on to various other people, whether they’re NHS, non-NHS, voluntary services, independent so to me it’s finding that common link.

***I2: Yes, okay. That makes sense, which probably means we have to try and find, as the next step, to find some people who are interested in walking that journey with us, so people with dementia who might potentially say, “I’ve gone through this service or this path,” so to look at this path from the point of specific individuals to see how they’ve gone and what we could do within that chain to help and then see whether somebody who goes through that system, whether they can benefit from that.***

P45: Could you do a little pilot initiative with somebody, I think, was it [P5] that mentioned the varying aged social prescriber, get somebody like that on board and see would they have the time, would they have the inclination, would they have the skills. I don’t know the answers to those questions but would there be something worth exploring?

P5: I was going to say one thing I could come in on for a pilot but obviously you’re going to have various avenues you can take for this, the pilot project I’m running with the global brain health institute is looking at memory assessments so it’s working within a memory assessment team and it’s training up someone we’re calling a brain health adviser and their idea is to look at motivational interviewing but also a lot of this kind of holistic support for people who have been given a mild cognitive diagnosis and helping them link in with the community and how they can maybe improve their brain health through different community activities. I feel like that individual, so we’re basically employing a new person, might find this work really interesting as well and getting that skills based questionnaire. So right now I’m actually working on the background for that and what kind of questions we’re going to be asking. We’re going to do a little bit of PPI and reach out around that so that might be useful. The other thing I just wanted to come in on is I was trying to type in the comments but I’m not sure if I’m getting my head straight so I’ll try but I think one thing is that you’re going to find that there’s a lot of support available in the community. There’s lots of activity and support groups but I think there are probably fewer empowerment opportunities for people.

They are there and there are a lot of these and I’d say so, again [P44], Fabulous Forgetful Friends, also the Gospel Choir and I’m sure, again, I don’t know as much about the Age UK service with you guys but I’m sure there are empowerment opportunities there. But I think what’s novel about the work that you’re doing isn’t so much that support that could be offered by social prescribers, it’s that people want that empowerment. They want to know that they’re giving something back. I think having something that can build capacity in the community to help people feel empowered would be a really useful thing. I don’t know whether, [P44], you can comment on this and where the Fabulous Forgetful Friends group came from but I think those kind of advocacy and empowerment groups are something that would be very beneficial.

P44: Yes. I mean I can talk just a little bit about the empowerment stuff and again, I (unclear 00:56:37) like that. It’s a tricky one. I mean we’re very much influenced by DEEP, so the network of empowerment and advocacy groups. They are a brilliant national organisation but unfortunately, something that nobody particularly wants to fund really because it’s not about numbers, it’s about output and quality of stuff. It can be quite time consuming working in that way with people. Rather than getting fifteen people in, giving them a good time for two hours and sending them home, it takes more resource than that but it should be happening nonetheless. But yes, it’s about getting people together, getting them talking about what works, what’s difficult for them, encouraging each other, working out strategies to test things out and celebrating the success that they have. As I say, the DEEP network are brilliant in terms of all the supportive work they do for it but the groups are still a bit few and far between, aren’t they, because they’re not a resource skill.

P2: My group is part of the DEEP network, [P44].

***I2: That’s great. So definitely what I take away from that is to enable people and that empowerment, that sense of empowerment in the community so that’s something definitely to look into but also to see whether we can work possibly through some of the social prescribers at the moment or possibly future global brain health advisers so that sounds great. Are there any other thoughts on how we might deliver this, from your perspective? We’ve got individuals such as the wellbeing plan, I presume it will be that that’s delivered between… sorry, can you remind me who delivers the wellbeing plan?***

P5: It’s going to vary depending on location but at the moment we are hoping to have it on EMIS so GPs will be able to see it and access it and it is a GP that we’re working with right now to pilot it.

***I2: Great. Excellent. So that would be on a one to one basis then but of course there could be a totally different model of delivery in that perhaps working for example, thinking of the empowerment aspect, working through the DEEP groups as a peer social support, starting small and developing it through the people who are advocates or within the advocate groups potentially. So there could be a group aspect to it which we found in just simply through the co-design groups that actually worked very well and made people feel more confident because it takes away the power relationship. So that’s perhaps something to consider too. Sorry, [P44], did you want to come in there or was that just an agreement? Good. So we’ve had quite a number of different ideas that we’ve brainstormed in terms of user experience, guided toolkit, multiple choice questionnaires. It could be a web app, a game board, an open informal discussion, a social discussion and possibly trailing somebody who is already doing something to see how it works. So we’ve got a number of ideas already so perhaps one of the things for it might be to just sketch out multiple paths that we’ve now discussed to try and see where we’re getting with that. Would that seem sensible? Great.***

P5: Yes, I think it would. I guess just for me, I’m still a little bit shaky on the deep dive between the two ends of the connection. I guess that you’re looking at forming the connection between taking with people and working out their skill set and what they need and then linking them with a service that enables them to develop those but I guess it’s looking at those two ends and seeing what’s currently available and what support the organisations that are currently available need to be able to take that forward as well. Sorry, again, I feel Springboard and Age UK are probably better to come in on things like that but it’s where those people will be going and what support they’ll be offered then.

P8: I agree. I’m just trying to get my head around… I think of it as it working with those that are accessing our service and this is stuff that we would pick up as we go along at our assessment stage, as I said before and then when we explore it further, if there’s something that they’re particularly interested in then we would try and do that as a group. Then if it was something that they were particularly confident in, that they could then show others, show their peers, “This is how I do it.” It works that way. I’m just struggling to picture this, it might be just the way my brain works, how to picture this as one (unclear 01:03:15) service. I kind of think that all of us should be incorporating this somehow anyway. Do you know what I mean? I’m just trying to get my head around how it would sit as something separate to link up what’s already…

***I2: So would a tool, as in a creative, we call them creative toolkits, that enables staff or groups to work through that kind of thinking of where the strengths is? Would that be a useful thing from your point of view then?***

P8: I think that would be useful for us. I think if we had a specific toolkit so that we could explore it further where we could work either as a one to one or whether it would work within a group setting, I think that would be something we would use and would be helpful. I don’t know. Would you find that useful, [P44]?

P44: Yes. I wonder whether a bit of the problem that maybe some of us have got is thinking there isn’t a lot out there and there isn’t a lot out there with the amount of support that might be needed to enable somebody to participate. Transport being the obvious one. Somebody might want to go and do pottery and they might find a clay studio they can go to but will that studio reach out and help with transport? So that’s me not wanting to put a dampener on everything because I still think you’ve got to start somewhere and you’ve got to aim for something but there’s also the issue simply about what there is out there and whether those organisations are willing to reach out and make the effort that’s required to enable…

***I2: I think that’s a really good point but we can take that back to some of the voluntary organisations who we’re meeting in the co-design groups.***

P2: Can I just say that there is a group in Liverpool, or should I say Merseyside rather than Liverpool but I think they are Liverpool based, who are part of the DEEP network. I can’t remember the name of them but they are seemingly active in transport for people with dementia. I expressed an interest in it over a Zoom meeting but I’m still waiting for the call. It seemed very attractive. They’ve done some good work for people with Merseyside, certainly on the railways, where people have been met, meet and greet, at the station and, more importantly, put on the receipt and advised at the stop, assuming they’re not getting off at their destination, that they will be alerted when they get to the booked arrival point and escorted from the station at that point to whoever they’re going to meet. That seemed to be a good service. They were trying to make that nationwide and involve the airports and the coach companies to get involved as well.

***I2: Yes. So it’s really thinking about how can we connect all these opportunities that are out there so if there’s something around transport and there’s also voluntary services around let’s say, stay with the example around pottery, how can we get that linked up, identify the person’s interests and then identify the available services to enable them to do this. Yes, that’s a challenge. I’m not saying that we’re going to have, by October, a fully functioning service but if we have the service concept that we can say, “If we could make this happen, this will work,” and we have tried it with perhaps two or three people who have worked through this where we’ve manually connected things and said, “This is how it could work,” then we have a stepping stone to hopefully take that further. That’s our thinking at the moment, if that makes any sense.***

P2: I think so.

P45: Yes. I would see it as a little bit like asking… I can envisage it a little bit better actually if you see it in a smaller context of one group or six groups as opposed to this being a national tool that everyone can use because it’s almost like, on an individual level, “I want to go swimming. How can I do that? Who can teach me?” isn’t it, which you could do if you created some sort of model that every group could use from a design perspective then I think that would be quite useful for empowering.

***I2: Yes, I think so. I think you’re absolutely right. So I think designing a model, then trying it out under specific circumstances to see how it can be made to work for those individual examples as it were, individual test pieces, instances. I think it’s something that we need to try and get at so I think that would be really useful. I think we’ve got different settings now that would be really interesting to explore from my point of view. It’s the one that, [P8], you’ve mentioned as a toolkit that sits within or is used by Age UK and the other being working through the social prescriber and/or the brain health adviser, possibly the wellbeing toolkit. So we’ve got three or four possible avenues I think that could be explored where we can try and map a path as it were of how the journey would work and what would be required to enable this. I think that probably will be our next step. That sounds good to me at least. Sorry, I’m just looking at (unclear 01:10:01) who said we have a dementia (unclear 01:10:03) group, various different professionals come along to it and they have a guest speaker and can highlight different topics. Yes. Do you get people who are diagnosed with dementia also as speakers?***

P56: Yes, I think they have in the past. It’s on this Thursday. It used to be a virtual meeting obviously because of COVID but I think they’re hopeful they’ll get it but yes, they do have. They had a lady who was a carer for her husband for many years and she was quite heavily involved in a lot of stuff. You get a lot of professionals, health professionals and voluntary organisations as well. So I go along from Age UK but we have the Dementia Society go along, the Healthwatch, all different things. It’s quite interesting. Quite a lot of people go to it.

***I2: Okay. Any other comments, questions, thoughts? Should we go back to any of the other screens again? Did you have any further thoughts on any of these?***

P44: In terms of format, I mean I’ve finally embraced apps and I do think if one was just helping conversation, talking to somebody about strengths and interests and so on, being able to put some information easily into an app. If you’re uploading it to a database, it’s quite appealing because so often things can get lost. I suppose it depends for whose benefit. I mean things can get lost in people’s notes, wading back through the notes, looking at the conversation when you ask them what they’d like to do. So having something that’s easy. I can’t quite work out about how somebody’s ID would be kept private but I’m just wondering whether it would be good to have some sort of Greater Manchester database where you could look on and see there are ten people interested in this and there’s some sort of service that offers that over here. It could be just a quick, easy way of people seeing what there is out there or what the interest is. I don’t know. I mean it would rely on the professional or the helping person to maybe have a smartphone with an app on that they could use but I can see some sort of appeal in that in terms of a quick and easy way of uploading some data maybe.

***I2: Yes, that’s definitely something we have actually been thinking about previously, not in the context of this particular service but more generally and something we can bring back. [P8]?***

P8: I was just going to say, responding to what [P44] said then, would that or could that fit into the Greater Moments app do you think? Could it fit in there somewhere? [P5], I don’t know if you’re still there.

P5: I am, yes. It might. I was actually thinking of Elemental. Elemental is a software that social prescribers use and it does a similar thing. So it kind of has services listed based on what they provide and you’re able to do interviews with members of the public and to talk about what they want and to link the two together. I think there’s an element of evaluation built into it as well but as with everything we’ve talked about today, not all parts of Greater Manchester use the Elemental software. I think there is another one and I’ve forgotten the name of the second one. I think Elemental themselves, so it might be worth actually, [I2], reaching out to the software developers because they’re doing some work with another part of the UK, I can’t remember exactly where it is, another big city, about dementia and social prescribing. They’ve added some extra elements to Elemental to make that work. So I can give you a link to their home page but I know there was someone I spoke to a while ago so we’re thinking of doing some work with them and then it never came out but it could be someone you could contact.

***I2: Yes. If you have any direct contacts that you can put us in contact with, that would be really appreciated. I think that’s a really great idea. Who had the Mr Alzheimer’s project?***

P5: I think I may have got that wrong. It was one of the groups, it might not have been yours. Sorry, it was when you were speaking. Was that [P56] or [P8]?

P8: You thought it was [P56] but yes, Mr Alzheimer’s is sat with Age UK Salford.

P5: It was you guys. That was a really good answer.

***I2: Excellent. That sounds like a great idea too so we’ve got loads and loads of ideas again which we can work through. I think that’s really useful working through the potential person’s journey but also then looking at how we can deliver that either as a physical toolkit or as an app based delivery, potentially with and through Elemental. So that sounds really great. Excellent. Do we have any other ideas, comments? I think that’s give us a much clearer, at least in my mind, a much clearer idea of where we might be heading towards. We have another group session later, I think this week or next week, [I1], so we’ll ask those questions again and see what answers we get then and then, as we’ve done this before, I’ll amalgamate them and try and draw up these journeys. In mid-March we have the next session with people with dementia at Age UK, [P8], so we will ask some of those questions and perhaps already we’ll be able to present some of those potential journeys and maybe some mock-ups for tools that we can then discuss. Thank you, [P56]. Thank you for participating.***

P56: I’m sorry about that. Thank you.

***I2: It’s been very great, thank you. Bye. Great, thank you for the contact on Elemental as well. We’ll have a look and see whether we can follow that up and make some contact there. Any other comments or thoughts? Maybe that’s a natural time to finish. An hour and a half is quite long on Teams anyway.***

P2: The only thing I would say is that when we do produce this document, we consider the end user by keeping it in lay terminology the best we can do and keep the acronyms and things like that out.

***I2: Sorry, keep?***

P2: The acronyms out.

***I2: Yes. Keep acronyms out, I agree. Yes, definitely, we’ll try and do that. So we can pass them on to you as well outside of any further co-design groups. If you want to give us feedback, we can always pass those on to you for any feedback so that’s great.***

**I1: Of course if you have questions or remarks, you can contact me and I can send you information.**

P5: Brilliant, thanks. It’s really interesting. I’m really excited to see where it goes. I think it’s still struggling to see what it’s going to look like, isn’t it, but that’s why we’re here and that’s what we’re doing so yes, it’s exciting to see where it goes.

***I2: Yes. I mean in an ideal world, if we’d all been in a room we could have had all the colourful pens and just mess about and say, “It could be like this,” or, “It could be like this.” It’s much more difficult. We tried to have the board but it’s so much harder because everybody would have to link, sign in and do their bit. In the end it’s more difficult than just a felt tip pen or something. So we’ll try and, I think, come up with some visuals and some things to make it much more specific than it has been so far and to hopefully then start coming up with some very concrete things that we can then perhaps pilot in the early summer. Great. That’s wonderful. Thank you all so much for your time. It’s been fantastic having all your thoughts and your input. Again, we wouldn’t be able to do that at all without you so really much appreciate it and we’ll of course feed back to you as to how we’re getting on, what we’re taking away from these sessions, how we’re processing and digesting it and what comes out in terms of the next design ideas and hopefully they will be more specific, more concrete and bring all these loose ends together. I promise you there’ll be more loose ends. It’s always like that with design but bear with us. Is that alright? Brilliant, thank you so much.***

**I1: Thanks a lot.**

***I2: Thank you.***

P2: Bye, bye.

***I2: Thanks, [P2]. So that was interesting. It was much…***

**[End of Recording]**