**WORK PACKAGE 2 – SESSION 6**

**Focus group with stakeholders**

**2nd March 2022**

Audio File Name: IDoService – Workshop 2 – group B

Duration: 01:10:40

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

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

P9: = Stakeholder

P48: = Stakeholder

P43: = Stakeholder

P49: = Stakeholder

P46: = Stakeholder

**I1: I think it’s okay now. So now it’s recording I indeed have to just ask you two questions. So before we start, a brief reminder that your participation in this study is voluntary and that you can withdraw from it at any time, so it’s ethics. So can you please 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. It’s okay for you, [P9], too?**

P9: Yes, I consent.

**I1: Great.**

***I2: Super, thank you.***

**I1: So I know we are already recording but I need the proof. So we would like to video record this workshop to facilitate analysis. Anonymous transcripts will be made of this recording and the video will be destroyed after transcription. Do you agree to be recorded?**

P9: We do.

**I1: Great, perfect.**

***I2: Excellent.***

**I1: So the last time, I will just give you some insight from our first workshop and after that [I2] will give you more information about today and what we will do together. So I will just share with you my PowerPoint. I think it’s this one. Okay. So the idea of the IDoService is to support access to and participation in meaningful activities. So today it’s workshop number two and just a very brief reminder, so the IDoService project aims to develop a service to support people to plan, connect with and participate in activities they enjoy. This project is funded by the EU Commission and it’s implemented in Greater Manchester. So we began in October 2020 and we will finish in October this year. So this project, as I mentioned earlier, is focused on participation in activities, specifically on meaningful activities. So they are daily living but also leisure activities, so it’s really a large variety of activities, for example reading, singing or gardening. They are meaningful because they are tailored to the person’s needs and preferences and they provide some emotional, creative and intellectual stimulations.**

**So this project is divided into three steps. Last year we had some focus groups and interviews with people living with dementia, with care givers of people living with dementia and also with we will say professional stakeholders, people like you. So for example people working in charities or people from research centres. So these interviews and focus groups were about preferences, barriers and facilitators to participation in activities. A main outcome of these interviews and focus groups was potential interest to develop a skills exchange service, so some service favouring a skill exchange. So the idea of this workshop, series of workshops is to co-design and to work together to design this skills exchange service. So it’s the second step of the project. In the last steps, so it will be May and June, maybe July this year, it will be the evaluation of this prototype. So we will ask some feedback to potential participants about the prototype, so for example perceived usefulness, usability, etc.**

**So I just forgot to say that for this co-design workshop we had the first workshop in November and December last year, so the first one was with people living with dementia and care givers doing a Dementia Café organised by Age UK Salford. We also had three online workshops. So it was the first workshop and, as I said, we’re now in workshop two, so the second one. We had a group last week, a group of professional stakeholders and the middle of March we will go again to the Dementia Café to share insights and have more discussion with them about this service. I’ll go to the next slide. Okay. So very briefly just some insight from this first workshop during the Dementia Café. So we asked people, participants, for which kind of activities they could give some help to other people around them. So someone said for example they would be very happy to share memories for example with children or veterans. Another one would like to share skills related to cooking, maybe support someone or teach someone how to cook or improve his or her cooking abilities. Or it could be also something like supervising or teaching swimming.**

**So it was really a large variety of activities and it’s quite the same pattern with our second question. It was about which kind of activities you will need or you will like having some help. Some participants said, for example one of them said, “I would be very happy to help to organise some cultural and social activities for myself and my wife.” Another one was interested in support for short journey or travel and another one said, “I think mosaics are very beautiful so I will be very happy to learn more about how to do mosaics and craft activities by myself.”**

P9: I love the parachuting one.

**I1: Yes, indeed. It’s quite an original one. It was in a group. This man, I think, had some, in the past, training to try to jump and to have some parachuting activities but sadly, I don’t know exactly why, it was not possible at this time. So he said, “I would be happy to do that again.”**

***I2: So he had all the training but never got to jump. He still wanted to make the jump, maybe not on his own.***

P9: There was a gentleman I work with that wanted to go pot holing. His health deteriorated and we were in the process of trying to organise that but I think what that comment does is show that just because someone’s living with dementia, they can still have a bucket list and they still might want to do things that are quite daring.

***I2: Yes. I mean we put this in because it really highlights this aspect of people having still a vision of what they’d like to do. Even if that wasn’t possible in real, maybe there’s a simulator or something these days that he could do.***

P9: Exactly. There’s that air flying place, isn’t there, in Manchester, the wind tunnel where you can just go up so high.

***I2: Okay. Anyway, so it’s basically about just… it was great to see how much, once you allow people to really speak out and get in that convivial atmosphere that people start really talking about what is dear to them and what’s important to them and what they’d like to do, their visions. But it does need that time. We prepared people by asking them to bring objects that they could talk about in the first instance to make it a more rounded session rather than making it an interview, “What do you want to do in the future?” kind of thing. This is where some of the design processes can come in around objects and sensory things and storytelling of course. That can be helpful. Anyway, I’m digressing. Back to you [I1].***

**I1: Yes, no worries. But indeed it was really a large variety of activities and some of them were quite surprising at first sight but quite understandable in the end. So as [I2] just said, a really large variety of activities and of course needs and preferences are very individual so it’s really important for services to be individualised too. So during this conversation and discussion around objects and around biscuits too, participants highlighted the importance of friendships, local groups and social support to participate in activities but also to develop new interests and trying new things. Sometimes they said, “Yes, I just tried this thing because my friend said, “We could go to the gym,” etc., and I really like that now.” So this support is really a nice way to try new things and to gain confidence because quite often people are not very aware or not confident enough about their skills and how they could help their relatives, friends, neighbourhood, community, etc.**

**These topics came back again so we discussed them during three online workshops with people working for charities and voluntary organisations or other organisations related to health and wellbeing in Manchester. We discussed about the fact that indeed there’s already some organisation in Greater Manchester offering a lot of very nice and well-designed and very dementia friendly activities but there’s also really a lot of disparities and probably a lot of people having no access or even no knowledge, being not aware of all these activities around them. It was a discussion about the fact that it’s important to have dementia tailored activities, so more or less dementia friendly labelled activities but it’s really important that in a way all community activities are dementia friendly as much as possible, to be including for everyone. So we discussed a very large variety of topics but a common thread, a common aspect was this interest to develop a strength based skills audit, so a little bit like during this workshop with people from the Dementia Café to try to have a better knowledge about what they like to do and what maybe they would like to do and share with their community and the people around them.**

**So today we would like to discuss with you this idea of a skills and preferences inventory of services and how it could help to define opportunities for people, so for example active participation in activities as well as volunteering, for example helping someone or being helped by orienting people to the good organisation charity or services. Now I will just let [I2] give you more information about how we will proceed today.**

***I2: Yes. So we’ve got a number of questions and in an ideal world we’d all be in the same room and we’d have some colourful pens and paper and things where we could mess about. But because we weren’t quite sure what the situation would be at this point when we were organising them and also because everybody’s time is precious and it’s easier to squeeze in an online meeting than going somewhere where it takes you the whole afternoon so we decided to stick with this format for now. So thank you for making the time to join us this afternoon. So we’ll stay in this slightly clinical setting of the online meeting but we’ll try and make it as colourful as we can anyway. What we want to explore, so what [I1] said is we’ve already, from the first set of co-design groups, really what has crystallised is that people with dementia do have these visions of what they want to do if you allow them to speak out but very often that setting isn’t given. So we wanted to think about, in that first set, the outcomes basically focused on there really needs to be something that allows people to speak out and that connects them then with the available service because there’s quite a lot of volunteering services as well as dementia activities out there.***

***One of the key things also that was discussed at the first set of co-design groups was, especially people with early stages, following the diagnosis, and, [P9], you’ve helpfully, and I was just going to respond to that but haven’t got around to that yet so I’ll say it anyway rather than reply. People, following diagnosis, lose confidence. They very often go into depression. So to try and allow them to have that support and that time and that stimulus to think about who they are and what they want to do, to re-establish their confidence and their aspirations for what they want to do because they may as well have ten, twelve, fifteen years even to live and hopefully they want to live them well as long as possible. So the skills exchange service, as a whole set, is what we’ve envisaged but within that we’ve identified, through those co-design groups, that it’s really that bit is missing where people have an opportunity to talk about their skills and preferences, their aspirations of what they’d really like to do.***

***There are some bits already available in the whole service package that’s available in Greater Manchester and it takes a slightly different path for different people but there’s clearly still, from what we’ve heard, both from people with dementia and their carers, as well as from all the other stakeholders, there are some things missing that connect all of these available things. So what we have done since the last set of co-design workshops before Christmas is we’ve started to think about how do these all connect and where it is exactly that we should position what we now call the skills and preferences inventory and maybe we’ll still find a better label for that, so if you have any suggestions. None of this is set in stone. It’s design so it’s malleable, it's quite flexible so if you’ve got good ideas, throw them out and let us know and we can take them on board to develop this in the best possible way. As [I1] also said, we’ll take these ideas back to the group, people with dementia and carers to get them to reflect back on it and also to tell us about how they would imagine that story.***

***So what we want to do then today is think about what would that service look like and at what point should it be delivered, possibly who should deliver it. [I1], do you want to go to the next slide? So this is a bit of a work in progress as I said. So this is how we’ve come up a little bit with the journey at the moment. Most people go to their GP first. They are referred to the MA(T)S and also to other things, get medication, physiotherapy, occupational therapy once they’ve had an assessment. At the moment people then get sent home. Sometimes they get connected to dementia charities. I think Salford is a good example where Age UK is particularly strong and looks after people very soon, possibly directly from MA(T)S to Age UK. Then there’s also volunteer organisations who are open to people with dementia but not necessarily connected. Then we have something at the moment that are either generally memory advisers or social prescribers. So that’s the situation that we have at the moment but none of these are perfectly connected.***

***So what we’re thinking is that we could introduce something possibly as part of the memory adviser or social prescribing service, a wellbeing mentor who delivers this aspect of the skills needs and wants inventory.***

P9: I like the idea, [I2], of it being at the point of a wellbeing mentor being the person that shares your inventory even if it might not be called that moving forward because it’s not labelled as something for people living with dementia either because I was just thinking about your IDoService. I know obviously this project is specifically for people living with dementia but there could be people diagnosed with other health conditions that could equally benefit from the IDoService as well. If the implementation or sharing of what the inventory is and raising awareness sat with the wellbeing mentor, they could share it with more people, including people who have recently been diagnosed with dementia.

***I2: Great. Thanks, [P9], that’s really helpful for that feedback. We’ve just lost our slide a little.***

**I1: I’m not able to see everything. I’m just seeing this slide so it’s quite disturbing. Sorry, I tried to find a way to see you and the slide too. Sorry for that.**

***I2: Oh, I see. Okay, great.***

**I1: The pleasure of sharing things.**

***I2: So please all chip in if you have comments like [P9]. So the idea is to possibly use existing services but change what is being delivered because we’ve got the memory advisers, we’ve got the social prescribers so rather than adding a new person which might, in reality, be quite difficult, to thinking about can they provide this service if we give them the tools. So it’s been really helpful to hear, [P9], that you think that that seems to be the right place to locate it. You’re on mute.***

P9: Although people most definitely need support when they’ve been through the memory assessment service and they get a diagnosis, they’re going to be probably reeling from the news that’s been delivered to them so to start saying straight away, for some people it might be important to hear, “Look, just because you’ve got this diagnosis, your life isn’t over. You can still have a good quality of life for many, many years.” I think it’s important to hear that message at the memory clinic and signpost people to the wellbeing mentor for when they’re ready.

***I2: So we could in fact move that arrow, couldn’t we, that blue arrow that goes from the GP to the wellbeing mentor potentially, from the MA(T)S to the wellbeing mentor or add an arrow anyway. But anyway, so it’s the next step, once they’ve had their assessment they would meet this wellbeing mentor. One of the things we’ve also learnt is that there’s a wellbeing plan I think that’s being rolled out by, is it Dementia Together? Together Dementia? [I1], can you remind me?***

**I1: I think it’s Dementia United working with other organisations.**

***I2: So we’ve been looking at that as well with [ANOTHER RESEARCHER]. That’s a really useful plan and there are similar things, we found something similar from a project at Exeter University as well which is even more extensive. But staying with the wellbeing plan as something that’s delivered in Manchester, there’s only one of the questions that is about this kind of wellbeing aspect. So again, we could use this as an existing thing but make it bigger. At the moment it’s only a discussion point in an interview but from our experience of working with people with dementia, what is really needed is having more stimulus to get people to think about how this works in order to allow people to talk about it and have the confidence even to talk about what they might want, especially when they’re not feeling confident at that point is the environment and situation where they feel comfortable enough to articulate that. So at the bottom here then we’ve got these two bubbles, individual and group or peer session.***

***So we were thinking that the wellbeing mentor could deliver these sessions either to individuals, if people prefer that, or they could be in peer sessions in order to have that peer support that people can choose because just having a choice gives the responsibility to people in a very small way in this case but it helps benefit people, it gives them more of a sense of agency. So we started then looking at what these individual or group sessions might be and how they might be delivered and that’s really where we’d like to focus on today unless anybody else, [P43], [P48] or [P46], do you have any comments on this picture? Can you make sense of it?***

P48: Hi. Yes, sorry, apologies, I entered the conversation quite late in the day so I will catch up but no, certainly this all makes sense. I guess the thing [I1] raised about Dementia United, that being a group that, in my experience working in North Manchester particularly, is something that is really meaningful to a lot of people.

***I2: Yes. Obviously we’ve closely worked so far with Age UK and they’ve also said they sometimes deliver this kind of aspect but don’t really have a tool for it. So they might be interested in having some toolkit or something that helps them deliver this kind of wellbeing mentor plan, wellbeing plan. [P9]? You’re on mute.***

P9: Sorry, I just wanted to say, you’re probably already aware of this, you’re probably going to it yourself but Dementia United are digitalising the care pathway for people living with dementia, aren’t they? There’s an event, there’s three events but different workshops where they’re going to showcase and gather feedback about the digital care pathway.

***I2: [I1], is that the one that we have the invites for?***

**I1: Yes. I’m joining, I think it’s one tomorrow so yes, indeed. I will have more insight about that. Dementia United is doing a lot of things.**

P9: Also the one next Wednesday. But what I was going to say was it would be really worth you, in some ways, waiting to see about this pathway, to see whether or not what you’re trying to create could fit, will fit into the pathway and if you could have it integrated someway so that when people viewed that digital pathway, whatever they’ve created, and assuming it will be shared with people living with dementia and the carers, that your service is something that is included in that pathway somehow.

***I2: Yes, great idea. [P43]?***

P43: Hi. Sorry, just to echo [P9] there really in that I’ve been working with Dementia United on the pathway in particular, particularly around physical activity and how we can signpost people to it at the right stage, whether that be at diagnosis or to support people to live well and who particularly has that conversation. So this type of pathway would be absolutely something that would fit really well. I guess just in reflection of the diagram, I think maybe more reference around the families, the friends and the peers and the carer in particular having that conversation. Just from feedback of consultation we’ve done before and people living with dementia, ultimately it’s the carer that you’ve got to get on board and have that conversation with to make sure that you can signpost to the right activities and that they’re aware of things like transport issues, all those other elements. But yes, I think the plan is brilliant. I think it looks great.

***I2: Lovely, thank you. Yes, I think you’re absolutely right of course. We’ve got family, friends and peers looks quite small at the moment but we probably should make that bigger and also perhaps put a little purple bubble next to the wellbeing mentor so that it’s clear that they’re part of that conversation, that makes absolute sense. [P9]?***

P9: Just another quick comment. Obviously the service is called IDo and that’s how you’re funding for IDo but a very common phrase that we hear is can do, someone has got a can do attitude. I really like the idea although obviously you’d have to ask people with dementia as well, if this pathway, this service was called Can Do, is getting the message over that you can still do things, your diagnosis doesn’t have to get in the way.

***I2: Yes, absolutely. In fact, the original name was the I Can Do service but to make it more snappy, in the end it got shortened to IDo but the original is actually I Can Do. But that’s just the name that we had. As you know it’s European funded and you have to make an application, you have to call it something that’s snappy and that catches the reviewers eyes so that you can get the money to do things but there is nothing to stop us to change the name of the final service. We might call it the wellbeing mentor service. So great, excellent. Shall we move on then or, [P43], do you have another comment?***

P43: Oh no, sorry. That’s (unclear 00:30:26) from me, apologies.

***I2: Great. Let’s move on then to the next slide. That was great, thank you all for the input on that. That was really reassuring that we’re on the right path. So this is quite a manic slide but I’ll try and talk you through this. It’s like our stickies. Imagine we had a piece of paper or white board and we all put our ideas and stickies on there. So these are some of the ideas that came up previously and in our little design sessions in between the last session and this session. So various things happened here, one was a toolkit that allows the wellbeing mentor, whoever they may be, whether they’re a social prescriber, whether they’re somebody from one of the dementia organisations or a dementia adviser, to allow them to deliver or work with people with dementia to find out what are their aspirations, what they like to do, who are they as a person. So as we said, these sessions could be delivered with the individual, possibly with the family, carer or friend of the person, a single person, without much family. I mean it’s one of the things that people have told us in the past, most times people are expected to have a family carer but that is not necessarily the case of all people. [PERSONAL INFORMATION DISCLOSED]. Anyway, so a toolkit to deliver this. We’ve been thinking about what could be in the toolkit. One of the tools that’s really helpful is around storytelling, possibly life storytelling. As I mentioned, we’ve got this All About Us game that we’ve developed which is based on life storytelling and which has been quite successful with people with dementia at the early stages to get them to reminisce but also with that positive feeling to think about the present and the future. So something along these lines, perhaps not a game because that might set the wrong tone but something similar that offers and allows people to think about who are they, what skills do they have or have they had in the past or what interests have they had because so many people have either skills from their jobs or outside of their jobs doing the most amazing things, whether it’s music making or gardening. Sometimes it’s the most, I can’t think of an example right now but sometimes the most awe inspiring things. You think, “Wow, how do people do this?” and they do it alongside their regular work in some ways or volunteering or maybe they have had lots of experiences, historical experiences you can tell about them.***

***So people tend to have lots of skills and experiences that they can share with the right people in order to contribute and then get valued for that contribution. So thinking about life storytelling and thinking about how that might be delivered in a playful way, in a visual way, in a sensory way so that people can relate to it. This can be anything from bringing objects. I don’t know, I’ve got this really odd thing hanging on my lamp which I don’t quite remember where it comes from but probably from a beach, one of my beach visits. So people tend to bring or have these objects that they have associations with [DISCUSSES OWN PERSONAL ITEM]. So it could be around objects, it could be prompts for storytelling or it could be a game around storytelling or it could be various other things that we might think, photographs. So we need to think about this as one of the things we want for a group session but also for an individual session potentially. So that was the first idea we came up with and that’s because we have existing work that might be made to fit.***

***But also prompts could be videos about dementia friendly opportunities, postcards, cards written by service users so have the peer support, bring the peer support into the session. We might have three types of people that come to these sessions, those who already do some of those things and they only need a little bit of nudging. Oh yes, we do have some…***

**I1: Sorry.**

***I2: Thank you, [I1], for fast forwarding through this. So they have already established connections. They might only need a little bit of support and reassurance to carry on with what they’re doing. There may be some who would like to do things but they come to the sessions and want to do things and for them it’s really important to have those sessions to really find out what it is they want to do and can do and to connect them with the right services. We might have the person that’s represented through the grey bubble who is not really the social type and who don’t really want to engage in this way at this point. So we might think about them, either they don’t even want to go to that session or they want to think about it longer so there might be an online version of that to enable them to walk their own way through this at their own pace or it could be an online or it could be a paper version of doing that. Sorry, can we go back? Yes. Then potentially perhaps have people from the volunteering centres come into the session or come into a follow-up session or have a visit to the volunteering centre to allow people to get familiar with it so that there isn’t a sense of don’t know anxiety, that kind of aspect. In addition to having that session, it’s probably also helpful for people to have something to take home.***

***We’ve called it a goodie bag for now with aspects that might help them to follow up on those discussions with the wellbeing mentor, so thinking back to the wellbeing plan, that’s already something that people can fill in with the wellbeing mentor and then can be printed out and they can take away but there could be similar things, the diary planner, map of personal support available, wellbeing plan. Living the Life is another booklet that we’ve developed to support people with dementia by offering mindful advice and exercises to relax and reflect on their life and how to approach it. There might be mundane things like activity vouchers to help with finance or accessing things, etc., etc. So this is quite an open map of all the things that might support these wellbeing mentor sessions in the broadest sense. Does that make sense? Does anything chime with you? Do you think it doesn’t make sense? Any ideas that it’s generated for you at this point? So we’ve got lots of question marks in those bubbles. Bubbles with question marks. We’re hoping to fill some in, that you can fill some of those in.***

P9: I was just going to say, [I2], with regard to the storytelling, I think that’s really, really good but also, for people who are newly diagnosed and might be coming through, it might be good to have some case studies of people who have used your IDo service and it’s enabled them to live well with dementia.

***I2: Sorry, my connection was out there so I only heard that you said life storytelling was important. All the rest I couldn’t hear. Would you mind repeating?***

P9: Of course. I was just saying that I think life storytelling is important but also, for someone who’s newly diagnosed, hearing the experiences of people who have maybe used the IDo service and it’s enabled them to live well with dementia, we can tell people how good this IDo service is and the toolkit but it doesn’t really mean anything unless you can underpin it with examples of where people have used it and it’s enabled them to live well with dementia and sharing… it will take you some time to gather those because obviously you won’t have them at first when you first launch a service but it would be good to follow up with some of the people to find out how it’s helped them to live well with dementia and be able to share that, if you’re going to have a website of some kind on this service, don’t have everything written. Have some talking heads where people are videoed sharing. We could be having a meeting like this on Zoom. A member of our panel at Health Innovation Manchester is living with dementia. He joins Teams meetings, Zoom meetings with us. He was also filmed a couple of months ago for an event we were in and we just recorded him talking on a Zoom meeting, with his consent obviously.

But if he for example benefited from using the IDo service and the toolkit and the pathway that you’re thinking about doing and stuff, it doesn’t all have to be written because people might have problems reading as well as their dementia progresses. They might have problems with reading anyway. Even people where English isn’t their first language, they may learn to speak English but they may not be able to read it so things that are audio.

***I2: Absolutely. Audio visual definitely if we have a website then it should be multi-sensory. It’s something that we were working on in fact with another application but our first attempt has been turned down for reasons I disagree with of course. So we’ll have to give that another go but yes, definitely, I totally agree with you on that multi-sensory aspect and to be inclusive for people with either visual impairment or languages, etc., etc.***

P9: What I’m going to suggest now might sound totally off the wall but you know how you have jobs fairs and things like that, why can’t you have IDo activity fairs where different organisations, community groups come and have stands and people living with dementia, not just people with dementia, anybody can go along and hear about what activities they offer, get their contact information. There could be information about support with transport, if there’s volunteer driving services locally or something like that so that it’s not all online because there’s a lot of people don’t use online. There’s a lot of digital exclusion, isn’t there? I’m not saying those people would go along to an event like that but like in the dementia cafés, taking some of the services and different activities to those groups rather than expecting people to come to them might be a way of raising… I don’t really know what I’m trying to say but I think I’m just trying to say we can’t always rely on online approaches to reach the people who really need this support.

***I2: Yes. I think that’s a great idea. As we’ve said, in some previous sessions we’ve had representatives of the volunteer groups in Manchester and they would be the right kind of people to bring in for those kind of sessions so yes, having a fair where you can say, “We offer this, this and this,” and transport volunteer service, etc. It’s a two way thing. People with dementia might access services through those volunteer services as well as them being potentially able to offer services and those volunteer organisations being able to create opportunities for people with dementia. I mean we’ve had some in the past where people said, “I know how to cook but nobody to share,” or, “I know how to knit. I like knitting but nobody needs what I make,” or people, because they’re elderly, they have experiences of what it was like in the ‘40s, ‘50s, ‘60s, they could go into schools to give a history lesson or something from a much more experiential point and interesting than you get from a school book. So there are so many opportunities in which people with dementia could also contribute, if only we can make that work. I think having that fair where people can, hands on, where they can say this is what I like and this is what I can offer but this is also what I need in terms of help. I think that would be really useful.***

P9: It comes back to what we were saying before as well, [I2], about lacking in confidence can be one of the first things that happen when you’re diagnosed with dementia. Actually going along and meeting people face to face, although it can be quite scary, if they get the courage to go, meeting people in person, it’s not as scary as they thought it was going to be. It might give people the confidence. I just think back to years ago when I went to [DISCLOSES A PERSONAL EVENT WHERE A FACE TO FACE INTERACTION MADE A DIFFERENCE]. If she’d have been on the phone or if I’d seen something on a poster somewhere, it wouldn’t have had the same effect. It was because she believed in me that I decided to [DO THE EVENT] even though at the time I didn’t think I could do it. Does that make sense? So it’s those relationships, isn’t it, that you build in that face to face contact that can be crucial to enabling people to live well.

***I2: Absolutely. Thanks for the link to [A COLLEGUES] work as well. I used to have my office next to his or he used to have his office next to mine which was nice because we could talk to each other. I don’t quite know where he’s got his office now. Since COVID everything has gone haywire. Sorry, I’m just looking at all the lovely comments. Oh, [PROVIDES ADDRESS]. Great. Yes, absolutely. I think that’s definitely something that we can follow up and perhaps also have some visuals, maybe we can mock up some visual before we meet at the dementia group in a couple of weeks’ time. I think that’s a really nice thing that we could do. Anything else? Hello, [P49], you’ve joined us quite late. Do you want us to summarise anything?***

P49: No. I just thought if it was going on another hour but if you’re wrapping up then it’s fine. I can catch up.

***I2: No, we’re not wrapping up yet. We’re just in the middle of things really. [I1] has made a bit of an introduction to the background of the project and then we’ve been talking about where this IDo service or I Can Do service or skills exchange service, where this can sit. [I1], can you just… yes. So we drew out and we discussed what the current situation is and where we could situate this idea to enable that service within the existing framework and so it’s the middle one, the wellbeing mentor sessions which could be delivered potentially through existing people like memory advisers or social prescribers and so the current slide, sorry, if you can go forward again, [I1], was about what should those sessions be like? What do they need to deliver to enable people who have just been diagnosed with dementia to get over the shock of the diagnosis and to engage in social activities and to figure out what the skills and aspirations are that they can contribute to society in order to feel valued. So we’ve talked about storytelling and [P9] has just come up with the activity fair to connect people to the volunteer services to allow a better contact rather than just doing things interactively. I think that’s a great idea.***

***The other thing was the goodie bags, something to take home for people that helps them, that they can go back to, something that’s colourful, friendly, non-stigmatising. [I1], do you want to go to one of the next slides. I don’t quite know what we’ve got. The next one. The next one. Yes, so one of the things that I mentioned is the All About Us mindful life storytelling game that we’ve just launched as of last week which is basically a life path. Every decade has a different colour and each decade has six fields corresponding to six question cards. The question cards deal with experiences, hopes, wishes, activities, relationships so motivational questions around a person’s life, who they are and what is important to them, what do they want to do. So it takes them from reminisce into the present, into the future, depending on where their age is. But it doesn’t matter if they’re 50, then they reach a little bit earlier. If they’re 80 then they have a bit more to reminisce but there will still be a future for them. So the game goes to 100 plus. Obviously I think the oldest person got 122 so we’re perhaps not quite catering for them but anyway.***

***For most people 100 is quite a sizeable age. So yes, just to give you an idea of what we could think about in terms of what these kind of tools could look like, [I1], the next slide. I don’t think we’ve added another. Oh yes, we haven’t added the other picture.***

**I1: Which one do you want?**

***I2: Living the Life. Yes, we haven’t added a picture of the open book but this is our little booklet. Again, thinking about to help people approach every day life after diagnosis. As [P9] knows, this has gone under the wheels of COVID. While we have the booklet and it’s also online, available with the task, we haven’t yet fully evaluated it so that’s a forthcoming task but nevertheless, as an artefact or online artefact at least, it already exists. I know that we have some people giving us feedback that are already using it. So these are the kinds of things we’ve been doing in the past and therefore, in some ways we’re thinking about, if you go back two slides to the overview, sorry, three slides. Next. Yes. Things that could go into a goodie bag that helps people think about how to approach life, practical things as well as motivational things in terms of how to live well. Does that make sense in terms of taking something home? Does that seem sensible? One of the feedback we got in an earlier session, I think it was with you, [P9], was that people get far too many leaflets and things that they can’t really take in. So one of the things we’ve been trying to do is design things that are minimal and approachable so you can memorise them well because they’re visual.***

***Any ideas, thoughts, comments around either of the two things, either how to create the session, what you think is important for delivering this wellbeing session and connections, finding out, getting people to talk about what they’d like to do like skills, opportunities they would like to have or else to take something home with them to help them further reflect on it and manage the situation? [P9]?***

P9: All I was going to say, [I2], is that it could be that these sessions need to be delivered in venues that are accessible and familiar to the people that you’re trying to engage. So for example we’ve just been working on a project and I was doing a session with some Bangladeshi sisters and we had the session in a mosque. So it’s about using or making connections within communities. [P46] is on the line, who’s perfect, if you were trying to reach out to BAME communities, [P46] and people within this network would be much better placed than me to say where you should be delivering those activities and getting advice and guidance from the communities and people you’re trying to reach rather than having a generic approach for everybody.

***I2: Absolutely. It would only work through, I suppose very specific settings for wherever it’s being delivered, yes. [P46], do you want to add to that?***

P46: Yes. Just to add to what [P9]’s mentioned. So what really matters to communities (unclear 00:57:46) but also what we know for example, and I’m sure if you’ve engaged with Dementia United then… I’ve forgotten their name now but (unclear 00:58:00) then using music and hymns is quite a powerful one. I wonder, as we design this, to think through some of the equality issues and how we improve access and making sure we’re addressing that at the design stages. So the spaces in which it happens is really important but also one of the things we know, and I know it was referenced to earlier on around the stigma, so how we’re breaking things down or offering some sort of reassurance so that in some communities where it’s taboo or it’s not well understood or it’s a whole stigma so that we’re not leaving those communities behind but we’re really promoting this in a way that is encouraging. I know a few years ago, one of the pieces was a simple thing we did with Manchester Foundation Trust was just getting some information sheet with black people just to get a message out there saying dementia affects people of all communities and all backgrounds and so therefore this is what it looks like and this is the support and the offer of help out there.

***I2: Yes, absolutely. I think that’s an amazing point that you make there. In fact, one of the things that we wanted to ask at the end of the session and I think now seems a good point to actually bring it up, is I think the next step for our project will be to actually work specifically with individuals to try and create a simulation of how the service might work. That only works if we work with individuals on their specific care path. [P46], I’m wondering whether you might be interested in working with us for example to identify somebody in the BAME community who would be interested. We’d work with you and them to map out what that journey is, how would they want to see that session happen. Would they want objects or hymns? What would be the best place to deliver it? We can only find that by working within the community and with you. So if you are happy then I think that would be really great to work with you to ensure that we have that inclusive aspect, especially with the BAME community in the project. So we’ll hopefully work through somebody at Age UK once we’ve had a session there as well.***

***So we’re hoping that we’ll have perhaps three individual paths that we can go to simulate what the journey would look like. So we call that a conceptual prototype. So we get people to work through it to then say, “We’ve worked through it, people have tried it out. Here are the different ways in which we can potentially make it happen,” so that we have this proof of concept that we can then hopefully, by the end of the project, which will be in October, that we can then say, “Okay, so we have a proof of concept, this what we want to take forward,” and then we’ll hopefully find some new funder who wants to allow us to take that proof of concept forward to a realisation or maybe we can use crowd funding or something. (unclear 01:02:05). That’s brilliant, thank you, [P46]. That would be really great. So we’ll be in touch with you then after the session. Anything else? Any other comments, thoughts at this point that you want to make? No? Excellent. [P49], did you have any…?***

P49: I’m just still trying to just get my head around things and listen for now but I can always email you later, can’t I?

***I2: Yes, absolutely. We’re trying to facilitate this journey through the… well there is an established journey through the care system at the moment but what we’re trying to do through this wellbeing session or wellbeing mentor is to really help people with dementia look at what they can do, what they want to do, what they can do and to re-gain their confidence after diagnosis and then to connect them with the volunteer services or other opportunities. Great. So we’ve got quite a number of things actually that have come up which is great, everything from life storytelling to real examples, real people, talking heads to having an activity fair with the volunteer services, delivering in accessible venues, thinking about accessibility and inequality, general such as relevant venues, music perhaps, etc., etc., toilets, ramps. Language so making things multi-sensory and/or possibly multi-lingual and think about how we create those reassurances to not exclude people.***

***[P46], you gave that nice example of dementia affects all. That was a nice example as well. Is there anything else that we should discuss, anything we’ve forgotten perhaps, something you can think of, something we haven’t yet mentioned. [P43], do you have any further thoughts or [P48]?***

P43: No, I don’t think I have anything else to add than what’s been discussed is great.

***I2: Thank you for your contribution also on the Dementia United aspect. Great. Okay, in which case I think we’ve had a really rich session. Thank you, [P46], again for offering to work with us more closely. If you have any thoughts afterwards or something that we could consider or any ideas of what would be useful then please do get in touch and we’ll be in touch with you, [P46], and in two weeks we’ll work with the dementia group in Salford and see what their view of this journey is. After that, as I say, we’ll try and recruit three groups, [P46] being the first of them, to then map individual journeys and see how it works for people to, in the end, have three examples, possibly three talking heads of how this journey could, should and may go and how people have benefited from them. Yes, thank you. [P9] has now left but yes, I think she’s made some great input there as well in today’s session. Thank you all for your time, it’s been really great having you. If you have any more comments or thoughts then just get in touch.***

**I1: Yes, thanks a lot for your participation. You can of course write to me if you have some questions.**

P43: Thanks very much.

P48: Wonderful, thank you. Apologies I had to miss the first half hour. I look forward to talking next time.

***I2: Absolutely.***

P48: Also I’m going to put it in the chat. Because I missed the start, I don’t know how relevant it is but there was a really interesting report by Dementia United and colleagues at the University of Manchester a couple of months ago now about dementia and housing particularly but I think it resonates with a lot of the themes in terms of how information gets out there and some of the pathways people have which may tangentially link in some way, I’m not sure.

***I2: Great. Yes, I think that’s always an issue because that’s why we haven’t got all the connections between all these different aspects of the care path at the moment so communication and connection is a really great, important thing. So if there’s something about communication, that might be helpful.***

P48: Yes. I think one of the things that they’ve got, so within a GM context particularly, I think there’s something really interesting about the role of people like the GMCA and the GM Health and Social Care partnership and these umbrella organisations that theoretically have this coordinating role between the different parts of the system but obviously whenever you try and consolidate something, you create schisms and silos and all of this. It’s the ongoing perpetual problem of how you break those down. There’s something in this report about dementia and housing that it tries to address but I guess more broadly, when you’re talking about working with GPs, interagencies and… from our research, one of the big challenges we have is that no one is even working on the same geographic footprint. So we want to do a project in Hulme we’re using the electoral ward boundary. Then the GPs are using a different boundary and it just becomes really difficult to coordinate. Anyway, I’m happy to talk about any of that if you want to get into the complexities of local government. I spent a couple of years seconded…

***I2: That would be lovely. I mean we can always have a cup of tea on campus somewhere.***

P48: Wonderful. Thanks for your time. I’ll let you go. Speak to you soon.

***I2: Brilliant. Thank you, [P48]. Bye. Great.***

**[End of Recording]**