**WORK PACKAGE 2 – SESSION 3**

**Focus group with stakeholders**

**11th January 2022**

**Audio File Name: Workshop 1- Group 2**

**Duration: 01:03:00**

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

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

P2: = Stakeholder

P43: = Stakeholder

P44: = Stakeholder

P6: = Stakeholder

P45: = Stakeholder

P46: = Stakeholder

(Started at 00:00:15)

**I1: …that it’s very important to them, being able to contribute and to feel valued. We also, in fact from our previous project, already found that the point of the diagnosis can be quite unsettling where people feel that they can’t take responsibility anymore, etc., and then close down. We all know that that doesn’t need to be, and shouldn’t be the case really. So today’s session is really thinking about opportunities for active involvement. So what skills perhaps are already on offer. We know all of you are here today because you’re already doing lots and lots of things that are already on offer but also think perhaps what is missing, what is it the exchange service might be able to offer. For example in the last focus group, the discussion arrived at the idea that it would be really good to have something at the stage of the diagnosis or from diagnosis that identifies the kind of skills for people to identify what they’re good at and what they might be wanting to do so this affirmative aspect at that point.**

**So I think I’ll just unshare the screen so we can all see ourselves and I’d like to invite you to think about and tell us about opportunities for active involvement of people with dementia from your point of view but also perhaps the gaps, things that you think would be really useful to have. [P2]?**

P2: Yes, I’m quite happy to have some input on this. I think initially I think it depends where you’ve been diagnosed and who has done the diagnosis on the basis that is your next point of delivery and pointing people along and we experienced in Oldham over time, there is occasionally groups which are run by the NHS but has found difficulties during the COVID period and prior to that, financial reasons, we used to hold a post diagnostic working group which will provide eight to twelve weeks, depending on how it was being done, where newly diagnosed people could go and learn about it and what support there is within the area. Because of the lack of support, that’s where we formed ten years ago, that’s our main (unclear 00:18:23) getting people to us but I think (unclear 00:18:27) picking up what you were saying, looking at it in a wider world because we’re going across boroughs now, across financial barriers and things, perhaps what we should be doing is having some form of independent skills audit of the diagnosed person on the carer because it could be a really active diagnosed person but there’s plenty of opportunity still there but your carer could probably want to become a carer in the sense of the definition of a carer and put that protection around you and restrict you from moving on with the thoughts possibly of safety in mind or the fact that you haven’t got that skill to assist (unclear 00:19:19), if that makes sense.

**I1: Absolutely. Having an independent skills audit I think would be really useful and as you say, probably both for the person with dementia as well as the carer.**

P2: Yes.

**I1: [P43], I think you were next.**

P43: Great, thanks. I think there’s a couple of things really. The first one being similar to what was mentioned before around I don’t think anyone has that conversation around what people with dementia would want to take part in for example. We’ve been working with Dementia United on the dementia care wellbeing pathway and actually there was a conversation around providing people with support as to what’s on offer at the point of diagnosis, as you say, it could be very overwhelming and it might actually be better to have that conversation slightly after that to allow the time for that to sink in for both the carer and the person with dementia because otherwise, it’s probably not a good point of engagement. I think there’s something around the activities that we provide in Greater Manchester. Obviously there’s a number, particularly within physical activity, that are badged as dementia friendly. Actually that really narrows the offer. So for example there is dementia friendly swimming or there’s dementia friendly dance but all activities, if you do speak to providers, are technically dementia friendly but actually they’re just not advertised and it should be.

That’s a question whether carers of people with dementia would prefer to have it advertised as dementia friendly so they know they’re going to be in a safe space and have the right support. But I also think it really narrows and makes it really specific because if someone’s not interested in swimming, there are a range of activities that they should be able to access. So I think there’s something around trying to understand how people want the sessions to be advertised and portrayed to make sure that they’re inclusive.

**I1: Yes, I think that’s a really good point. It’s of course one of the key points also in terms of how do people want to access these and do they want them to be badged as dementia appropriate, friendly or however because especially at the early stages, people don’t tend to want to go to these badged events in cafés and things because they often tend to be for later stage offers. So yes, that was definitely one of the things that was raised in the interviews we’ve had earlier this year so that’s definitely a point to look at and perhaps if that needs based or this independent skills audit can cover that to find a pathway. I think that might be really useful, mightn’t it. [P44]?**

P44: Yes. First of all, you haven’t got to answer this but I do think the sample of people living with dementia or the families of, could be a skewed sample anyway because they tend to be the motivated, engaged people already that then give you this information. I just think working, as we do, across Manchester, honestly, the people that we end up working with, there are so many people that would not come forward and do anything unless they were proactively contacted, persuaded, persuaded, persuaded, make it as simple as can be for them to come to something which is definitely badged as dementia friendly because they just wouldn’t do anything otherwise. So I think there are so many reasons for it. I would love your project to be able to really speak to a consultant about what messages he or she gives when diagnosing. I have a real problem that I suspect they’re just very much a medical model and they don’t give positive messages, “Yes, you’ve got this brain condition but the way of trying to manage it best is by keeping as active as possible.” I would love to know what they actually say.

I’m sure the focus is on taking flipping medication which, sorry to sound so negative but I just think the keeping active should be the most important message and I’m not sure that’s given. I’m sure we know that by the time somebody is diagnosed, the person living with dementia might already have become apathetic and given up, depressed and the family might already have decided, “She can’t do that anymore. She doesn’t do anything anymore.” I found, when I visited people, you have to say, “Well okay, so she doesn’t knit anymore but I bet if she comes to a group and we’re all knitting together, she’ll be able to show us how good her knitting is.” So I just think a huge amount of work has to be done to counter the negativity of the carer sometimes. I even wonder whether we should all, I think this of our own groups, should we be trying to move our groups into places like leisure centres where there’s more awareness, “Goodness, there’s physical activity available here.” Actually I think even our groups, I keep saying to my staff, “We don’t want people sitting on their bottoms for two hours. We want them to be up, moving around,” and so I definitely think there’s something to challenge us all about offering more physical activities, whether they’re dementia friendly or general. I could go on for ages but I won’t.

**I1: Feel free to go on. But no, I think the point that you’re making about consultants, I think it’s really interesting because we work with the head of the psychiatric and geriatric clinic in Germany as part of our previous project, amongst others. In fact, it was really interesting what she was then saying, how the project helped her to see what she was doing differently. There was discussion around that, which I have experienced as well, that patients are not… I mean because they are being asked to come with a carer or care partner of some sort, that the doctor then speaks to the care partner instead of the person with dementia. Just because they now have a diagnosis, doesn’t mean they can’t take it in anymore. Usually, or in an ideal case, they’d be at a fairly early stage that they get diagnosed. So that’s certainly a key point. Sorry, there was something else you said that I meant to think about. Oh yes, you mentioned knitting. I’ve had a student, she’s just about finishing, I think, her PhD, working with people with dementia and clothing as a means of talking about, creating this map of their life and maintaining some of their personality.**

**She found one of the people she worked with, she couldn’t articulate any more how she’d knit but when she had the jumper in her hands that she had knitted herself, she could actually articulate it and brought back some of her memories, language and things. So these kind of tactile aspects can be really important too and that’s obviously at a later stage. I mean people have said having a knitting circle would be really great perhaps or having one of the people in our previous project said also she likes to knit but has no outlet so maybe connecting them to a charity who then can sell what they make or something like that. I think there’s really a lot of opportunities there of what we could do. So we’re trying to collect and figure out what’s the things that we can and should offer in terms of this concept. So just to give you a little bit of the wider context, the idea is, obviously this is a two year project so what we’re trying to do is have this session today and then the next session on Friday and then we will try and collect all this information and all the ideas that have come up, to bring them together rand make some suggestions as to what might be the best way or ways forward.**

**Then we’re hoping to schedule some more sessions of this kind for February and hopefully have you all back and then discuss the ideas that we’ve come up with to see what might seem most appropriate and if so, how could we implement them, how could we make them work so that we can try and implement over the following few months as what we call a simulation where we try and pretend that it exists and we pull the strings by email and whatever else behind the scenes to make it happen maybe for a small handful of people with dementia who can volunteer for it to see how does it work. What are the stumbling blocks? Do they feel that this is helpful? So that we then have what we call a proof of concept that we can then hopefully take forward in the next stage project and lobby for support to make it happen. We can’t make it all happen, unfortunately, to the final dot of the I or the cross of the T in this project but if we can get a proof of concept going then hopefully we will be able to get future funding to develop it further to implementation.**

**So this is where we are now so your input is really, really important and we will use that within an iterative process to discuss how we develop things. Hello, [P46], thank you for joining us too. Sorry, [P6].**

P6: Sorry, my internet cut out a little bit so sorry if I’m backtracking a little bit. I think I must have lost you for a couple of minutes. But one of the things that City of Trees are currently leading on right now is about the green social prescribing that’s happening around Greater Manchester. We’re leading on that figuring out the entire infrastructure that’s around Greater Manchester. It’s more towards the health service rather than specifically dementia or specifically any other mental health illnesses or physical illnesses or anything like that. So I’m not really one to speak about this project because I’m not part of it, however we are recruiting a green social prescribing coordinator soon so hopefully then once they’re in position, they’ll be able to speak a lot more about this and get more involved. That aspect of it will link into the work that GPs do, link into any events or activities that are happening around Greater Manchester. That’s something then that any dementia activities could be included into that and then that will then be that prescription rather than a medical prescription. I know [P44] mentioned some time ago saying about all of this stuff is very medical usually.

So I think that’s where this green social prescribing initiative is starting to get more track now which I think this service that we’re talking about right how is going to really help in the future with all of this green social prescribing stuff as well. So I think that’s something that’s going to be really exciting in the future. I know as I said, once this coordinator of ours is in place, then there’ll be a lot more information out there and a lot more knowledge coming out there. Then hopefully then in the future we will get that prescribed activity rather than a prescribed box of tablets or something like that. So that’s really positive that we’ve got that going on.

**I1: That sounds really visionary. That’s great, I love that, green prescribing. Yes, I have heard, I think probably on year four a while ago, how important being a green space and blue space meaning water, lakes or waterways of some sort, are for people’s mental health, definitely. [P2]?**

P2: Yes, just a couple of points. Picking up on [P6]’s comments about the future which uses regular which I’m not personally negative but what is the future? Social prescribing starts when you get into the GP either by telephone or wherever, what I’m finding is at this current time, people with dementia, from my experience (unclear 00:33:03) my membership, telling the truth, but the majority are saying the same thing so there must be a relative amount of truth in it. The GPs don’t seem to be wanting to be get involved with dementia, their priorities are elsewhere at the moment. When you’re ringing up, it takes about three weeks for them to see you. If you’ve got dementia, you’ll probably beat the back of the queue. I can’t prove that by any stretch of the imagination, I’d like to but I can’t. Picking up on the knitting, (unclear 00:33:35), which [P44] may recall, did do a knitting session this summer where groups were invited to knit, I think it was something like six inch squares or something like that. They provided the needles and the patterns, and it was sent off to some dementia group. Was it you, [P44]?

P44: Yes.

P2: Sorry. I’m not sure I can remember your name (unclear 00:34:02).

P44: Yes, we got loads of blankets which are being distributed to care homes now but yes, that was a lovely project.

P2: Good for the ladies to take part in it. None of the guys took it up I must admit. They probably weren’t inspired by my thoughts. Going back to consultation and diagnosis, my wife was diagnosed eventually in 2012 after about three years of processing and again, it was a case of you got it, here’s a leaflet, this is your medication, bye, bye. It was only my own desire to learn about it that I actually found out about the post-diagnostic group I was referring to earlier. We got parked on a shelf. Having gone through that session, as I mentioned earlier, there was nothing there and that’s why we formed Springboard. One of our successes, and has been for quite a while, is partnering with the Oldham Council library department where we put a bid in together for a readers friends project which brought money in, which brought actors into our group. We got engaged with some poetry, didn’t we? We got engaged with the (unclear 00:35:29) for that which became a national event eventually. I know it’s ended up in the labour museum in Manchester and it’s still there apparently.

We also get involved with the Oldham Coliseum which is the Oldham Rep and they invite us along to shows and things. Pre-COVID, we were doing workshops in the theatre making miniature props and things and got involved in doing a very small scale production which was just exclusively put on for the members of our group. So there are organisations out there but unfortunately, they all competed for the same pound coin. That’s the difficulty, attracting that and sustaining it.

**I1: Absolutely. [P45]?**

P45: Yes. It’s perhaps problem solving, isn’t it, about finding what’s out there because every time I go to a meeting I find out something new, some fantastic, innovative project that’s going on and how do we then connect that to everybody. I mean [I1] and [I2] actually know this but we’ve just evaluated, it’s called Greater Moments app. It’s a downloadable app and it tells you all of the activities that are going on around Greater Manchester. So that’s one way of knowing but not everything is on there so you need constantly to link up. Then how do we get that information out and get volunteers involved? Is your idea to be web based and paper based at the same time, [I2] and [I1]?

**I1: We haven’t decided that yet. In fact, it depends on what it becomes because if it is something that… the scenarios that we’ve now discussed already or that we’ve heard, if it becomes a consultation session after you’ve had the diagnosis, so maybe you get three weeks to adjust to having heard this news and then you get offered the session to talk around your skills base interests, then maybe it is simply connecting to existing things, things that [P44] or [P2] or others have said. So we don’t actually have to be web based or paper based. We are a virtual thing that connects everybody. Yes, it might work through a website or it might work through a paper based thing in some way but we haven’t decided that yet because until we know where we’re situating it and what exactly we will be providing, I think that’s the last thing we’ll decide about basically. So first I think we’ll need to figure out the concept, where do we want to position it? Is that the right thing.**

**So we’ll probably need to do a little bit more thinking about that to figure out exactly what might be the best way and then going into these individual aspects, looking at what… so hopefully by the end of these sessions, so by February when we come back, we’ll hopefully have two or perhaps three different potential avenues of how we might shape or situate this service as a concept and then we can start thinking about what do we need to do to make this happen. Then we need to follow all of that up and then try and simulate it in one or two versions. Does that make sense?**

P45: Yes. I think social prescribers could be your connection there though, as [P6] was saying because they work across all avenues of groups and GPs and hospitals, voluntary groups. We’ve got tiers of different organisations providing care and support, haven’t we, and that’s where it becomes quite difficult because there isn’t any uniformity across the boroughs of Greater Manchester, we know that. Some have a very poor experience and others have a great wealth of resources.

**I1: Yes. So I think possibly this becomes the connection point between the diagnosis and some of the services offered and/or it might have something around volunteering as part of it to facilitate. We had, in the last group last week, we had somebody from a volunteer service included and they said, “Yes, we’d be really happy to be involved.” So I think it’s trying to bring all the pieces of the puzzle together and provide that little connector piece. I can make a nice image of that. I have some funny images in my head right now. Great. [P46], you’ve joined us a little bit later. Do you have any questions? Have you got the gist of what we’re talking about or shall we summarise something for you? How are you doing?**

P46: No, I’m following the discussion.

**I1: Good. Do you have any thoughts on this from your perspective of the BAME community?**

P46: I mean nothing that hasn’t been mentioned yet.

**I1: Great. Do we have any other comments, questions?**

P2: Just a point of information, my 4 o’clock meeting has been cancelled so you’re got to put up with me a bit longer.

**I1: Great. Right, so we’ve got quite a few ideas already. Shall we go through those again or do you want to… sorry, is that still a hand up?**

P2: For me?

**I1: Shall we just go through what we’ve already got and I can show you as well what we had last time. I can’t see you now so just speak if you want to say something. So we’ve just said what do consultants say at the stage of the diagnosis that there is an NHS post-diagnostic support group but it’s long waiting times, is that right? An independent skills audit would be useful. We’ll do a more thorough analysis of everything that’s been said later but I’ve just been trying to type key ideas that came out of it while you’ve been talking. People don’t do anything unless they have been contacted or persuaded, I think we had. So having that connection to the diagnosis but not immediately at that point would be useful. Dementia advertised as dementia friendly or not, that was one of the questions as well, should we do that. Then we had about green prescribing, finding what is out there and how to connect it, knitting group, blanket groups with blankets distributed to care homes, Oldham Council library project, so all really great examples. We also had dementia currently not so much a priority because COVID has taken over everything. So any thoughts on any of these so far? Sorry.**

P2: For Oldham Council you’ve put Oldham Rec, that should be Oldham Repertory not Rec.

**I1: Sorry, like that?**

P2: Yes, that’s fine.

**I1: Excellent, thank you for that.**

P43: The other thing I would add as well in the comment on the previous slide around consultants and their knowledge, not knowledge, that’s the wrong word, their ability to share and have that conversation around activity, I think as well, just from a personal experience, dealing with the memory service initially so long after the diagnosis and then being discharged and converted back to your GP, there then seems a real lack of support from the GP. In a lot of cases you have to remind continuously that there has been an Alzheimer’s diagnosis or any form of dementia. So I think they could be a real critical point in terms of having that conversation around what else might support, not just physically but what else might support their overall wellbeing. There never seems to be any conversation around that but I think they could be a critical point in connection to services. Also, in a lot of cases, that connection to the social prescribing team or link workers who tend to liaise with the GP surgeries, so I think that could be a key part of the pathway in terms of having that conversation and picking people up.

**I1: Yes, so educating GPs more to have that connection or offer something that gives GPs that connection into services because if the memory clinic refers patients back to the GP for the general service then GPs, we all know, are overloaded and don’t necessarily have that specialist thing unless they are given that at the forefront so they can pull it up. Really good point, yes. Excellent. [P44]?**

P44: Yes, it’s just a little bit of a complication of the picture. I know that the GP lead for dementia in Manchester is really keen to have a social prescriber in his GP practice. He thinks that will make life much easier for him. My only concern is that that could introduce another layer of bureaucracy for the family to get through, to get to the activity because sometimes social prescribers, they’re prescribing for all sorts, don’t know what there is. Again, I’m thinking that it’s dementia friendly and personally, I think it’s really important for the family or the person with dementia to build a relationship with an organisation that’s going to be there throughout their illness, they get to know, they trust, that can really help them at different stages of the illness, to connect to what might be suitable at that time. I’m just concerned that a social prescriber might be able to do that but might not. Do you see what I mean? So it feels to me that either mental health services should be really trying to help people to get engaged with whatever the support organisation is in their local authority area. Well that would be the desired thing because I think it’s a bit more precarious where you bring in the social prescribers as well because are they there to get to know the family well and support them throughout? I don’t know.

**I1: I don’t know. [P6], can you say something to that?**

P6: Yes. That’s a really good point, [P44], because as part of City of Trees, obviously we are an environmental charity and we don’t have that expertise, that knowledge around dementia. I’m currently on some online courses from the Alzheimer’s Society but it’s nowhere near enough as to what you guys on this call, that knowledge that you’ve got. I think that’s something in a way that, as an organisation like us, it’s something that we’d be lacking. So as you said, to have that relationship with a specific dementia charity, specific dementia organisation and then you build that trust, that rapport, that relationship with the family, then you could then technically, in a way, be that social prescriber even though that might not be your official job title or your official role. But then I think, as you said, that relationship building is so important and then that means then it can go on to other organisations like City of Trees that don’t necessarily focus on specifics. So I think that’s something that’s really important. It then goes back to saying you’ve got some activities that might be suitable for other people that are involved and not just those with dementia. It goes back to that original, the starting conversation that we had. Do we call it dementia friendly activities or do we call it age friendly activities or do we just call it the activity.

**I1: Yes. Again, that’s a really good point. I mean one of the questions that raised for me is how do people go through this because there is plethora of different organisations and they’re different in each borough in Manchester as well. So how do you know where to go? They’re getting the diagnosis, then they’re being referred back to their GP and then they’re left to their own devices and have to find Together Dementia or Age UK or whatever other groups or services there are. Is that right? So they have to find that all on their own? Are they given a list of these?**

P43: I think the experience I’ve had was when the referral was being made back to the GP from the memory service, we did receive an information pack in the post which had all leaflets in for Age UK and a range of support, not only for the individual but for the carer which was really informative. But again, whether someone’s got the confidence to make that step and not have a conversation around, getting more of an awareness of what those activities involve, so having a conversation with someone or someone to support you to do that. Plus as well, depending on someone’s situation and the caring responsibilities they already have, then finding the time to then not have that support and access those activities could be difficult. But like I said, the information is provided but the support to access is probably lacking. Also again, that awareness and if someone’s not had the conversation around the real importance of activity and connecting with those services, it can get forgotten. So you need that dialogue to support. Like [P44] mentioned, that constant persuasion of the benefits for both the individual and the carer.

**I1: Yes, I think that’s a really good point. That makes it quite clear as well.**

P43: Yes.

**I1: [P44], is that…?**

P44: Yes. Well I don’t know whether you’ve spoken to anybody at Salford Age UK but when I worked there, the dementia support service there was the recognised main provider for community based services. Almost everybody diagnosed was immediately, from the memory clinic, referred straight to Age UK and then it was the job then of the team there to phone them, visit them and talk to them about that community engagement. So that was really efficient because it just happened almost seamlessly, really quickly, almost straight after diagnosis. So I don’t know whether that happens in other areas. I know for instance in Manchester, initially it’s the mental health trust’s own support advisers that do those initial visits for the first year. So it is different everywhere.

**I1: Yes. I mean we have been in close contact with Age UK because the first group we ran through, the co-design group ran through them thankfully just before Omicron hit so we could do them in person.**

P43: I guess as well, I guess my experience has been through COVID. So obviously the demand and the stretch on Age UK and services and such like probably has affected that. So whether that’s different outside of pre-COVID, it was probably much different I imagine as well.

**I1: [P2]?**

P2: I mean Age UK are very useful but they all work independently within their own areas, don’t they? For example, Age UK in Oldham, that strikes a boundary around Oldham and (unclear 00:54:04) Age UK as you say you are, do you really mean the top of the pyramid for Age UK or just somebody you knew from Age UK or a collective of all the boroughs within the project who have an Age UK and possibly indeed getting them all doing the same thing from the same hymn sheet. I don’t know the answer to that.

**I1: Often these things do depend on the individual. However much you try to synchronise things, sometimes it really depends on the individual, how well a service is delivered. I mean we’ve heard that in the interviews, we had people saying they went to a class, I think it was a gym class or something, a swimming class and they had one instructor and then they left and then they had another and they just didn’t like it anymore because they didn’t feel it was appropriate to their level anymore or whatever, they weren’t treated appropriately or something. I imagine that’s the same with the service aspect, some people will have more connections than others or more ideas of how to do things, do it more efficiently, whatever it might be. I mean the individual factor there will certainly also be a facilitator or create barriers.**

P2: Well Age UK have got to be funded, haven’t they?

**I1: Yes.**

***I2: I think maybe a question is, so we worked a lot with Age UK Salford and they are really great. I think the question is okay, it’s good for people having access to them but it’s a lot of work also, as you say [P44], to have this confidence and people living with dementia and their care givers being confident enough to have access to the services. We are also thinking to this other people may be having no connection at all or just looking at this flyer for Age UK Salford and thinking, “Oh no, it’s not for me. I don’t have dementia.” It’s also that but it’s related probably more with stigma and awareness about dementia and these kind of things.***

**I1: Yes. Just looking at the chat, [P44] said that she doesn’t think that an app is the answer because so many older people don’t like using apps or don’t trust, they need to trust in the person so that’s for sure. [P46], said my organisation is at the early stages of scoping social prescribing for the Caribbean and African community. That’s really great to hear. What else can social prescribing include? Shall we try and brainstorm this? Are there a set of criteria or does it entirely depend? Does anybody know about social prescribing? How does it work? Is it a science or is it…?**

P43: Yes. Sorry, go on, [P44].

P44: I mean I think this word is banded around a lot but is it actually there and does any money following the prescribing because otherwise it’s a joke. I mean we’ve got to remember, this is all in the context of community based support for people with dementia being appalling, well just not funded, it’s just not there in most areas. The only reason my charity does something is because we managed to have funding from the Lottery and so on. So social prescribing, it’s got to be really clear if it comes with money but it doesn’t yet. It’s just directing people, signposting. It’s a fancy word for signposting people to something but the something has to be secure and funded to carry on for more than six months I think because sometimes projects… Manchester Camerata do wonderful stuff. I love their work but it tends to be short term projects. That might be fine, somebody does music making for three months and then it stops but I think there needs to be something else then they can go on to after that. So there just needs to be proper funding of these activities, in my opinion.

**I1: Yes, I think so. [P2]?**

P2: I’ll just agree with what [P44]’s just said. I think [P43]… I’ve lost track. What I was going to say is that I think they just signpost you and that’s it, that’s the direction you’re going in and if you get lost, don’t come back. If it’s not for you, don’t come back for an alternative or another idea. My limited knowledge of it is, I’m on [A COMMITTEE] for Oldham and they’re doing a mental health thing at the moment and that’s been cancelled for tomorrow because of COVID for some reason, that’s on Zoom. Oldham has been split up into five hubs and the hub managers are there and they’re supposed to be delivering the same thing throughout Oldham and they don’t agree with one another, the debates I’ve been involved with. So (unclear 01:00:02) are going to do and they’re under the guidance of these hub managers or the responsibility of them, as I understand it, haven’t got a clue what’s going to happen.

**I1: Sorry, I couldn’t hear the last bit, you haven’t got a clue?**

P2: No, it sounds good but what are they doing? What’s the job description? What are the KPIs? How do you measure the success? I have criticisms of it, genuine criticisms. I personally believe it will be all talk and (unclear 01:00:32) and you’ve got one social prescriber for how many people. Negative, aren’t I? Sorry.

**I1: I mean the idea of referral from the memory service and then the social prescribing I think sounds a really good idea because it’s the one thing we know helps people to stay mentally, emotionally happy and also keep up cognitive skills. The worst thing is to just be stuck at home. I think we’ve noticed it all during the last year or two while we’ve been working from home. The idea of that follow-up is where does it start and where’s that follow-up and what does it actually include. What social tasks are being prescribed? For some people it may be green prescribing but for others it may be something else, music or one of these other things. It’s that repertoire that’s actually matched to a condition or is it just… has somebody done some research into this? Are there some foundations for this? Do we know? Is that a new question we should investigate?**

P43: Not that I’m aware of. I think that the model… obviously as I say, social prescribing is probably not the right term and I know there’s work in Greater Manchester to move away from that language of again someone prescribing someone something, that medical term doesn’t support the outcome essentially. I think the idea that we need to move towards is that every contact counts kind of approach. So whoever within the profession or whoever that comes into contact with someone with dementia to support them can have a conversation around what kind of things do you enjoy. What matters to you essentially? Those kind of motivational interviewing approaches around trying to understand the person so that you can then have a conversation about what type of activities, whether that be a physical activity or a knitting group or whatever that might be so no matter who, should be able to have that conversation with someone. So whether that be the GP or whoever that might be, it’s ideally the approach that we want to go down.

As [P44] mentioned, the social prescribing network isn’t funded well enough and it differs massively across each of the ten localities. In some areas it works really well, others it doesn’t. So again, it’s that postcode lottery of the kind of support you would get depends on where you currently live in Greater Manchester.

**I1: That sounds a really interesting avenue to think about those lines but also it’s created a few more questions, absolutely. Any other comments, thoughts? What else or have we reached a natural conclusion to the meeting today, an early conclusion? Maybe we’re all a little bit tired ahead of Christmas. Any comments? No?**

P44: Sorry. I think probably [P2] and I have been a little bit cynical but I think that is because it’s a bit tiring when you’re doing the sort of work we’re doing when there has been such slow progress. Having said all of that, I mean it’s a really good idea to be trying to make it easier for people to see how they can get actively involved with things and to bring the opportunities to their attention. So I think the aims are really good, I just think for me it’s just about it’s a big task, so not easy to do and to reach the people that really, really need it, there will always be the most able people can find things and can drive there to get there relative to something and some of the people that need it most, the most isolated people won’t have a clue what’s going on because they haven’t got that support. So it’s just a big challenge. I realise I’ve been a bit negative but I just think it’s not easy to do. It definitely needs buy-in from commissioners and mental health professionals, that they really get it and it’s not just about them and the mental health services.

Positive images, we could do with a poster campaign of positive images of people living well with dementia, with bold statements about since I’ve been diagnosed I’ve got a new group of friends, I’ve been out walking every week. There are positives out there, they just need to be shown off to people.

**I1: Excellent, I like that last part. I’ve got a PhD student, she’s looking at mental health components not for people with mental health issues but for the general public, to reduce stigma. So she’s looking at exactly that. We’ll have to tell her that you brought this up. Yes, absolutely, I think that’s really important but no, I don’t think you’ve been cynical at all. I agree, I mean it’s always incredibly frustrating because these things, as soon as they’re complex, they are incredibly difficult to progress and tend to be terribly slow, especially now under COVID, everything seems to have regressed in some way or another. Sorry, what was that? Yes, positive images I think is really good. Thinking about what opportunities there are and bringing them altogether, I wonder whether we should try and collect a few more through the session or whether this is something, [I2], perhaps for your survey to do but we can discuss that later. Sorry, [P2]?**

P2: Can I just make a comment? I agree totally with what [P44] said previously. We’ve been talking a lot today about people being diagnosed with dementia and the carers, people diagnosed with dementia who have no carers and they will lead a different life, no support, depending on the type of dementia they’ve been diagnosed with and the level they’re at when they’re diagnosed.

**I1: Yes. So that’s where volunteers could come in as well potentially. I mean that point has been made a few times, that people who don’t have… I realise I’m still sharing. It’s probably much nicer to just see each other. I think that’s a really great point because a lot of the time we’re thinking of people having support but all those people who don’t have that close support, they might have a friend or they might have perhaps somebody in the wider family but then they might not because maybe their family is abroad or their friends have all died, these things happen especially as people grow older, they grow more isolated because of just natural reasons.**

P2: [P44] may agree with me but I think from my experience, people lose friends when they’re diagnosed with dementia, not gain them.

**I: Yes, absolutely. I think you mentioned a friends network, was that you, [P44], earlier?**

P44: No. Maybe just with what [P2]’s saying, undoubtedly people lose some of their former friends but for some people, I’m sure when people come to Springboard they gain a new group of friends which they’re really pleased about it. So I think it can work both ways.

P2: They become peer friends, don’t they?

P44: Yes.

***I2: We had that in our workshop the last time, it was a dementia café at Age UK Salford and they said it was maybe the only one good thing with dementia that at least now we have good friends and a very good friendship and it’s very important for us. There’s still some care givers coming even if their loved ones are not here anymore and so it’s very important for them to have this time together.***

**I1: Yes. They help looking after some of the others who perhaps don’t have that care and support within their family. We certainly had one in the group that I was looking after. Are there any other particular things, [P46] for example in your area that you might think would need to be considered?**

P46: Well I think there have been various conversations, [P44] has raised some of those crucial points. If anything comes up I will share with you.

**I1: That’s great, thank you. Excellent. So is there anything in terms of particular services or offers currently that we should be aware of and that perhaps we haven’t yet touched on?**

P46: [P44], just checking that you plugged into the work with Dementia United.

P44: Yes. Sorry, [P46], what was the question?

P46: No. I was asking if there’s any new intelligence from the Dementia United stuff.

P44: Not really. I mean you might be aware there is a training package being commissioned to get some training materials out there, to encourage people in the community to be more open and to make their services and activities more accessible to people with dementia. That’s something that’s going to be produced by the end of next March. Dementia United have part funded that project to make that training. That’s all I’m aware of.

**I1: Okay. That’s something for us definitely to keep in mind and watch out for when it comes out. That will be good.**

P6: I’ve just got one thing to say. So we’ve been doing walks at the [LOCAL PARK] for the last few months, well since January, and the December walk was originally going to be the end because it’s the end of our funding but again, going back to that funding issue, but as part of City of Trees, we are passionate about dementia work and I know that our director, [NAME], she’s done a lot of work for dementia studies in the past and it’s something that we’re really trying to get a lot more work done. So despite the funding coming to an end this month, we are going to be able to carry them on for as long as possible really. So it’s going to be a core part of the City of Trees initiative is to be able to work on these walks. At the moment it’s specifically just at the [PARK] in Manchester but again, these Bolton walks are still going ahead and then hopefully if other localities get in touch with us. I know it’s a big development phase for us right now. We’ve got these walks in Manchester carrying on which is really great.

**I1: Yes, excellent.**

***I2: But we were speaking about people being isolated and I think I was there sometimes at your walks and it’s really great but usually it’s a person with dementia and a care giver usually there as doctor or something like that. So I don’t know, we were speaking about volunteering so maybe it would be great to have this support, someone coming with… if the person is living alone, maybe it will be a possibility to have someone having this link with a person, this confidence and think, “Okay, maybe we can try this work or these things,” because it’s really great. I really like them.***

P44: We’ve got some money starting next year to deploy a volunteer coordinator with the idea of being able to take on, well try and recruit and manage more volunteers to do a project called Together At Home. So that will be the more individualised stuff because there’s many people who don’t want to come to our groups. But if we can get more volunteers and if they can be really carefully managed, it’s not easy doing stuff one to one, it’s more risky for volunteers, it’s a big responsibility, then we can enable people to access more of those sort of things. I mean I love what City of Trees do, it’s brilliant but there isn’t always the capacity for us to help the single people to get there.

**I1: Yes. So quite a complex picture so we’ll try and hopefully visualise some of that for our next meeting, to bring together what these ideas were and how we can group them and perhaps see what picture emerges from that so that we can then see what might be the potential avenues and where might we make links and connections to enable chipping away at providing more support for people with dementia in this way. I think some of the key is around volunteering, to enable individuals but also potentially encouraging people with dementia to become volunteers, whether it’s in a choir or in a knitting circle or whatever it is and to take all these good opportunities and good ideas that exist, to bring them together to allow people to access them if that’s where their interest lies. I think that sounds really great. So I know, [P43], you’ve got to leave shortly so that was great. Are there any further comments? [P2], did you want to say anything more?**

P2: No, I think I’ve said enough. I’m not saying that in a negative way. There’s a lot has been said and I’m sure you’ve got enough in your bag to sort out.

**[End of Recording]**