**WORK PACKAGE 2 – SESSION 2**

**Focus group with stakeholders**

**10th January 2022**

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

**Duration: 00:56:00**

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

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

P40: = Stakeholder

P41: = Stakeholder

P42: = Stakeholder

(Started at 00:00:12)

**I1: …access for people and support. Does that make sense?**

P40: Just a quick one, is my video still not working?

**I1: Your video is working.**

P40: I’m on screen now?

***I2: Yes.***

**I1: Yes, you are on screen. It’s just because I’m sharing the screen, you can’t see all of this. So actually, what I’ll do, I think I’ll unshare now so that we can see each other properly and I’ll hand back over to [I2] to get the discussion going or maybe you are sitting ready in your starting blocks to say something about what you’ve just heard, some ideas.**

P40: I’m happy to, now I know my camera is working, a lot of what you’ve touched on we do by default. It wasn’t specifically designed as a dementia service, it’s always been built on capabilities so people were always defined on the things they can do, not the things they can’t. In terms of having a social calendar of events that is online but also we have a paper version, it goes out to members. So every month they get a paper version. We haven’t done parachuting but we’ve done hot air ballooning, indoor sky diving, abseiling down Rochdale town hall clock. All of those events are open to anybody, anybody over 50, irrespective of condition. So almost by default, we have the framework of what you’ve pretty much described. We have transport. We run a volunteer driver service which brings people to the events or to hospital appointments, doctors. So we’ve got a lot of I think what you described sat there oven ready.

**I1: Okay, great.**

***I2: Yes, indeed we spoke about people living with dementia but they also say something very important for them is inclusiveness but they are not necessarily looking for dementia friendly or dementia services. So they are very happy with these kind of services, very inclusive and accessible. So we are interested in activities (unclear 00:14:31) and how also we can increase access to these things. So thanks a lot [P40] I think, [P41], you had a suggestion.***

P41: Yes, it’s probably just to touch on what [P40] has said but then also coming in on that question, that first one around brainstorming, what opportunities are there for people in Greater Manchester living with dementia. It’s probably a philosophical point that I’m going to make here but in our estimations and where we’re coming from, it’s more a case of, and it’s building on what [P40] said around capabilities, it’s not that there’s things out there specifically for them to do, it’s that we would convey and get behind a message that anything that we promote or put forward should be open to somebody living with dementia full stop. So that really broadens the pot. That’s not the silver bullet. I’m not calling it the silver bullet but that’s my overall answer. It’s philosophical, maybe a bit aspirational as well but I think it’s a valid point to make and it’s around maybe an education of or turning groups and organisations heads to the involvement of people living with dementia rather than maybe the other way round.

To maybe turn their heads and their understanding and put it forward in such a way that there should really be a recognition that somebody in that position can bring lots of things to your group or organisation in terms of lived experience, also from a quality and diversity angle as well and a whole raft of other things. Don’t worry though, I do have a list of suggestions for stuff that are potentially specifically used for people with dementia but that’s my overarching point.

**I1: That sounds great, thank you.**

P42: I’d like to know, are you talking about volunteering opportunities once we’re out of this situation and things are more back to normal or are you talking about now, when we’re in this situation or both?

**I1: Both.**

P42: Both.

**I1: I presume you asked us rather than [P41]?**

P42: Yes.

**I1: I have a question actually, [P41], to follow up what you said. I was wondering, I mean you said philosophically it’s open to everybody over 50. Those services that you mentioned, do they accommodate in practice, not in philosophy, do you cater for lots of people with dementia?**

P41: Okay, so just to give you a bit of flavour. Our role as a volunteer centre is we don’t have roles with us specifically. We work with groups and organisations to offer what’s called brokerage. So if you were Age UK Manchester and you’ve got roles for your Home From Hospital service and you want to promote them and get them out there, you can do that via us as a promotion leg to what we do. But there is also that thing around us doing strategic development volunteering, cultivating quality or good volunteering opportunities, at whatever stage that might be. That might be when they’ve gone to market stage and are really active with recruiting. It might be a group or organisation that’s coming up with new roles. We have a role to play in terms of offering that kind of, I guess, input, guidance and a key thing around that is around bringing in people to your group or organisation that represents the communities that you serve. That might well be made up with people who have dementia. So our role in that is to influence, put forward those practical points and champion that they should make those reasonable and practical adjustments if a volunteer does apply for their roles, irrespective of what the scenario or what the situation surrounding that application is.

**I1: That sounds great. Sorry.**

P41: Then I guess the other thing is I guess coming in a bit on what [P42] said there around are we talking about volunteering, big V, or are we talking about something else which isn’t strictly speaking volunteering but it’s universal volunteering. So potentially what I’m hearing about is either it’s skills exchanges and when you showed that image of what people could do and what they’d like to get, straight away I’m in, I’m thinking about Timebanking here because that’s what that is and that looks like a tool that’s lifted from Timebanking UK materials which I’ve seen in terms of what I can do and what I want to get. Timebanking is not volunteering, it’s in the universe of but it’s obviously predicated on reciprocal exchange, isn’t it, if I give my time and take something back which is at odds with volunteering because volunteering, in the true extent of the word, is about giving your time freely with the outside objective of not getting something back in return for doing it. We know that you do but philosophically you don’t.

P42: I actually meant once we’re out of plan B and out of plan C and it’s much, much easier to volunteer completely out of lockdown, just to clarify.

**I1: Yes. I mean we’re in a development stage. These things don’t go very quickly anyway. It also means obviously we’re not trying to set up anything that’s entirely new because that would be reinventing the wheel, as [P41] and [P40] have just said, there are already plenty of things out there. It’s how we can help to connect some of the things that aren’t yet connected and to help with… so bring everything, work with everybody and with everything that’s already there to add that little piece of the jigsaw I suppose that is perhaps not yet connected which is why your involvement is so incredibly important because we know there’s lots and lots of fantastic things out there but at the same time, from the other side, we get lots of people say, “Well this is not out there,” or, “We don’t have access to it. It’s in another borough.” Particularly for people with early stage dementia, who very often don’t engage with dementia activities, they find it difficult or perhaps don’t have the courage. In a previous project that we ran with people with dementia, it was a European funded project where we did interviews with people in four countries, very often we got this feedback once people had the diagnosis they really lost confidence, they very often went into depression, it could be up to three years.**

**So people really got out of the habit of doing those kind of things. So how can we get people at this stage really to engage which is a conundrum because they don’t want to engage with dementia things but they don’t have the confidence without the support to engage or continue to engage with the normal things they do. So there is the group that hasn’t quite yet been catered for and we feel that we’re trying to reach possibly through that exchange service but obviously, as I say, there’s the conundrum that probably will be quite hard to crack. So that’s one of the things we’re also looking for to see how can we make sure that we get people involved in this.**

P40: I really do think that inclusion in existing rather than defining by condition has to be the way forward. Nobody would approve of a wheelchair only social event and they’re stuck in a corner but by definition, they’re in a mental wheelchair. Dementia impacts on different levels, doesn’t it, so the more we can keep within normal, almost normalises the condition and people become more… when you have a group and it’s their first interaction with somebody with dementia, it can be a little bit uncomfortable, “Literally I’ve just spoken to [A MAN] and he asked me the same question again.” But the next time that happens at the next event, it isn’t an issue anymore but if you segregate, it becomes them and us. I think if we can work on some sort of blended system, I think that’s a far better option.

**I1: I entirely agree with you there. I think the challenge is really how can we facilitate that seamless blended system so that’s part and parcel of what we’re trying to work out through this project. Do you want to say a little bit more? I mean you’ve reeled off quite a number of things earlier, [P40] of things that you’re already offering. I think I’ve captured hot air ballooning and indoor climbing.**

P40: Obviously every month we produce a social events calendar and that social events calendar has about 70 events. Within that, all the events are suggested by members so over time, somebody may have said, “I’ve been to this restaurant and it produced a really good meal and they’ll do a set price,” or they particular coffee morning, all the traditional things that you would associate with older people but we also encourage not just the things that you like to do but the things you’ve always wanted to do. So it is those, and they are extreme events and don’t get me wrong, those don’t happen week in, week out. They are the exception. So things like hot air ballooning, indoor sky diving, abseiling, go karting, flight simulator, those stand out because they’re unusual. But in saying that, we would all want to have a go.

**I1: Yes, definitely.**

P40: As long as the members have direction of travel if you will on the events, the participants have direction of travel on the events, then you get engagement. If you go with a pre-set agenda, I’m going to get everybody to go to the ballet because they should be going to the ballet, you’re just going to get pushback. There’s nothing wrong with it being an aspirational organisation but it’s got to be the aspiration of the membership, of the participant that has to drive it forward. So yes, every month we produce 70 events and they are a mix of regular, so it can be a coffee and catch up, it can be we have a garden, we have our version of a Men’s Sheds type thing but it can be a one-off event to a new venue, a new show. We were at the theatre last night. Each event has a host who is a volunteer predominantly and that person has some level of dementia friendly training. We’re not clinicians, even staff aren’t clinicians, if you get me but everybody is aware. It’s more of a watching brief, just check everybody is okay, they can get there okay, they can get home okay and they enjoy the event while they’re there. It’s a very simple system which works for us.

**I1: That sounds excellent. So did you say that was across all of Greater Manchester or the city?**

P40: No. Well we’re very big in Rochdale and then we’ve inched into Bury, into Oldham, into East Manchester. The aspiration of the organisation is to become GM, wider than national. We do have a version in Harringay in London. So that’s our development thing but it goes back to that capabilities approach of nobody is excluded and you’re not defined by a condition. It’s those simple, not mission statements but our ethos as an organisation.

**I1: Yes, absolutely. That’s fantastic. [P41], you said something earlier, can I remember this now? Yes, you talked about the volunteer centre. Can you say a little bit more about the volunteering and how it works?**

P2 So as it relates to the volunteer centre, yes. So I maybe tried to describe it before that there are a number of us pretty much across Greater Manchester. There’s certainly six recognised volunteer centres which are accredited, we’re one of them. You’ve also got them in Rochdale, Tameside and Oldham which are under the collective momentum of an organisation called Action Together. Then you’ve got them in Bolton and Salford as well but there are also volunteering brokers which offer fundamentally the same thing, which is helping people connect to volunteering opportunities in Bury, Wigan, Stockport and which one have I missed, Trafford as well. So fundamentally, yes, so I guess our work, there’s two distinct sides to it. So there’s the work we do with people who live in the city of Manchester or wherever those people live. That’s a really interesting conversation as well. It’s always been the case and I’ve always felt there’s that thing where we’re not the gatekeepers of volunteering in our city of Manchester. We’ve got lots of intelligence as it relates to what somebody could do in Manchester just by virtue of where we operate and work and then the fact that Manchester, I guess, it’s that vacuum in Greater Manchester, in the middle of it all.

But there’s that recognition that somebody in Bolton would very much wish to volunteer in Manchester and of course that’s absolutely fine. Even working out what looks like and I’ve always talked about it and I think that’s become even more acute as a result of COVID, given the rise of… it’s always been there but the idea of that distance, remote volunteering, being able to do that or lots of groups and organisation pivoting into it, the whole argument around I live in Bolton or volunteer in Bolton, it could be the case but actually, feasibly, you could volunteer anywhere, couldn’t you, at a distance, if you’re able to do it through tech and things like that. Anyway, our role is to help people, find volunteering opportunities and that’s based on helping them make the most informed choice they possibly can and then there’s a whole sliding scale of ways in which people engage with us. There’s people that will self-serve and we’ll never ever speak to them. They just access our knowledge or our database of opportunities that are currently registered with us on our website which is great.

But I would say that’s quite a shallow view of what we’ve got because there’s myself and our team in our head, we have that collective knowledge of everything else that you could tap into that maybe not on our website, it’s not appropriate to go on our website, it doesn’t quite fit, all that stuff. That’s built through years and years of connections and working with groups and organisations and building that up, either way. So going back to that sliding scale, somebody could also say, “Actually I need a bit of help to find my way here. I’m not sure what it is I want to do, where I want to do it, how often I want to do it,” and they, by bringing in those ideas around my preconceived ideas about having a long term health condition which maybe sometimes we often challenge that. So going back to what I said before around feasibly, we would say that anything on our site is open to somebody irrespective of their circumstances. But maybe that’s a message we try to convey and at that point, if that somebody wanted some help and support from us to find a good connection, that’s where we can be useful. So we do also dispense that information, advice and guidance to those individuals, whether that be through telephone calls, meetings, in group settings when we can do them, around an introduction to volunteering.

Then all of that stuff, all of that knowledge is clearly powered by the work that we do with those groups and organisations involve volunteers. We do that from a number of levels. We’ll receive somebody who wants to promote their roles, we’ll receive somebody that’s never involved volunteers before as an organisation and they’re building a volunteering programme. Whichever point you join, it’s on that cycle. We do convey all those things as it relates to good practice when it comes to involving volunteers, considerations, the legal aspects, anything that we can do to underline this idea of when they do put something into us or they put something out there and it’s recruiting volunteers, it’s of quality substance, style and it’s safe, it’s secure. They’re doing everything that we would expect them to do as it relates to involving volunteers. The time, energy, all that stuff is given freely in the volunteering relationship but we underline that you should absolutely act in the interests of doing all you can to support volunteers, make them feel valued, welcome, give them the tools, resources that they need and the ability to move on when the time is right. So that’s as it relates to volunteering and what the volunteer centre does. That’s a very, very whistle-stop view of what we do.

**I1: Absolutely. We’ll definitely have to go and check out the website in a little bit more detail and probably get back…**

P41: I’m happy to help.

**I1: …to you with questions. [P42]?**

P42: Yes. I’m curious to know when it comes to reasonable adjustment and volunteering opportunities, how is risk managed?

**I1: Is that a question to [P41]?**

P42: Well just to throw it out there really because if you’ve got an organisation that it has activities for volunteers which carry risk, there’s a certain degree of reasonable adjustment that you can make. However, there comes a point where you have to make an assessment on whether the activity just carries too much risk for somebody and depending on their stage of dementia, you’re going to have to make that judgement for yourself. So I’m curious how risk is managed there. Would you need to do a regular assessment of someone’s capability and then make your own value judgement as a volunteer manager or as a chief officer, as to whether or not that person is in a good place to deliver on that volunteering opportunity. If so, are there any templates that we can draw upon that will enable organisations to just do that, to make reasonable adjustment which is safe and risk managed?

P41: I think [P42]’s point there is a really good starting point to call it risk management because all too often we encounter risk aversion which is to avoid risk at all costs which I think actually [P42]’s principle there starting at risk management is a really, really good place to start from. I think maybe it is an education thing like I said earlier on, the ability for us to engage, inspire, attract groups and organisations that do, in our experience, want to make these adjustments, want to involve volunteers in the broadest sense that they possibly can. But maybe the starting points are a little bit difficult to navigate or to work through. So nothing is occurring to me in terms of any templates or resources or things but they will absolutely be out there. So this is going back to that unique position we have as well in what we do around volunteer management. So that’s, I guess, the other bit of what our volunteer centre does, certainly in Manchester, we recognise, harness and champion the uniqueness of what it is to be a volunteer manager as a profession just on one level. If you’re a volunteer manager, you tend to be managing substantially more than a paid member of staff who is managing paid staff at your organisation, quite often.

So yes, I would say that there is absolutely the tools and resources out there that allow that management. Again, it’s just something we would always convey and say management rather than an aversion. Again, we’ve applied that in the context of COVID, haven’t we, because going out the front door has that inherent risk attached to it right now, doesn’t it.

**I1: Absolutely.**

P42: Sorry, do you know where they are, [P41]? Do you have any pointers for us to go and find them? Are they in (unclear 00:34:42) or anywhere? Sorry, to interrupt, [I1].

P41: I suppose it’s just like (unclear 00:34:48), isn’t it, [P42], but yes, I could certainly dredge and I’ll probably find something that is a good example. I don’t know if you want to meet in the middle after this meeting and swap contact details.

**I1: That would be great also if you can share those with us. I mean obviously we’ve got various risk management within the university inevitably, getting students back and so on but I think there are probably different approaches to that.**

P41: I’ll take an action then.

**I1: So yes, if you want to share that with us, then we can pass it on as well, share with the group.**

***I2: If you send me an email, I can share it with the group because it’s really something very important is risk assessment because we want to be inclusive but indeed it’s still some specific risk and things to keep in mind.***

P42: For me, I think it would be really quite tough for a volunteer manager to have to keep pulling somebody in to do another assessment to make sure that their risk was managed well. I think that would be really, really emotionally difficult for someone to do but it would have to happen, I mean depending on what it is. But some of the roles that you were describing there, [P40] about hosting an event, I don’t think it would carry too much risk, would it, but I think it would be particularly challenging and so something that supports the manager of the volunteers there would need to be put in place. So I think it’s not just the volunteers manager, I think it’s whoever line manages them and makes sure they’re aware that this needs to be picked up and monitored too.

P40: So in terms of ourselves, we operate like a dynamic risk assessment so it’s almost event by event. So we know the venue of an event each time, so we’ve done a pre-visit. Part of the skill is to know the participant and to pick up on the hard information that you have but the softer stuff and to make that dynamic assessment as and when of an event. I think I touched on it, we went to the theatre last night. It was an old theatre and somebody who wanted to attend, we knew they wouldn’t be able to manage that venue so we can make that assessment because of the information. So it’s always about you can only make an assessment on information available so you’ve got to make sure you have as much knowledge and information to make the correct and informed decision and also track the behaviour and abilities and health of any particular individual and that’s with or without dementia.

P42: I was going to say so you’d need a communications framework, wouldn’t you, that supports that work to make sure that that rapid information can happen but it can be done informally and dynamically, like you’re saying, it’s not a constant piece of paperwork that everybody has to fill out and sign every time. It’s easy to do but it’s there.

P40: We have a CRM system which we’ve built ourselves so each individual who participates has a log. So if an incident has happened, if there’s a condition has happened, when they come to book on something, we can reference against that individual, whether it is… like I say, we have various levels of walks. We have strolls which are around a park for half an hour or a walk which might be up to four miles. I’m thinking of a particular individual who used to come on the walks but now isn’t capable but desperately wants to come on the walks but we have to make that assessment that it’s not practical for their own health and wellbeing to do that so we restrict them to the stroll. In terms of say somebody we know with dementia who is not in a couple would need support to attend an event and if support isn’t available, if they’re getting to an event, so we may go on a walking tour of the centre of Manchester. For that person to be able to get to Manchester safely to the place without support is impractical so we have to make that dynamic assessment on each particular event.

But that’s based on the knowledge garnered over the consultation with the member, the volunteer who is involved with that event, previous events, venue assessment. That sounds quite bureaucratic but it isn’t in effect because it’s a living, breathing, every day, put a little bit more information in about what’s gone on.

**I1: Yes, absolutely. That’s something that certainly with people with dementia, you have to have that update every so often to ensure that whatever activity you involve them in is appropriate and that they feel comfortable of it as much as an outsider as it were, care or other assessment. There is always, certainly with people with dementia, that discrepancy between what the person with dementia thinks they can do or want to do, not always, but quite often and what the carer can do or thinks they can do. The carer, quite often, is over protective. So it’s finding other… sometimes you get it the other way round that the person with dementia is so intimidated by their diagnosis that they feel they can’t do anything. We certainly had people saying that in our data collection in the beginning of our previous project and obviously the carer trying to get them to engage more. So you get both ways round but I think the majority of times you do actually get people with dementia, once they’ve got over the… perhaps it’s a time thing after diagnosis. I think it’s more that people feel like they can’t do very much and once they’ve slowly got used to it, they feel they can do things but carers get more risk averse.**

**So it’s managing that relationship as well. Also, we always think about people with dementia as having a care partner but of course they often don’t. So if they are alone then that is an entirely different thing as well, especially people with early onset as opposed to somebody maybe a year ago or so and that can be quite different if, for example, an activity is required to have somebody else accompany them, a family member or something, they might not have a family member so it might have to be a friend or in fact a volunteer to support them to do that. [P42]?**

P42: Yes, absolutely. I think that’s why this is so important because what we found is, in our investigation, the report is called Beyond The Diagnosis if you want to have a look at it, people with young onset dementia are just referred to activities which are supposed to be stimulating in keeping their minds active, that are geared up for people in much later life. There’s a 20 year gap sometimes. So they go to these activities and they’re just not suitable for them. So this volunteering opportunity is just wonderful. I mean it’s so good to hear that this is happening, which is why I’m here today. I’m fascinated by it. Sorry [P41].

P41: No, not at all. We both put our hands up, [P42], so no, you’re right to jump in there. I don’t know where it quite sits in but it’s just this thing that’s rattling around in my head is it relates to an individual taking it upon themselves, feel, “I want to do some volunteering. I want to be giving of my time,” whatever we’re calling it and as it relates to that person who’s managing that relationship or that deployment or getting it going if you like and thinking about how that can be undertaken as it relates to the risk and that dynamic approach to doing things, having that thing that’s always talked about. But I suppose you’ve also got that thing that’s inherently the right of that individual, let’s talk about somebody who has dementia here, and that perception of themselves and how (unclear 00:43:47), how much it impacts on their lives. It might not even be disclosed or a thing at the point of getting involved in some sort of volunteering. So I guess that’s just what I was just trying to offer today. It might not be something that’s actively disclosed. It might not be the driver for any of this. I guess that’s quite important to consider as well, isn’t it?

But maybe, I guess, as it relates to having organisations and groups that are involving volunteers in the broadest sense they possibly can as it relates to their equality, diversity, whatever you want to call it, cultivating a culture and a safe environment where actually that individual, perhaps if it does deteriorate or things become more acute, the ability for them to be able to speak up about that, have that honest, frank conversation. Let’s say it was the volunteering that they’re doing, a specific role and perhaps they’re starting to feel that their diagnosis is having an impact on their ability to do that role, the ability through a volunteer manager which is doing that supervision, that checking in, cultivating that environment where they can say, “Actually, I’ve not told you this before,” and then the conversation starts from there. That’s where maybe then this suite of things around those dynamic risk assessments, doing things that are proportionate to the risk, maybe make you think is it in line with anything that individual has if they’re going to regular appointments or they have a regular check-up as it relates to their condition and any changes as a result, making those things fall in line with that volunteering that they’re doing and stuff like that. But it relies on the individual experience, the perception and that right of the person, doesn’t it, to disclose and share that stuff.

**I1: Yes, I think… sorry, [P42], did you want to respond to that? I think you’ve both touched on something that’s really important here because it is that, on the one hand, the diagnosis and being referred but on the other hand it’s almost that link between what you’ve both said. That seems to be the thing where perhaps what we’re trying to do could be positioned and to try and work with people as they get referred to what is it actually they want and what are their skills. I mean we have people saying for example, “I like to knit but I have no…” it doesn’t have to be something dangerous, it can be just something, they like to knit but they don’t feel that they have an outlet. We could connect them to a charity where they can actually give their knitted things to and they can sell them for a little or they just get a card or something back as a thank you. We had people saying, “I like to cook but nobody to share,” so we had a volunteer sharing with them the cooking to actually make it safer and give them social… so I think there’s some really great opportunities there.**

**It’s perhaps figuring out how can we get people to tell us what they really, at the point of the diagnosis, maybe that’s where it needs to be positioned, really looking at what are their skills, what are their likes and then trying to connect them to the existing volunteer programmes to tailor something. [P41]?**

P41: Yes, I think that’s a good point and maybe that’s a principle embedded into this because that’s certainly, in our experience, irrespective when we receive individuals, like I said, that sliding scale of different experiences that we engage with, those self-service, those that come to us who have simply no idea what it is they want to do, they just inherently know they want to do it. I think what you said there, and you introduced the concept in the slides that you shared, it feels like those are the strength based conversations I think we call them, don’t we, in certain circles and things like that and we do that every day when somebody comes to us and they’ll go, “I want to volunteer but I’ve not really got anything to give.” Then our role in that is to say, “Well you’ve shared with us and disclosed in the context of our conversation that you’re a mother and you’ve had to get three kids to school on time for the past three years and you’ve had to feed them and bathe them and look after them. That inherently has a serious number of skills and attributes attached to it.” That’s a really good starting point in terms of plugging people into stuff. I think that’s maybe a pillar of all this or a principle on the pathway to whatever you come up with. It’s a good one.

**I1: That sounds great having those strength based discussions and how we could, as a bridge between the diagnosis part and the volunteering part being available and seeing how that can then be made possible and to offer the right kind of support for people with dementia because as you say, it may not necessarily be disclosed in that context but if it can be disclosed outside of the context, because of stigma they might not want to disclose it but if we can work around that in some way by taking that outside of the actual volunteering service, that disclosure, that might be a way forward. Any other thoughts? I think we’ve already meandered into our second point which was about how to connect people with opportunities. I think we’ve already covered quite a lot of that including how can we make people potentially more actively involved by sharing their skills. I think what you’ve just said, [P41], there about the strength based working and getting people to understand that you do actually have strengths, is really good. But the other thing I think that’s also still one thing is once people do have a diagnosis, they feel that they don’t have anything to give, they might not look for these kind of things. They feel that they might not have an interest potentially, perhaps some skills but somehow they lack the energy to do that so that’s another thing I think we want to address but, [P40] first to you.**

P40: It was just touching on one of the big things that does stand out to me is having an event or an activity where, if somebody does have a partner, the partner can come along and they can engage in the activity without it feeling like they’re not just at a dementia café, they’re at a normal event so the partner can relax and have a good time. That’s as therapeutic to the person with dementia as it is to the partner. I think that’s an important thing to factor in, that if somebody does have a partner they’re a 24 hour carer but give them that window where they can come along, have a social activity that’s suitable for them both. It’s a great tool for everybody’s health and wellbeing.

**I1: Yes, absolutely.**

***I2: I think also during the workshop something that some people said, it was caregivers and the people living with dementia, they really enjoyed having activities together but maybe the carer would be happy to have a person checking on the people with dementia and giving them maybe time to enjoy the activity too or maybe having also someone to talk with. So doing the activity together but having some external people to support them and meeting new people and speaking with other people.***

**I1: Yes, that sounds great. [P42], did you want to say something?**

P42: I think you maybe need to do some work with the organisations and the people providing the opportunities as well, I mean maybe it’s just around reassuring them that actually… if you were to say to somebody when they were filling say an online web form about a volunteering opportunity, if there was a box you could tick that said is this opportunity open to people with dementia, highly unlikely someone is going to tick that. So before that happens, I think there’s some work around our volunteer coordinators, managers and the leaders for the organisations to say, “Actually it is doable, you can make a reasonable adjustment within your financial envelope and this is the tools and the tricks that you need to pull that off.” Then they’re far more likely to tick that box, aren’t they, they feel ready for it. So the capacity building would need to happen I think first as well.

**I1: Absolutely. [P42], I was also wondering, you mentioned… sorry, [P41], do you want to say something there?**

P41: No, it’s okay.

**I1: You said something earlier that set us off on this track of discussion about people being referred to, at diagnosis, these services but then they’re not being adequate support or offer or later stage activities. Can you say a little bit more about that point of the referral that you were thinking about, how that works and what… just starting to think about what would need to happen to have that strength based discussion at that point.**

P42: Well it’s people my age. It’s people in their 50s who are getting young onset dementia and then they’re being referred to reminiscing opportunities where people are talking about 40s and 50s and things and of course they weren’t born then or they don’t remember it. If I was reminiscing, updated to include the ‘60s, ‘70s and ‘80s then fine, that’s great. That stuff needs to happen and those services need to change accordingly. We have asked the mental health trust to do this and it’s not really got anywhere. So that’s what needs to happen there. Other than the actual NHS providing these opportunities and services, this is where the voluntary sector comes in, isn’t it. This is where the civil society steps up to the challenge and fills that gap and provides that probably really excellent, elegant professional model of helping people in this situation. That’s where I would see it occurring.

**I1: Yes. I think that’s a really good point. [P41], do you want to elaborate on that?**

P41: It was just on [P42]’s first point around educating, that thing around if you have an opportunity and you tick a box to say this is suitable for people with dementia. I think that’s where you’re really clear when you ask what your offer is in this regard, so whatever it is you come up with. I guess this is more of an offer than anything but we, and other volunteer centres all around Greater Manchester, we convene forums for people that manage volunteers. We call them volunteer coordinator forums in Manchester. They might be called volunteer manager networks or whatever. I don’t know if it helps you to build on your intelligence or richness of your information as it relates to the experiences of those people that are potentially going to be brokering this stuff that’s going to be coming up on this or connecting people into. It’s just an offer there that you can come and workshop this sort of stuff with that cohort of people as it relates to things like that. I guess the key question is how prepared are you to involve somebody, a volunteer who has dementia. That would be a really open and frank discussion about that. It would be really quite fascinating I think.

**I1: That would be absolutely fantastic. I’d like to take you up on that offer.**

P41: I am going to stick my email in the inbox for everyone on the call but obviously I know you guys have got it as the organisers but yes, do come back to me regarding that. Then I think the other thing is an observation maybe like a health warning as it relates to developing, and forgive me for the way this sounds, but developing yet another platform or a way with which people can find good and useful stuff to do. They’re ten a penny, they really are out there. We’re in that crowded market putting forward what we are. So I think it’s just that kind of health warning about what you put out there. Is it going to become yet and if it relates to the experience of a volunteer manager or something that’s involving people in good and useful stuff. Does it prevent them yet, another platform of dozens that are already out there. If you think about somebody in Manchester, if you’re a volunteer coordinator in Manchester, there’s potentially anything up to twelve different websites, key ones. There’s many more than that but key brokers of size, you see your opportunity twelve times over on other websites. That’s a substantial admin task onto itself.

**I1: We may not want to develop any website.**

P41: No. I’ve read in between the lines there.

**I1: But one of the things we’re trying to do with our design project, we’re trying to be open to figure out what we find to then identify what’s needed rather than saying, “We want to do this.” So I think what we’ve identified today is really interesting because it’s that interconnection between the scenario [P42]’s described and what you, [P41], and [P40] have described as scenarios. We can think about… that may not need a website but it may actually be designing that service, that invisible service that you don’t notice to the eye but it’s implemented a little bit at [P42]’s end and a little bit at your end, [P41], and [P40]that then enables that connection to happen. So it may not be visible as a (unclear 00:57:26) service but it may just be that little interconnecting piece that perhaps isn’t just quite there yet. [P40]?**

P40: I thought [P42] made a really good point actually that like the reminiscent stuff, it’s set in a bizarre time warp. When we talk about circle, I always start with a question of in what year did the Sex Pistols play in Manchester Lesser Free Trade Hall? Does anybody know? Anybody want to guess?

P42: Is it ’77?

P41: ’77 yes.

P40: It was 1976 so you’re not far off. In parallel to that, the average age of a person who attends a concert is 27. A 27-year-old who attended that Sex Pistols concert is 72. They don’t want Vera Lynn. They have no memory or knowledge of Vera Lynn or that early post-war. Whoever designs it, you can go, “I’ve been to activities, dementia friendly activities and we’ve built a front room from 1945,” you’d have to be 100 odd to actively remember that. The delivery needs to up its game and not be set in that 1948 Bevan era. I think when we design things, we have to design it for the people who are going to be using it.

**I1: Yes, absolutely. We’ll actually, well we’ll be launching a game from one of our previous projects. We’ve developed a board game for people with dementia. It’s targeted for those with early stage diagnosis. It’s about life story telling so it’s like a life story path going through the decades so it takes people from reminiscence to the present and actually to the future to enable them to think about the future because that’s very often where they feel they can’t do it so trying to give that. So fingers crossed we’ll get it launched in January. So yes, that made me think of, [P42], what you were saying, maybe we can use it at that point to try and figure out what people’s skills are or something like that. Any other comments, thoughts? You’re on mute, [P42].**

P42: No, it’s just thinking out loud. I was just thinking long term, whatever the model ends up looking like, I would love to see this being adopted by statutory services as something that people would be referred into or if it was commissioned from a local provider even, that would be… I mean is that the long term goal?

**I1: Yes.**

P42: People with young onset dementia are supported better. I hope so.

**I1: Yes. I mean what we’re trying to do, this is a two-year European funded fellowship that [I2] is working on. So we’ve got another year to run, until mid-October next year. What we’re trying to do is have an iterative process of these workshops until… so we’ll continue into February/March with these. We’ll bring results from these groups back to… so hopefully we’ll have a second set of these workshops and I hope you’ll all come back to join us. So we’ve got another two workshops next week and we’ll collate all the results from that and come up with some ideas to discuss in the next round to then really go into detail, what are the right routes to go down. We’ve already started discussing some of that today so that was really helpful and I think really promising and then to look at how can we make this potentially happen. Ideally, if we can, we would like to simulate that service in a very down to earth, hands on, maybe just for a handful of people where we can work through what we think it should work like so that we have a proof of concept if you wish that we can then present to Greater Manchester Health Authority or whoever is the right person to present it to.**

**I’ve only been three years at Manchester and half of that during lockdown so I’m not that well connected. So I’m very happy if you want to suggest the right kind of place where we should present this or who we should contact to get interest to actually then get it implemented. So we’re hoping to get to a point where we have a proof of concept that we can then go to the right people in Manchester to say, “Look, we’ve done this. We’ve worked with all these groups of people from a wide range of health care and dementia care, dementia organisations, voluntary sector to develop this. This is what you all told us we need.” So we shape that little piece of the puzzle, here it is for implementation.**

P42: When you say Manchester, do you mean Greater Manchester?

**I1: Yes.**

P42: This trips us up all the time here. We get a lot of out of area calls. Yes, well just to let you know, we’re networked up as a ten health watch network across the piece, health watch in Greater Manchester. That’s one immediate place you could go to because we will have a representative at the Greater Manchester integrated care system. The new integrated care service is the locality board and then the partnership board and the commissioning board at GM. So I mean that would be an obvious place but there are probably other areas too. I think GMMH and also they do the west side, don’t they, of Greater Manchester.

**I1: Yes. So Age UK and some of the other providers. So the idea is then once we have run the simulation and have a really clear idea, to then do some result seminars to Health Watch, to Greater Manchester, to maybe the APPG, the right kind of people to say, “Look, this is what we can possibly do. How can we now implement it for real life?”**

P42: Yes. That’s the really hard part. That’s the really hard part.

**I1: Yes, we’re aware of that. So obviously we’ll try and get further funding and hopefully once we have that, there might be NIHR or [s.l. Nesta 01:05:07], there might be some other funders out there that can help us draw down money but obviously it’s… so it will be a mixture. I’m not saying it’s going to be easy but that’s the plan, yes. We’re obviously developing this to get it implemented. It’s not something that we want to stay on the shelf. Great. Have we reached a – I can’t even talk anymore – natural break or are there any other thoughts you might have, something that we have missed entirely, some things that you can think of? Excellent. I think that was a really useful, really helpful discussion. Hopefully not just for us but for you too. In which case, thank you very much for your time, for your input, it’s been really fantastic meeting you even though it’s only e-meeting. I think that’s been really rich information and really creative thinking around some of what’s happening. As we said, we’ll have another couple of workshops in the next week and then we’ll break up for Christmas and we’ll work through all the information that we’ve gathered.**

**Then we’ll set up some new workshops for February/March to work out how that service really should run. Then we’ll also discuss how can we do that simulation. So if you want to then be involved in the simulation, that would be fantastic, so that we can play through presumably, it probably might have to be run somehow from the diagnosis stage into getting somebody to a volunteer service and see what do we need to put in place, everything, risk management, all these kind of things but also the strengths, talking about people, what are their strengths, what are their skills, how can we do that best. So we can try and design that, I don’t want to say patient journey because we don’t want to regard them as patients at this point, a people journey.**

P42: Citizens.

**I1: Citizen journey, that’s good.**

**[End of Recording]**