**I-Can-Do Service project\_Stakeholders Co-design session 1 (alternative) -20231121\_transcript**

November 21, 2023, 2:07PM (1h 10m 15s)

Brief note about participants

S6: Service designer of dementia organisation

I1: Researcher from Manchester Metropolitan University

Cannot decipher = (unclear + time code)

Sounds like = [s.l. + time code]

|  |  |
| --- | --- |
| I1  0:07 | Perfect. So, thank you again for joining us in the case. So, I'll just call reconfirm your consent to participate in the ICanDo service project and in particular in this session. Uh. |
| S6  0:20 | Yes, I consent to both that joining the project and this the session file and to this being recorded, yeah. |
| I1  0:27 | Lovely. Thank you. So, I'll bring up our little PowerPoint just to give you more of an idea of what the I-Can-Do service at the moment looks like. There we go. Right. So, I've already given you a mini introductions that our project is. It's the ICanDo service and see to service is really… has been developed to help people with early-stage dementia in getting engaged in social participation in the community, in particular volunteering. And this current project is to develop this service for real world implementation. So, the starting point was that people after diagnosis said that they were often depressed, they lost contact with friends. They didn't feel that they could go out anymore as much and things like that, and it caused significant depression, and they're really wanted to stay socially connected and be able to make a contribution and feel valued. And it could be anything people said. As you know, small things like I like to cook, but I have nobody to share it with or I like to knit but nobody needs what I make or simply giving people directions on the street. Perhaps. So, with that in mind, we started in developing the service with a number of stakeholders, including people living with dementia. Of course, their care partners, staff from service providers including dementia organisations, researchers and designers. And out came a result of…I can’t quite remember now… 15 interviews, 5 focus groups and equally many Co-design groups we designed the ICanDo pathway booklet as the underpinning means to deliver the service. Before I go into the booklet so, the… to service was meant to sit, people get diagnosed through the year, the memory assessment services, and then go back to the GP or directly go to dementia charities. Sorry the ICanDo service was meant to be delivered through the wellbeing mentor sessions and they can be delivered by anybody who's, uh, dementia support worker or possibly a social prescriber. So, we designed a service to sit within the existing service landscape. Just to give you a little bit of an overview. So, it's not trying to design a completely new service, but utilising the skills and the contacts that already people already have. The activities that people already have. So, our little booklet, this is what it looks like from the outside. And in terms of the contents, it's delivered through three baseline sessions by the Wellbeing mentor… and those three sessions are about exploring strength and interests for the people with dementia. What do they really like doing? What skills do they think they have or had that they can draw on. Umm, the second session brings them together in a peer group or small number of peer people with dementia and the Volunteer services representative, who can introduce them to what's available in their local area, and so, that people can get an understanding of what's on offer. Perhaps things that they haven't yet thought about, but also, have the peer support to discuss in the group what they might like to do in response to that offer. And then the third session is a session where people with their dementia wellbeing mentor, ideally their carer and a person from the support from the volunteer service. We'll meet to then make a decision as to what one or two things there may be able to take forward and realise And um…this is the baseline 3 sessions that can be repeated as necessary.  We found that sometimes people need more information or more time to get more confidence in actually starting, and I can go through a little bit more in terms of the individual sessions. The way we structured those sessions is to each session has an ice breaker, either to relax for the first session. People might be a little bit nervous and so, there's a little mindfulness exercise to get people to relax and then a little exercise around objects that they bring or have with them and could be a piece of jewellery or little key ring or photograph or something they have a wallet to get to know each other. And then that leads into exploring strengths and interests around these four areas. What do I love? What am I good at? What does my community or those close to me need and what can I do or help with? And so, we're giving quite a number of examples and then and, uh, space for people to write in their own ideas. Finally, there's a short reflection on the session, so, that's about a one hour session, possibly 1 ½. But generally it could be done in a one hour session by the by the Wellbeing mentor.  Then as the group session that would be more of a 2 hour session where people again a bit of an ice breaker for people to get to know each other, find out what's on offer, explore together, what they each might want to do or possibly together and reflect on the session, including things like what people might recognise. Would like to get recognised for and then session three is more hands on, so, again a bit of a planner, some planner pages with an explanation of what should people should think about and then some empty planner pages to allow them to make decisions. And as I said, these sessions can be repeated as necessary So, we've trialled the service so, far with two people in the previous project. With two ladies with early stage dementia, one of whom, as a result went into volunteering for a while. And the other one could have benefited with one or two more sessions to pick up her carriage to do something. Umm. But basically both of them were very positive in terms of their feedback to having participated in the session. So, the sessions themselves help with wellbeing.  The other thing that came out of it, which our wellbeing mentor, which was [Name of wellbeing mentor], who's the dementia worker from [Name of dementia organisation in local area], observe, was the benefit of a digital version to help the Wellbeing mentor share any notes and decisions made with everybody involved.  So, in this brings us to our current project to think about what does the service needs generally, if we wanted to roll it out, umm, and then what? More specifically, does the development of a digital prototype need um and [I4] said earlier… We're hoping we're aiming to conduct in February, March, another trial of the service, hopefully with six people with dementia and their care partners. So, that's at where we're at so, today. are there any questions that you have until now? |
| S6  9:31 | No, no. I'm just making some notes as well, so, if I'm not looking up that's why not just… not just getting on with something else. |
| I1  9:36 | Yeah. OK. Good so. I can send you the slides if you want…want to slides. There's no problem. |
| S6  9:48 | So, yes, please. Yeah, that be great. Thank you. |
| I1  9:51 | Yeah. So, today we we'll have a little overview map after service as a problem for discussion to help us focus on different parts of the service delivery and implementation where, umm, at where your organisation not you know, but dementia organisation service… service and volunteer organizations could be involved and here you views about how you would promote and implement the service or any ideas about it, if it wasn't, you have best decide to directly.  so, and explore what types of support would be needed to deliver and facilitate the delivery of the service. Yes. And finally, hear your thoughts about the service. How we could be shared through digitization, but we can the yeah. So, here's the here's our little map. So, this is uhm basically trying to just to give a little bit of an overview of how that service would work, could work or has worked so, far in practice, although at the moment as we said just we've made some of those connections between volunteer organisations, dementia organisation. So, there's all of those. So, wht are the things that we now need to consider? So, at the moment it just works that the person with dementia was invited by the dementia organisation to participate in the service. They would allocate a wellbeing mentor. Then they attended the first session and attend the second session of the group session, then they've attended the third session…Uh…which was in our case not attended by the carer or carers. And it turned out that would have been something that was really important. So, we added that to our map here. Umm, but it was attended by the Volunteer organisation representatives. So, this is how awesome basic map, and then we have a few kind of questions around that, shall I keep the map up for you? Is that OK? |
| S6  12:19 | Yeah. Yes, that'd be brilliant. Thank you. |
| I1  12:22 | Umm, so, do you want to just have a minute to just look over it or? |
| S6  12:28 | Now I'm there. I'm with you. That's good. |
| I1  12:31 | Great. So, if the if the ICanDo service was already in was available. One of our questions is and [I4] chip in if I'm missing something, please. I can't see you now because of the shared screen. |
| I4  12:45 | OK. |
| I1  12:49 | Umm, how would you promote the ICanDo service to your clients? |
| S6  12:56 | So, I don't like to answer a question with a question, but I'm going to probably have to. |
| I1  13:02 | That's good. These are just discussion starters to. Just get us into… We can completely go off our questions. Umm. And just have a loose discussion. |
| S6  13:12 | We'll come back to it. I think promotion is a separate thing. I think the first thing for me is and I think, I mean this is great… the… the first thing that stands out to me is I suppose there's two aspects to it. As a dementia organisation, we have an infrastructure set up to support volunteers already. So, would this be something whereby we would then be recruiting people into an external volunteering scheme or is it something that could be incorporated and embedded into our organisation as a as a way of working and how we do things so that the scheme is almost run within our volunteering organisation. |
| I1  13:59 | Ohh, it absolutely could be. I mean, most of the time, we don't encounter that set up, but yes it would definitely be a possible one of the things that I haven't really… it's on the map, but I haven't really highlighted. This is that slightly bigger yellow box is one of the thoughts that we had in order to help people with dementia be more confident and have the support that they need.  They could also, once they start off, once they're ready for volunteering, there could be assigned a healthy volunteer, or health in terms of not having memory loss who can support them in their volunteering? Maybe in getting there or in something. So, if you already have a volunteer organisation just to throw that back at you, then you could use some of those volunteers also, to pair them. Basically, does that makes sense? |
| S6  15:04 | Yeah, I mean, we could even go one step earlier than that as well. And as well as part of that support. Is that just slightly earlier? Is that opportunity to shadow? So, like you were saying about the one of the participants could have done maybe with a couple of more sessions to kind of build that confidence actually is shadowing, could shadowing be a good way to build confidence for people with dementia that would like to volunteer? |
| I1  15:21 | Yes. Yeah, that's really nice that would be great. Yeah, that's a really great idea. Because also, it then builds up trust because that's one of the issues and we were talking also, one of the considerations involves how do you vet those volunteers in terms of being fed to support a person with dementia, if they're in an ordinary volunteer service. |
| S6  15:38 | And. Yes, yes. |
| I1  16:00 | Yeah. So, that that's great. Shadow. So, they could come in….Well, I suppose they can only come in once the person has decided what they actually would like to do, but once they know roughly what they're like to do after the second session, perhaps even before they make a choice, and they could already start just going through a session or two to just watch what people are doing and whether this is something they feel there would be capable of or confident or interested in doing. |
| S6  16:10 | Yeah. Yes, yes, I think because it might be a bit of trial and error. I'm just thinking of some other research that I'm involved in where it's what's coming out of the research as well was just around actually takes people time to find the right support in the same ways. It takes people time to find the right volunteering and some you're combining those needs and sometimes like what you think you might want to do isn't always the same because like depending on like as what you then end up doing sometimes as well. It's like your needs change and evolve over time, don't they? And ability capabilities and things so. |
| I1  16:52 | Yeah. So, we are thinking that the ICanDo service could be they could participate in it every maybe half year or something depending on their progression. They might need a reassessment or re-evaluation and don't worry I want to say I mean assessment about the re-evaluation every few months probably umm, so, they can then join one of those sessions. Again, think about, could be session one that it could have a one to one to think about. Is this still the right thing for me to do? How do I get on? Is this still the right thing to do and if they need to change if they want to change it in some way then they could go into session two again and then they could have another session three. So, in that sense it's quite flexible because these tend to be more or less one to one sessions. So, it's something that from [Name of dementia organisation in the local area], our experience is that the wellbeing mentor does do house calls, so, it could be done in a house call and as one of the things to do. Uhm, certainly the one the first one to one session, possibly the third session as well and the group session obviously has to be in the offices or one of the dementia groups or something. |
| S6  18:41 | Yes. And in terms of conversations I've had with people living with dementia as well in terms of, like, some people might want to volunteer at the dementia organisation. And we are set up to obviously to have people. The other is for example, and someones love and passion might be steam trains. So, therefore actually, they might want to volunteer for a steam train organisation, which are often charities as well. And so, would that be applicable to if someone to highlight that that's supporting them getting into the volunteering sector, how would it work, is it? |
| I1  19:30 | Yes, I mean it's really quite flexible and it's one of the things that we're trying to figure out. So, at the moment we've been obviously working with locals. The assumption was that it would be local volunteer service so, that people, if they're at very early stage, could possibly still walk too, whatever they're volunteering.  Uh, or else they obviously need support in getting wherever they need to be getting at so, it couldn't it…You know, if it's a weekly thing. And also, our monthly even still need to be able to get there in some way and need that support to get there. If it's not walkable, or possibly even if it's walkable, if they have issues with orientation so, but yeah, it could be flexible, so, it depends on…If they have an idea already, where they could go, then they could bring that to the volunteering organisation. The volunteering organisation could help with that contact. Through the scheme, So, all of these are possibilities. |
| S6  20:44 | Yes I was just thinking of, I mean, I was the other ones, I would like people's love for, for example, history, local National Trust houses (unclear + 20:50) and it's volunteers that do the… I'm just talking general in terms of the one thing that's coming out is that from a lot of our conversations is that people want to do something that they love doing, not do something with people that are considered to be either living with dementia or frail or older or, as in it's like they want to go to the seaside, their love is for stream trains or history or art or so. I could really see the value in this is then just me getting my head around how that then works and interlinks then so that people can get those opportunities within some of their passion and their wants, their love. Because then they're also getting to be with people that have the same interests rather than being grouped by their disease or their age or their condition. |
| I1  21:51 | Yes, I mean that is the idea of the service because umm, to get them out and get them into the normal community. And one of the reasons that we ended up with volunteer services was that actually when we had earlier research, we were talking to the volunteer services, and they were actually or somebody from volunteer service who was part of the initial folks group said that they in principle support of people with dementia. But didn't have very many, so, they needed support to cover for that and get the kind of have the contact, whereas but at the same time, there's umm, yeah. And dementia organisations needed to contact with the volunteer organisations.  So, there's something about the contact and the trust and a support system between those two organisations. I think that perhaps needs working out, so, I think all your questions that are really, really helpful guiding questions that we can start thinking about. So, bringing that back to what you said you were thinking about how it would work at [Name of the dementia organisation that S6 works for]. |
| I1  23:04 | Do you want to just think out loud a little bit how that you think it would work in the [Name of the dementia organisation that S6 works for]? |
| S6  23:07 | Yes. Yes, I think I think it's two kinds of the… it was a number of ways. So, I think one is to present my questions relating back to this question in a way, we’re not seeing it, but they are. So, I think one is that obviously… post diagnosis. I'm thinking we have our dementia advisors there, in contact with people. We also, have volunteers that run groups as well, and sometimes those groups are like singing for the brain. They're not for everyone, and my [PERSON I KNOW], he's just been he's going through dementia diagnosed at the moment and he thought he'd really like the singing ones and he didn't - completely the opposite. So, it's like, but actually [PERSON I KNOW] he wants to, he wants to do something. So, it's like I'm gonna talk through it. Sometimes it’s easier to talk through those live situations, so, at that point the volunteer could promote the scheme because there's an opportunity for someone to help, support him, find something else that he might like to do and I'm thinking whether that's volunteering or an activity thing that's really useful anyway. |
| I1  24:21 | Yes, I mean we, we've, focused on volunteering, but actually in many cases I think it won't be necessarily volunteering but more participation in external activities, individual activities. Whether that's singing or drawing, music or art in some way, or sports or gardening or any of the leisure activities that people like to do. And the idea is, if it's for volunteer service that it might also, you know… there might be that volunteer support in turn for them. But yeah, it might actually end up more being more participation than actual volunteering. |
| S6  25:04 | Or it might be that it starts off as volunteering and then goes into that participation, or there's lots of (unclear 25:07) which may be easier from a transition perspective as well in terms of different needs of and levels of involvement, and also, that kind of safeguarding piece as well then and so, I'm thinking that there's opportunities like through other groups that are ran and to promote it again. I'm thinking through dementia advisers in terms of the conversations that they will have around, so, forcing people to live with their condition, I think that we do have to consider as well that in terms of future proofing, that's a little bit too is that it is going to change from… the landscape will change and outcomes will hopefully change too with testing come biomarker testing and then new treatments coming as well. That people will be living well with the disease for longer, potentially with a diagnosis and therefore in terms of, often when people are getting a diagnosis now, as when they're symptoms are really starting to impact their life going forward in the future. Actually, it might be earlier, so, volunteering will become viable for more people potentially and as well as that you said participation, but the two are both voluntary somewhere and so, I think the dementia Advisor route is… if we were an organization, we'd like to promote it through that because the conversations can be had understanding someone's needs and wants and what their challenge is. It's helping people if they're feeling… they'll know if someone's feeling isolated and… cause equally it's important not to make people feel overwhelmed and like they should be doing more. Or and everyone else is doing more, and then after it's well known some of those emotional and aspects as well. I'm just thinking back to [SOMEONE ELSE I KNOW] response to volunteering when she was diagnosed and she said that she's spent many, many years working. Why would she want to go work for free now? That was because that was how it was trying to get her to engage with some community groups or some dates, centres and by volunteering and so, in the end I just had to say, look, can you come and help my friend out? She just needs some help today, so, I'm thinking that there are challenges too that it's not for everybody. |
| I1  27:50 | No, definitely not, we can never capture everybody, but we can try and provide something that enables, especially those at the early stages who want to remain independent and not go to those dementia cafe groups where they see the much later stages and that have a very specific program. But really want to do something, but maybe don't …you know they’re not able to work anymore because either they’re retired or they you know, or for reasons of the dementia… of memory loss. And it was quite interesting. I mean, there were two people, one within the trial that we did. She was desperate to get out of the house. She was very much cooped in by her spouse, and so, she was the one who eventually volunteered, and it was just simply a volunteer in the Dementia Cafe. So, it was not… not much extra work on all the safety aspects were done there but you know, but even there somebody needs to make the coffee and bring it to people and those kinds of things. So, she had a little bit of a task, which she was really very intelligent, and we had a Co-design session for this project on Tuesday, no sorry, Friday last week? And one of the participants had dementia. There she was also very focused on having a job. So, and again, when she seemed to be still under the impression of having to apply for jobs. So, when I asked her, she said, yeah, anything that she can do would be welcomed. So, there's lots of people that we've spoken to through our project that have voiced that kind of need to be able to go out and do things and participate in things. |
| S6  30:08 | Yes. Yeah. And I think it was exploring that as an it through, umm… like you said that what is coming out as people want to do something that they love doing or might be to help others. And it's like what it's there I think for as it's like actually through kind of dementia advise or volunteering services. So, through our services, we could promote, I have, I'm saying we will obviously… can't commences in the organisation, not the… not the decision back there. But you know, we could work through this type. Hypothetically, we could recruit people, work through conversations that we're already having and through our dementia advisers, through our support lines. Obviously we have and we sign post a lot from our website as well. So, where people are using digital resources and there will be people looking for very specific things like what to do with their time, it may be that they aren't... Like you said, they've had to retire early from a job because they're not able to do a particular aspect, but they're still very capable and able to work in other capacities, but they may not want paid work and so, they might want that reward, that volunteering can bring. And so, I think that they're really good opportunities to have conversations and they're probably in terms of the reach, it's the you've got passion and that could decide when it's the right time to approach something like that. And it's not necessarily like day one of diagnosis. That's a lot to offer people to come to terms with and understand around their condition. I think also, as well, the one thing I'm not seeing on here and I don't really have explored it as well, would be through social prescribers. |
| I1  31:58 | Yes. |
| 14  31:59 | Yeah. And I have a question about social prescribers. So, uh, because social prescribers are a person who can also, offer different type of choice of activities to people with memory loss problems. So, is there any way or anything that we have to be accredited by an organisation so, that they could recommend this service? or just any service… They think that it is good and they can do the referral. |
| S6  32:33 | So, it may vary from local authority to local authority, and I don't know where you were planning on testing this and whether it's gonna be in particular localities and that might be a good way to test it and then getting the some of the primary care networks involved then with their social prescribers to understand what they've got within and out of scope. But they will have all sorts of services on there from mens sheds to walking groups and…. depending on need and so I think that its bigger to explore those frameworks. It’s a while since I've worked with local authorities and healthcare systems around kind of so, social prescribing programmes, we did it for falls prevention. And in one of my previous consultancy roles people referred into things from exercise programmes through to other services that would help them with kind of finance things as well. So, I'm thinking from a social private prescribing perspective, if it's established and there's a clear structure and it's clear as to what a person support and duration as well on how it works then and obviously depending on the local authority or the local and prescribing network then. But there's no obvious reason as to why it shouldn't. It would. It's supporting what they're doing and what they're objectives are. I think the key thing is that some areas social prescribing stops at 65, other areas they carry on, but people with dementia could be younger than 65. And I think it fits with the ethos of social prescribing very well. That's ultimately it's the bar that empowerment keeping people active and social and they….But I think that's a really interesting area to explore the one that there's a pathway then for people and it's a form of social prescribing, isn't it, in essence. |
| I1  35:02 | It is absolutely yes, we we're have been thinking about that and we haven't yet worked with them, partly because of the well, the participant group, people with dementia that we're looking at specifically that they're not necessarily working with. There may do, but probably not exclusively. Although the service could be used by anybody that they're prescribing for but at the moment we're very much focused on people with dementia, because that's where we started off with. UM, but it could be broader. One of the questions I have around social prescribing is we did try and get somebody for our previous research project and we had problems in actually getting contact with somebody from social describing and I was wondering whether you'd be able to help with any contacts. |
| S6  36:00 | Yeah, we can certainly have a think about that. I'm just thinking in terms of where we've got work going on good relationships, where we've got to venture advisors in GP practices. That's probably a good place to start because we'll have existing relationships and I'm thinking as well that in terms of with the social prescribing piece, it's like you could still keep it purely for dementia. But because then it's like a route for them. If they've got a person living with dementia and it might be that some of the services that they normally refer to are restricted because of conditions. So, it's like actually, there's still a referral route then. So, I'm thinking it would be a really good one to explore it in this format you do it. I don't think you need to change it. I think it gives them an avenue that they could follow that they probably currently don't have. |
| I1  36:54 | Yeah, absolutely. And the way this is how we were trying to design a service so, that anybody in those kind of capacities, whether it's a dementia advisor or a memory advisor or a social prescriber, can take that service to then apply it basically. And at the moment, but as I say at the moment we have simply got this booklet and anybody could take the booklet. But all these connections around it that we've now discussed and all obviously they would have to do. So, there's a question is there's something that we can provide as part of the service? Umm. And to what extent should we provide these? It's like making that handshake….Between…Prescribers or dementia organisations and volunteer organisations, or possibly they're already existing. So, for some that may exist, like you said, some of yours exist, and the social prescribers will have lots of contacts. So, in some areas there will already exist and other areas they exist less so, or you know. So, there's all of those kind of things that we are thinking about, but also, then the sharing aspect of it in order to keep everybody on the same page and to keep people with dementia or other vulnerable people safe. |
| S6  38:35 | Yes. Yeah. Yeah. No, I'm sorry. I'm just thinking and…. |
| I1  38:44 | Sorry, I'm kind. Yeah, go on. Feel free to say anything you that comes to your mind. I'm just looking through our press and I think we took quite a few through that discussion already. |
| S6  39:04 | Yeah, that's good. That's always about this, isn't it? |
| I1  39:08 | Absolutely. |
| S6  39:08 | So, like you said it, I see this very much as it's a cycle as well, isn't it? It's like someone may already be volunteering. As well, so, actually could be used to help sustain that. |
| I1  39:30 | It's sure. Yeah. Yeah, certainly could. If we get that bit about the support volunteer right? |
| S6  39:37 | Yeah. So, in our… I… and it's a shame that it my colleague who was supposed to join on volunteering. |
| I1  39:46 | Yes. |
| S6  39:46 | And yes, it's a shame he's not here because he would have much more in-depth knowledge around volunteering and I wouldn't have, I hope. |
| I1  39:52 | No, it wasn't your colleague. It was somebody from [someone’s name]. Do [someone’s name] and? |
| S6  39:58 | Ah OK ohh. I was gonna say I. Yeah, I don't…I don't know why some…. obviously it's relevant for me because of the service design aspect, but I'm thinking it would have been great to involve someone from our odd volunteering team. |
| I1  40:12 | If you still want to bring them in the next session, please do so. |
| S6  40:17 | Yes, I'd love to. The reason for that is I just think that they could like then we have to. So, in terms of volunteering, they'll be able to say how we support our volunteers, kind of what they're and you know, we have everything from what this, what a person's volunteer with us, we treat them as not as the an employee obviously because we can't. But in the same way, there's many things that we can replicate that we can provide to employees as well as to volunteers to give them that support and infrastructure that communication and they will have a volunteering manager that's going to. But they can go to with any problems and challenges. So, I'm thinking something like this lends itself to if we're landing at how we enable volunteering to become more dementia friendly and more inclusive in that aspect. Actually, could this be something that could be piloted within volunteering and that infrastructure that already exists where there is support in place and there are we have people with dementia that are already volunteering, so, there's probably loads of learnings from that too.  And I'm just thinking one of my colleagues would be out to give you so, much information on that. This this part of the question around how we can support people in a volunteering environments with living with dementia. |
| I1  41:49 | That would be great if we could bring your colleague in as well still. |
| S6  42:00 | Right. I’ll write that down. So, I don't forget that. Excellent. Yeah, I'll, I'll speak to some people and see who's available. |
| I1  42:07 | Fab uh. Yeah, I think we talked a little bit about .... You've told us quite nicely about how you would implement the service, how it would work within the [Name of dementia organisation that S6 works for]. Umm. |
| S6  42:24 | One thing that has come out in other research and conversations and people's experiences is that sometimes people with dementia are not allowed to participate in something or for example, probably volunteer without a carer. But not everybody has a carer and that's the best person living alone with dementia then they're not. They're immediately blocked out and to someone might have a carer for that. Carer has work commitments or other commitments or need some respite and again that either, so, I suppose it's just what that infrastructure and those organizations can do to be able to support someone to volunteer or participate without the need of a carer as well. And I think that's just something just to bear in mind with organisations, is that, yeah, where there might be that kind of carte blanche there shouldn't be, but unfortunately there is. |
| I1  43:33 | Yes, this is something that came up in the first session that we had as well and that's actually a question I wanted to ask you because you might be able to tell us something more about that and that is if we were having a volunteer to support pass with dementia, so, they become their carer, they accompany them to the volunteering maybe or in some support capacity. What kind of training would we need to give them to be able to do that role and where could we give them that certificate as it were, so, that's another a question that has arisen from that idea really. |
| S6  44:22 | Yeah. And I think it depends on what it's doing. Again, we do have training that we provide to employees, but also, to volunteers. Ours is mainly the online training, but again there's probably other training that happens in person in localities. And I'm thinking that it's like it's such a big thing as an exit. Depends on what they're going to be doing, and therefore I suppose there's some of that is almost like a safeguarding framework in terms of what means to fall out of scope and what can fall in scope that can be safe for people that are volunteers and but also, then that in fact the clients as well, uh.  And then also, I think it's just that consideration of perhaps the transition from when a volunteer becomes a participant as well and what that looks like for me. And does that train the conditioning about conversations with some of the work that I did was also, on looking at how we could make workplaces more dementia friendly and support people stay in work for longer? And one of the… one of the challenges of around it is which doesn't mean it's the charge that can't be overcome is how you then manage when that person needs to have… you make adaptations and what those reasonable adjustments are and at what point then you know, do you then need to transition because a person can no longer…It's not safe or a person can no longer do the job that would they were due that they were doing and suddenly it would happen with volunteering. Actually, how do you help that transition and those difficult conversations when you need to then when that volunteering role might need to stop or change and how do you make those changes in the adjudgments? And I think there's a benefit as well because you could look at how that transition into participation happens because the person is used to the environment and the people and actually it might just be a different role that person was then taking. And I mean that's hopefully what you've seen in the research then tell you as well is how do you support the transition? |
| I1  46:46 | Yes. Yes, I mean, our research sadly doesn't cover that yet, we're not quite as far as that yet. But I think that's good to think ahead because it shows us all the ins and outs we need to look at.  But I would be thinking still. yeah. So, in terms of transition definitely, and that's why we're thinking of these volunteer session can, sorry do the wellbeing mentor session can be repeated over time and they become that discussion forum for the past with dementia, with their wellbeing mentor through their comfortable with who they trust hopefully. And to then also, be saying say I found this difficult now. Uh, there might not rationalise it in this way, but there might be unhappy about something. And then the wellbeing mentor can suggest another way forward. So, it's then in the gift of the wellbeing mentor, the managed that situation. Umm. |
| S6  47:55 | Yeah. Yeah. And I think it's because it it's ultimately it's like getting obviously it's different skills and stuff. But and yeah it it's possibly not that. A person may come to come to acknowledge themselves that they are having difficulties, and it might be the volunteers for even service users or within that and then it's just kind of then …just being aware that I mean it has to happen sometimes anyway for different reasons. But it's just making sure that everyone is equipped with those skills to be able to deal with that in a way that is respectful and considers the person's needs. And I'm just taking [THE PERSON I KNOW] in her head is still a [PROFFESSIONAL], but I wouldn't want to have to [DO HER JOB]. I know, and that's just an honest piece. That's like so, she said she'd probably still be very capable at [HER OLD JOB], but just think how control of [THE EQUIPMENT NEEDED] isn't that good just in terms of just thinking about that. Like that is just managing people, isn't it? So, that they're not suddenly dropped and let down and suddenly left feeling like they've lost something. |
| I1  49:11 | Yes. and that I hope the ongoing nature of the ICanDo service would enable it means the wellbeing mentor accompanies them because the wellbeing mentor is if they're of… especially if they're dementia worker they will accompany them anyway. So, they can make sure that they have good communication with the person. The regular communication with the person and their carer, if they have one, and Or… I'll call him now the volunteer partner and so, that the volunteer partners and they can keep tabs on as well and they can be part of those decision-making session and along the way as well to have some input and give some directions suggestions if necessary. So, hopefully that will work, but definitely that's something in the longer term, once we actually that would need a slightly longer-term project to actually do those sessions, get people into volunteering, observed them during the volunteering, get those volunteer partners. Uhm, in place, they obviously need to be. Presumed they would need to be better with the DBS check and would there be some other training that you would recommend? They would need to do some qualification of any kind of certificate or is there anything that is good practice or that's prescribed or? |
| S6  50:49 | I think that's they're good in terms of good practice there. That needs to be an induction to an organisation and that people know who they need to contact? What support is available? Are they enable and in what kind of benefits are available? Sometimes there's additional benefits that people think it's better. |
| I1  51:14 | I'm not talking about person with dementia. Now I'm talking about the volunteer who would support a person with dementia. |
| S6  51:17 | Yeah, OK. I was talking about the quality as in the person with dementia, yeah. |
| I1  51:24 | Yeah. So, I'm just I differentiating it now between the volunteer in the person with the dementia and the volunteer partner. I, as in the support person, a volunteer who supports them in volunteering. |
| S6  51:32 | Yeah. Yes. Yes. So, yeah, so, the volunteer. |
| I1  51:39 | Is that OK so, that we know who we're talking about? |
| S6  51:42 | They support them in volunteering, do they? Yeah. So, I mean, they would need to have an understanding of dementia and how it can impacts people, how it can you know… just in terms of… living with dementia. They're obviously going to need to be DBS checks and they really safeguarding processes in place as well. |
| I1  52:18 | And so, the understanding of dementia is that are there some courses that you would offer that the [Name of dementia organisation that S6 works for] would offer or maybe [Name of another dementia organisation]? I think offer something perhaps like that. |
| S6  52:27 | We have a variety of courses so, that help volunteers and other professionals understand. And how to you speak as well with people with dementia. And it's soft skills as well as kind of understanding around. |
| I1  52:53 | Yeah, I found that that's the most important aspect. I mean, [SOMEONE I KNOW] had dementia as well. So, I have first-hand experience. |
| S6  53:03 | Yeah, yeah, I think, I mean, again, I think in terms of volunteering team would be able to give you, they will have processes in place.  They'll have like processes, protocols umm. They would definitely be asked if you more in fact information on that kind of best practice because we obviously have volunteers that support people living dementia and there's a robust kind of support around that. And also, then that kind of like management structure as well in place for them and escalation and safeguarding et cetera, so. |
| I1  53:42 | Yeah, that would be really, really useful to hear about that as well. |
| S6  53:47 | Yeah, definitely. I will find someone for the next the next meeting. |
| I4  53:57 | Would you mind…I ask one question about training because I have looked through some dementia awareness training across the different website and is the content of those trainers more or less the same or they actually design for their own organisation only. |
| S6  54:22 | Yeah. So, I think they said anything from kind of dementia friends and that we have. So, that's kind of a high level one, but it's how we understand what the disease are of dementia, how they might present, how it might affect people as well. And I think also, very much not looking at how it's looking more and we focus a lot on what people are able to do rather than what they're not able to do. And I think then we're going to obviously deeper dives as well then for our volunteers. So, they're not, but that's around and we use those for external organisations as well. We've given access recently to our accelerator partners so when they were carrying out their interviews as well, they had a deeper understanding of the diseases, but also, then of living with the condition. |
| I4  55:13 | That's really good to know because when I read through some of the training offered by NHS, kind of not fit into the situations that we have now. |
| S6  55:24 | Yes, I could find out if we were able to share our training with you and we've done that for other partners, so, I can find out. |
| I1  55:36 | That would be great. |
| I4  55:37 | Thank you. |
| I1  55:40 | Yes. And then also, to safeguarding process that would need to be in place again, obviously it would be different if it was internal volunteers like you say, you already have a volunteer programme where people with dementia could volunteer. But also, though some of those volunteers could then become volunteer partners to support the people with dementia, well in volunteering. So, that's a bit recursive, but hope that makes sense. So, yes, any safeguarding process around that would be really helpful too because these would be the standards that the service would need to prescribe because at the moment we started off with the booklet and then we were thinking, OK, maybe we can be supported by an app that has the same content, but some people will still want the booklet but and possibly stripped down version of the booklet. But having that app that allows that keeping track, which is perhaps less for the person with dementia, also, some people are still very good at digital and they'd like digital and they will use it digitally. But, it's probably, I don't know what the percentage is of those who do and those who don't, but certainly for the communication between the dementia organisation, uh, the care partner under volunteer partner or volunteer organisation staff and I think probably digital communication would be uh a lot more helpful where we could then include some of those safeguarding processes through the app to ensure that certain things are being put in place.  Umm. So, it'd be really good to know what they should be, would you know? Could and should be to think about. What would the app need to what? Yeah. What would those processes be and how could they be reflected in the app to ensure that they're there? |
| S6  57:43 | Yeah. Yeah. No, and I I'll definitely be able to get some of from my volunteering team and hopefully come to that next session as well. I'll definitely ask the question and I'm sure someone would be able to give a lot more depth than I can and accuracy. |
| I1  57:58 | Yeah, brilliant. Excellent. I think that was really rich. |
| I4  58:06 | Yeah. |
| I1  58:08 | Yes, sorry, we have a few more questions around sharing information. |
| S6  58:15 | Ok |
| I1  58:16 | Obviously we're thinking about sharing this information in terms of safeguarding, also, to make sure that if the person with dementia is expected to be somewhere at 4:00 o'clock, then there's supposed to be there at 4:00 o'clock and in a particular occasion. So, how could information be shared digitally during the delivery of the service? So, are there any particular things you can think of between sharing between organisations, between wellbeing mentor and a person living with dementia and between the person living with dementia and their carers, friends, family and anybody who supports them? So, it's, it's that kind of thinking. Do you have any thoughts on that or? |
| S6  59:01 | I think obviously anything can be shared with consent. So, I think consent has got to be a big one there. I think it's worth exploring with people that are living with dementia about what they want and how they want it shared. Like I'm talking in terms of how other kind of services and assisted assistive technology approaches are and it's that the person with the diagnosis can choose a carer, for example, to be notified if they didn't answer their door. Or would have been like didn't have other door or didn't answer the phone or didn't…um So, I'm thinking in a similar way actually then that if there's a consent piece about who to contact if you don't turn up by the time you're supposed to and in the same way as sense of emergency. And I think it's then probably just around the like language and positioning of that because it's not to check up on them. It's just to make sure people are safe and healthy. Then some people might want that automated in some kind of way. And I mean you go anywhere with technology, can't you, I think. |
| I1  1:00:19 | Yeah, yeah, yeah. The IT could have the kind of process consent built in that once they had another session and they save it they bring it up and say, do you want to share this information with your wellbeing mentor or with your carer or your volunteer at partner or something? |
| S6  1:00:26 | Yeah. Yes. That beyond the field. And then I didn't. That makes that easier. I think other considerations just to kind of bring into it again are around appropriateness. That's the kind of opportunities that goes into the safeguarding. This section can change at night time, for example, and so, and obviously from a safety perspective. So, actually, considering the times of day that opportunities are the people to be involved and how you can then say, God, people getting to and from those volunteering opportunities because as an organisation when whilst we're not responsible for that the like our participants when we involve people living with dementia, we're responsible to them to a point. And so, in terms of like picking venues that are safe and locations that are safe, easily accessible and all of those other aspects that kind of go with that and there has to be a cut off though there has to be that kind of clarity of where the, the roles and responsibilities lie to. |
| I1  1:01:36 | Yeah. Yes, I think that's also, why it's this communication between the different parties in a dementia organisations, volunteer a provision at whether that's in the same house or not. The carer, care partner and the person with dementia. So, I think that is why the continuous communication is needed that that we think that app could provide. |
| S6  1:02:30 | Yeah, yeah. Communication, like you said, it's actually, if someone supposed to be somewhere at certain time. So, if someone is meeting them, train station to take them to the popular, it's volunteering opportunity. What happens if they're not there? And with whose responsibility is that? Is that the volunteers volunteering to support their volunteer or there's an emergency or It's, it's just again that goes back to ensuring that people are everybody involved is safe and kind of knows what their responsibility levels are as well. |
| I1  1:03:10 | Yes, yes, absolutely. So, I mean, at that point, if and when we're getting to that point, I'm sure we need to include legal into that. |
| S6  1:03:20 | Definitely. |
| I1  1:03:22 | To get not just to the language friendly. I don't think legal is known for that. I think we need to do that but to also, ensure that we're not promising anything or in a way that isn't acceptable. |
| S6  1:03:29 | Yes. Yes, and the whole team.  That hygiene things as well, just around that information governance and what can and can't be collected and shared. |
| I1  1:03:49 | Yeah. Quite. So, just backtracking a little bit. If [name of dementia that S6 works for] were delivering the service, if you're interested and what, what types of support we talked about the booklet we talked about an app. But is there anything else? Or is anything within those or anything beyond that you would think it would be required in terms of support to deliver the service?  Experience skills training with ohh you've covered quite a bit of that, haven't we? |
| S6  1:04:26 | Yeah, I was thinking that it's like the skills and that’s abit of safeguarding kind of. It's the framework and if I if I put my head on my hat on, is the trustee of a smaller charity. It's kind of like, yeah, you probably want the framework as to how to safeguard your…. What that potentially needs to look like and consent. Obviously you have to make it unique to your own organisation, but some guidance on that, I think it's obviously it is training to ensure that people have the knowledge and the empathy and the skills. You said you've got the booklet, the kind of tool kit is to conversations to have umm. Yeah, I think we've covered most of the aspects that I should have. |
| I4  1:05:26 | Umm, but I have a question back to the sharing of information, if the service was referred by the advisor, the memory loss advisor or the post diagnostic advisor, do you need to do the documentations about how these sessions going on and do you want the platform to match with the systems that you already use in your organisations? |
| S6  1:05:58 | There I would probably say yes, it's would be, yeah. |
| I1  1:06:01 | That's an easy answer, isn't it? Right. In which case, what systems are you using? |
| S6  1:06:05 | I don't know the one. |
| I1  1:06:09 | This is the question that the company partners will ask. |
| S6  1:06:14 | I think we will need to ask my colleague that in terms of how that should work I and I will. I mean it’s the same as you could ask did would we need too? And there's other ways. There's always ways there's and it might be that it's a link from a system. It might be that it's them to a secure like or something. So, it doesn't need to fully integrate now. Does there need to be some easy way to be able to do it? Yes. If you're asking GP's and social prescribing, they will definitely say yes or you'll be looking at like EMIS and probably is that and system one has the main two within GP practices. |
| I1  1:06:59 | It's called emus. Is it? |
| S6  1:07:01 | Yes, EMIS and yeah. |
| I1  1:07:05 | OK. Yeah, I’m. I’m sure Reason. Digital, who I am working with on the project, will know that. They have worked with other projects with people with Dementia and Parkinson's as well. So, that's one of the reasons why we chose them, because they have quite umm, but it does seem to be quite a nice company and quite a good track record. |
| S6  1:07:28 | Excellent. But there's always ways to do through that like API that so, that they don't have to fully integrate. Those can actually then securely exchange information, and that's done good in the NHS as well, so. |
| I1  1:07:43 | Yeah, I don't really know very much about that, to be honest. But we'll need that back. |
| S6  1:07:52 | Technology is never usually the issue, and there's always usually a solution for technology. |
| I1  1:07:58 | Yeah. Good. Good. Is there anything else? I think we've covered big wide ground and it's been really terrific. Is there anything else you can still think of that we haven't covered that. You want to say or anything that you want to ask. |
| S6  1:08:16 | No, no, I think it's, it's a really great concept and I think that my colleagues and volunteering will be out to add like another level of richness to the information and just in terms of being able to share that would be I think it would really, really be beneficial for you to just have their knowledge. |
| I1  1:08:27 | Fabulous. Yeah. I think if you can put us in touch, we'll find some time to do another session just like that. It can just be one to one, and because it's such rich information and it reveals how much more there is to developing the service that perhaps we haven't yet considered. |
| S6  1:08:57 | But yes, yeah. No, definitely there after this. Once you open that, can the worms come out and? |
| I1  1:09:01 | And Ohh, and we kind of knew that there was, but this project is there to bring it all up so, that we can then shape and say we need this, this, this and this package to make it all work and then hopefully we'll get some follow on funding too. |