**IDO SERVICE – WORK PACKAGE ONE**

**INDIVIDUAL INTERVIEW 12**

**WITH P18 & P13**

**2nd July 2021**

Audio File Name: S3 & S4 – IDoService project\_Individual Interview-20210706\_133642

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

***INTERVIEWER 2: = Secondary Interviewer (Interviewer in bold italics)***

P18: = Participant – PwD

P13: = Secondary Participant – Stakeholder

P13: Don't worry. I can print another copy off and get [P18] to sign. And I can scan and get it sent to you after the session if that’s okay?

**INTERVIEWER 1: That would be great.**

P13: (Over-speaking 0:00:13) I don’t know if you’ve had time to look through.

P18: No. (Over-speaking 0:00:14). I left it there and forgot.

**INTERVIEWER 1: Good, thanks. Excellent. I thought before we start the… so as [INTERVIEWER 2] said, the interview is to find out about how… you know, what support services and leisure activities you're accessing and how we… you know, what things you like? What things perhaps you're missing? What things could be better? I thought before we… before we start, we could just all introduce ourselves a little bit. So, we get to know each other better and feel a little bit more sort of we’re in one room. So, I thought it might be useful to just say our names and how we feel today and perhaps what the expectation is from this session. And perhaps just one fun fact.**

**So, shall I start to give an example? So, I feel excited about talking to you. So, I'm [INTERVIEWER 1]. I'm a researcher at Manchester Metropolitan University in design. And I feel excited to be talking to you today. And I think my expectation is that we’ll probably learn lots from you. And one of the fun facts about me is that I like having cats on my lap.**

P13: I don’t think we’re cat lovers, are we?

P18: No.

**INTERVIEWER 1: [P13] or [P18], do you want to say something about you, about yourselves?**

P18: About cats? No, I don’t like them.

P13: About myself.

P18: Oh, about myself. My name is [P18]. I was diagnosed about eight years ago with Alzheimer’s. But I was put on medication straight away and I think it’s helped. Helped me keep going anyway. Is that all she wants? Is that all you want?

P13: Well, I think it's interesting to think that you were a district nurse by occupation. So, there’s not a background that [P18] doesn’t take me down when we’re making shortcuts around Salford. I drive and [P18] gives me directions because she’s excellent at remembering every little back street and every cubbyhole as a past district nurse.

P18: But I've now forgotten the name of the streets. So, I just call that way.

P13: Go left. Go right.

P18: Yeah. So, Salford is my home and place of work and always has been. Yeah, so. Born in Salford and lived all my life in Salford. Some people don’t like Salford, but I think it’s okay.

**INTERVIEWER 1: That's great. And do have any expectations? How do you feel today? Do you have any expectations of the session? Is there anything you would like to get from it?**

P18: Oh, I’ve never thought about it to be quite honest.

**INTERVIEWER 1: That’s good. [Participants swap chairs 0:03:40 - 0:04:05]**

P13: Well, my name’s [P13]. I am the lead for the [DEMENTIA SERVICE]. So, I've been working for the trust for 27 years now in various different guises. But mainly in this role since 2009, where we set up a limited-service called the [ DEMENTIA SERVICE] about how we can involve patients with the way we run our services, look at gaps, which we were very fortunate to be able to do a very… at a time where there was no support whatsoever for the person who’s been diagnosed with dementia. So, we run lots of engagement and social support groups which we’re only just getting back up and running again after lockdown restrictions. And (Unclear 0:04:51) were shut. So, over the last few weeks, we've started these up again. And then hope to be able to (unclear 0:04:56) a lot wider because we can only do groups at the moment of fifteen for staff that’s involved (unclear 0:05:01).

We've been also involved in lots of aspects of research, mainly with University of Manchester. We just finished a big piece of research with a (unclear 0:05:14) called [PROFESSOR]. Six years piece of research looking at dementia and neighbourhoods where we had a lot of fun sort of producing some films, looking at some aspects of our neighbourhood and community life and how we can sort of engage better with our patients and family carers. So, my expectations, really, I suppose is to sort of network together really. That we can hopefully use this meeting today. That we can learn something a bit more about one another’s services. And, you know, if any future aspects of research come up, we’d like to be considered.

**INTERVIEWER 2: Yeah. That’s quite –**

P13: And also, sorry, I'm a Salford girl. I don’t know if the accent gives it away. And like [P18], Salford until we die. We're very, very proud of our little city. We don't like to be known as coming from Manchester. It's a real no, no. So, be aware, anything that comes from this when you write it anything up, it needs to say that we’re from Salford. [laughter]

**INTERVIEWER 1: Great.**

P18: Salford is a city the same as Manchester is a city. We’ve got a Cathedral, yeah, yeah.

**INTERVIEWER 1: Now. I didn't know that.**

P13: Well, there you are. You’ve learnt something today.

**INTERVIEWER 1: But I lived in Wolverhampton before. And I worked at the University of Wolverhampton before I came to Manchester. And that's usually subsumed under Birmingham and they're very proudly Wolverhampton. [laughter] They also have their little… well, church at least, but they do have city status. So, yes. So, I know the situation.**

P13: Well, there's similar stories all across the country, I think.

**INTERVIEWER 1: Great. [INTERVIEWER 2], do you want to say something about yourself too.**

**INTERVIEWER 2: Oh, yeah. I don’t know. I'm very curious today and excited to by this discussion. And a fun fact maybe, so I'm French. I'm from [REGION]. But I really am not able to drink wine, especially red wine. So, it's really in [REGION], I think, for me to be (unclear 0:07:31). So, it’s really problematic because as a French girl, people have expectation. And I’ve said, no. Sorry. So, yeah.**

P18: And why don't you drink red wine? Don't you like it?

**INTERVIEWER 2: No. I'm really not drinking that. But some people say you have to drink it and you will learn to like it but no.**

P18: I don’t like wine either.

**INTERVIEWER 2: Good.**

P13: I’ve stopped drinking wine. It doesn’t make me feel good the next day. So, I’ve kind of stopped. But I was never a big wine drinker. But when we went out, I liked a drink of wine. But it doesn’t make you feel good the day after, so I’ve gone on to something new.

P18: Bottle of gin?

P13: Yes. Gin and tonic. [laughter] How did you guess?

P18: Because my granddaughter goes on gin and tonic.

P13: I have a gin and tonic especially with the football at the moment. So, yeah, I’ll have a gin and tonic once or twice a week.

**INTERVIEWER 1: I am sure there are good health reasons for gin and tonic.**

P13: [laughter] Perhaps there is. Prescribed by the doctor.

P18: On prescription only.

**INTERVIEWER 2: That’s perfect. So, yeah. I sent to you, I think ten days ago maybe, a list with some questions. But it's quite an informal discussion. So, it's more broad topics. So, I will ask you a question. And after that, you can just speak about what you think about that.**

P18: Okay. I was just going to say if you expect me to remember them, I’m not.

**INTERVIEWER 2: So, is it okay for you? Can you hear me well? Yeah.**

P18: Yeah.

**INTERVIEWER 2: Perfect. Yeah, my first question. So, we are talking about today about meaningful activities. So, physical, social and leisure activities you like and that are good for your needs and preferences. It can be, for example, shopping, reading, gardening, all these things or volunteering. And my first question is, I would like to learn more about the activities inside and outside of your home. So, what do you like to do? And what is a typical week for you, [P18]? What are you usually doing? What do you like to do?**

P18: My typical week at the moment. Not very much, to be quite honest. The fact that for the last eighteen months since this stupid lockdown’s been in place. Yeah, but the worst thing was when they stopped the swimming. That was the nail on the head that or the nail in the coffin. Whatever you wanted to put it down as. Yeah, it was awful that. And the clubs I used to go to. They just stopped overnight. Once we were there, the next time we just got an email saying there won't be in anymore. And we was confined to barracks if you know what I mean. And it is like life only revolved around COVID. It didn't revolve around… it didn’t revolve around anybody else unless you did die of COVID. And then you were in the newspaper all the time. It didn't matter that we were stuck in a bubble. And I say a bubble, and I don’t mean that bubble where you’ve got your next-door neighbour as part of your... or you’ve got your family member. I’m talking about being stuck in a bubble and not being able to pop it and get out. So, I've been…

P13: What did you say? Can’t go swimming. (Unclear 0:11:31) a little bit of background if you don’t mind me saying, [P18]. [P18] was diagnosed some years ago, but very sadly lost her husband six years…

P18: 2017.

P13: Right.

P18: Beginning of the year.

P13: So, four years ago.

P18: Four years ago. But (unclear 0:11:47) on my phone today because I couldn't remember how many years ago. But I just said to him on the phone this morning and they didn’t know really because they would have known he was dead, wouldn’t they?

P13: Yeah. Phone call came through asking to speak to [P18]’s husband this morning, which clearly states that they don’t know [P18] and her husband very well. But there was a change in the dynamics further on, wasn’t there? You know, your husband helped to support you and then he sadly passed away and [P18] lives independently with support from the daughter who lives next door. But when did you take up swimming?

P18: About I don’t know (Over-speaking 0:12:20 - 0:12:23). Yeah, because he used to take me and [MALE 1]. Not [MALE 1]. The lad who died.

P13: Oh, yeah.

P18: Yeah. [MALE 2].

P13: [MALE 2], yeah.

P18: He used to take me and [MALE 2] swimming. Because he’d pick [MALE 2] up on the way, so we went together.

P13: And did you learn swimming?

P18: Yeah, I couldn't swim. It must be six or seven years ago. It wasn't when I was first diagnosed because I couldn’t swim. So, it was about six years ago after my diagnosis, we went to the swimming. They wanted to set up a dementia swim. And I said, “Right, there’s no use talking to me about that because I can’t swim.” And they said, “Right. Well, we’ll teach you.” I said, “Well, we’ve tried before but nobody’s ever got me to put my head under the water.” Anyway, we went in and within about half an hour she got me swimming and I had my head under the water. And I don’t bring my head up from under the water all the way when I'm swimming now because if I bring my head up to get to the side, I breathe at the wrong time and then I kill myself nearly by chocking on the water. So, I swim from one end of the pool to the other. And then I have a breath and then a swim back. But because I still can’t get the logic of how to breathe between strokes if you know what I mean… it probably would have come if I had a bit more… I don’t know. What do they call it? Not exercise. Tuition or whatever. That kind of thing.

So, I did like the swimming. And we did set up a dementia swim. But like everything, once we got it going, they stop it, which, you know, is not good for us because we enjoyed it. And there were quite a few people that were going. And now all of the sudden, it was stopped and called Aquafit or something. But then instead of being in a big swimming pool, we were in a little tiny baby pool while flapping around and doing nothing really. So, I stopped going then. But then I just went in the normal pool and my husband used to come with me and just make sure I was okay. My daughter’s took over now, but it’s a bit hard for her because she’s got her job.

P13: How many laps? You’re going to be very impressed when you hear how far [P18] can swim considering she was a novice some years ago. How many laps can you do?

P18: Yesterday, I did 74 lengths in an hour.

**INTERVIEWER 1: Wow.**

**INTERVIEWER 2: It's really impressive.**

**INTERVIEWER 1: You are very fit.**

P18: I wasn’t the fastest in there though. There's a woman there who did 92. But (unclear 0:15:33) flippers on. And I think flippers make you go faster, I don’t know.

**INTERVIEWER 2: Yeah. They do.**

P18: (Unclear 0:15:39) like little (unclear 0:15:43). But she was flying away. But I think the was flying away. But I think the flippers (unclear 0:15:49).

P13: We were laughing today, weren’t we that you’re going to take… I mean, jokingly, so don't take this series, that she’s going to tackle the channel between England and France.

P18: No. Because I swim underwater and I’d get lost. And I wouldn’t know which way I’d gone. Because in the swimming club I can see the blue lines. So, I can follow the lines.

P13: Well, you did actually say, didn’t you, that when you were sort of on your back it was very difficult because you couldn’t keep –

P18: I couldn’t keep straight. And I used to end up bumping into (unclear 0:16:21) people and they’d get angry and started having a fight with me in the pool, which didn’t help the situation.

P13: How often do you go now each week? How often do you go?

P18: Because it’s only round the corner now, I’ll go on Mondays. So, I went on Monday. I would have gone today for two hours. But I’m only going to be able to get one hour in today. And then I’m doing an hour on Wednesday. But normally I do about four hours in the week. I can’t do Thursdays and Fridays because… and Saturdays and Sundays they’re always full up anyway, you've got to book them in (unclear 0:17:06). So, I just think… I do four hours a week. So, I don’t do too bad. And I enjoy it. You get the push (unclear 0:17:22) but you can’t wait to push you out the way. But I’ve started fighting back a bit now and pushing them back, so.

**INTERVIEWER 2: Yeah. That's really great. And so, yeah, indeed, currently the situation is quite… it's going better. But it's still difficult with all these COVID-19 restrictions. But have you changed your habits during the last month? Are you having more activities online, on Zoom? Or these kinds of things?**

P18: No. I don’t do online.

**INTERVIEWER 2: No. Not at all?**

P18: I mean, I’m doing it with you now, but you wouldn't get… I had one go online and if your views are not the same as the people who you’re in the thing with, then they don’t really want you online really. So, I've only tried it once and I’ve come off and I won’t be doing it again online. I don’t mean with you two. I mean, groups that are supposed to be set up for people with dementia. I won't be doing that online again.

P13: For a sort of a bit of backstory, it was with the University of Salford. They were running monthly Zoom meetings, support Zoom meetings and a carer of another service user made some quite disparaging remarks about [P18], which were quite upsetting. So, [P18]’s (unclear 0:18:43) from doing those Zoom meetings.

P18: So, the point is it came to me and it was two [P18 – SAME NAMES]’s in the group. One’s meant to be supporting… what would you call it, [P13]?

P13: She’s like the secretary. Like she’s admin.

P18: And then there’s me. And it must have gone to her. And because I was [THE SAME NAME] as well, it had gone to me. And I didn’t like what was said about me. So, I waited until the week after and I just said, “As from today, I won’t be coming on this meeting anymore if I’m not allowed to say how I feel” Because at the time to be quite honest, I was suicidal. I would have quite easily jumped under a bus because I’d been stuck in for that long. And although I’ve got my family next door, it’s not the same as having my husband with me. I mean, it’s handy that she’s there. But at the end of the day, she’s got [ ] kids to look after. It’s not as though she’s just got me. You know, she’s got [ ] kids to look after. And things weren’t running good for her with her business and everything because her business was just closed. One day she had the business. The next day she had no business. You know, and no money. That was the point. She had no business and no money.

P13: And I think it’s all right (unclear 0:20:03) to speak freely, but [P18] had a role within my organisation as our (unclear 0:20:08) facilitator. So, [P18] helps with the running of the support and engagement groups that we run. So, you know, before lockdown, [P18] and (unclear 0:20:19) was very, very busy. She would come to all the different groups. And we run five or six different groups. We run first diagnostic support group and a book club and dementia café –

P18: I come to the dog walking a couple of times.

P13: And a dog walking group. Dementia dog walking group. And also, we did a lot of (unclear 0:20:41) big research group (unclear 0:20:43) research group. So, we had quite a lot going on really. And so that’s had a rather big effect not being engaged in those kinds of things as well. (Unclear 0:20:55) leisure activities because it was a role for you. Well, I like to think you enjoyed them (unclear 0:21:03).

P18: I enjoyed all that I did. But as I say, it just stopped overnight and (unclear 0:21:15). And I’ve just moved house. And I have no curtains because they were supposed to be being put up the day after this stupid lockdown. I ended up with pieces of paper up for months and months and months on the windows. So, I couldn't even look out the window because I couldn’t take the paper off because I would have had to stick it back on again. You know, newspapers up at the windows. And it was awful. It was like (unclear 0:21:44) to deliver that was put on hold. Then my wash machine broke, tumble dryer broke down. And getting somebody… I only needed a belt on it and I ended up having to pay for a new washing machine because that's the only way. They would just dump it at the door. And you had to get it in yourself. It’s all right when you got… we’ve got no men in our family. We’re just two women with women with no men if you know what I mean.

P13: So, (unclear 0:22:16) house moved in, but the house (unclear 0:22:17 - 0:22:20). It was only two weeks before we went into lockdown. It wasn’t (unclear 0:22:23) tight.

P18: It wasn’t that it was weeks before but the house that I was moving into was kind of… can I swear on this a little bit? It was a shithole. The house I was moving into. So, I had to take it right down to the brick and start again. So, from the October until the March when it was all ready to move in and apart from the window thing, the blinds and my table and that. You know my television (unclear 0:23:00). They were all ready. But (unclear 0:23:04) that day everything was (unclear 0:23:08). And it’s like you’re stuck there in limbo really without what you need. Yeah, I was sort of like… it was like, you've got this euphoria of going to move into a new house. Well, it wasn't a new (unclear 0:23:24). But it was new because everything was new. Going into a new house and you’re stuck there with it not being what you expected. And I was… and then I was thinking, I should never have moved house. I should have stayed where I was. At least then I would have had a house that I knew my way around. You know, and as I say, I mean, it’s all right now. It’s a house but it’s not my home. Because it will never be my home without my husband.

P13: You’ve had your garden done. So, you’re going to be a keen avid gardener now, aren’t you? That’s going to be a new hobby for you maybe. You can garden now. You seemed to be proud showing me around your garden a few weeks ago. Stopped by for a coffee (unclear 0:24:16) garden.

P18: And I’m having a summer house built in the bottom of the garden, so we can sit out in the summer house and do a bit of leisure in there instead of just being in the house and looking into the garden, we can be in the garden in the summer house, or, yeah.

P13: What do you plan to do with your summer house?

P18: Well, I was going to start up reading again but my eyes are bad now, aren’t they? I was halfway through my Cliff Richards, what’s it, when my eyes disappeared, you know. My sight sort of going on me.

P13: (Unclear 0:24:56) to the eye hospital and they found that she suffers from –

P18: It’s called [DISCLOSES MEDICAL ISSUES]. But, I just set of reading this book and got really into it and then all of the sudden my eyes just went mad. And getting hold of the doctor, it’s like getting hold of gold dust, you know. [MEDICAL DISCLOSURES] And they eventually sent me to the eye hospital, you know. They picked up (over-speaking 0:26:08 - 0:26:09). Well, I can cope with the dementia. But I couldn’t cope with the dementia and being blind. And that’s what they said could happen, you know. And that would have just been the end of me, that would have been. And that book I was really enjoying because I enjoyed the book club. And I’d got this book for Christmas. And I was really enjoying it. And now, I'd have to start all over again because I forgot what it was all about.

**INTERVIEWER 1: Yeah. So, I –**

P18: (Unclear 0:26:41) but then [DISCUSSES MEDICAL ISSUE]. And it’s the same with The Chase. I mean, I used to like (unclear 0:27:05) but it’s very hard for me to watch The Chase now. That was my programme, I liked. I like quiz programmes because it makes your brain function, you know. And even that, just trying to read the things on the television it’s really hard now. And now people say, oh, it’s… and I think, yeah, it’s just another thing of getting old. And that is the thing when you’re getting old all these problems.

P13: Well, (unclear 0:27:36) you enjoy doing though, isn’t it, and like sort of The Chase. I sometimes pinch the questions of the programmes like The Chase for my dementia café quiz. And [P18] always pulls me up. She seems to remember.

P18: I always remember the questions. It’s funny. I always remember the questions but I never remember what the answers are. [laughter] I always remember the answers that I say, but sometimes there are instances I give up. So, yeah. But, yeah, I do enjoy trying to keep track of things that are happening in life and, you know. Because my memory doesn’t really go. Some of the questions are what were within my lifetime, so you don’t forget them, do you? So, you’re thinking, why have they got that wrong? It’s because we were in that age, you know, like these youngsters here, they wouldn’t (unclear 0:28:31) questions because they weren’t (unclear 0:28:33).

P13: They have no idea, do they, [P18]?

P18: No. No idea.

P13: Rather long-winded answer, wasn’t it? Sorry, we tend to go off on a tangent [P18] and I.

P18: That wasn't an answer to the question –

P13: Oh, it was. We just went off on a tangent.

**INTERVIEWER 1: No. That was really great. Really great to hear, you know, all the initiatives and activities that you're doing. No, that was really great.**

P18: I do my hula-hooping in the house.

**INTERVIEWER 1: Sorry. I couldn’t hear that?**

P18: You know, hula-hoop.

**INTERVIEWER 1: You do that as well?**

P18: I can stand in front of the television and do that for hours on end. I never drop the hula-hoop. Just keep going, yeah. Because it’s a (unclear 0:29:32) hula-hoop. You’ve just got to keep moving your body a certain way.

P13: It’s very good for focus, isn’t it?

P18: Well, I’ve got to be careful when I do it on my arms though because I’ve broke a few lightbulbs, you know, when it shot off. So, yeah, that’s one thing. It seems I’ve got to be able to do on my own because there’s nobody else to join in with it. And with me having knee problems, I can’t get down and do them kind of things. Yeah, so I keep fit. I do keep fit.

**INTERVIEWER 1: Yes. Clearly. And you started with swimming. You started new things. Have you started any other new things?**

P18: Oh, my hula-hoop, I’ve done for years and years. I’ve always had a hula-hoop. Do you know what a hula-hoop is?

**INTERVIEWER 1: Yes.**

**INTERVIEWER 2: Yeah.**

**INTERVIEWER 1: Yes. I was never very good at it.**

**INTERVIEWER 2: Me neither.**

**INTERVIEWER 1: I didn’t have enough hips.**

**INTERVIEWER 2: I am (unclear 0:30:38). [laughter]**

P13: At one time, I used to like drawing at one time. I would take a picture and that. You know, I used to like doing the cartoon guys. You know, like Snow White and the Seven Dwarves. And when the kiddies were little, I used to draw and draw them pictures of them and then I’d stick them on the wall and make a thing. But I’ve not done that for a while.

**INTERVIEWER 1: Would you like to do that again?**

P18: Probably, I’ve never tried it since, you know, for a while because it’s about looking at the picture and drawing it down. I don’t know whether I would be able to as well as I used to do. But I did use to like that.

**INTERVIEWER 1: Yeah. We’re you doing these for you or for others, or?**

P18: Well, I used to do it when the children were little. I used to do it for bedroom posters and that, you know. And funnily enough, my daughter's the same as me and when she moved into this house, she did Snow White on the… a full one on the bedroom wall. Of course, when [CHILD 1] took the room over, he decided to use it as a dartboard. So, it had (unclear 0:32:00) really. So, he had a lot of whatsits and then they covered it up. And I think they actually painted over it. It was quite a while ago. Yeah, because [MY DAUGHTER] is very artistic as well. But it’s not a thing I thought about doing really. And I suppose I could have done. It’s not something I just thought about. I mean, it was quite hard.

P13: Do you mind me saying as well that some years ago, you undertook a fitness programme, didn’t you, with (unclear 0:32:35) university, which was about (unclear 0:32:38) programme of fitness for the blind.

P18: Yeah. It was with (unclear 0:32:43), wasn’t it? It was Manchester (unclear 0:32:45) like mental health with the physiotherapist for me. It was a place (unclear 0:32:54). It wasn’t Norwich but it was something like that. I can’t remember where it was. But it was down south somewhere. I can’t remember the name of it.

P13: Wasn’t the (unclear 0:33:05) programme, was it?

P18: No, no. I don’t think it was called that. Yeah. It wasn’t called… I’ve got (unclear 0:33:14). I’ve not thrown it away.

P13: (Unclear 0:33:17) fitness beforehand and how you learn your balance and all those kinds of things effectively. And did you do it for sort of a week… the programme for six weeks? Was it longer than that?

P18: I think it was longer than that because we went to the swimming baths. We didn’t do any swimming because the swimming thing was closed. But we did it in the gymnasium at (0:33:40).

P13: Ah, that’s (unclear 0:33:41) pool.

P18: Yeah. But we didn’t actually do it in the pool. We did it in the gym.

P13: Right. And then was it evaluating afterwards how it sort of affected your memory and fitness.

P18: And your heart rate because you had a heart monitor on all the time. I mean, I had to be told to slow down because my heart rate was sort of like to –

P13: But (unclear 0:34:10) an Olympic swimmer you can imagine.

P18: But, yeah, because even when I’m swimming and that. You know, my heart rate doesn’t go above 70, you know.

**INTERVIEWER 1: Doesn’t go above 70?**

P18: Yeah.

**INTERVIEWER 1: Wow. That’s where mine starts.**

P18: You know, and it was the same (unclear 0:34:35) because they kept saying to me, “You need to slow it down. You need to slow it down.” I was like, “I’m okay. I’m okay.” Because I went on a bike, a speed bike and you had to raise your heart rate. But I remember saying, you know, “What’s your heart rate?” And I said, “I don’t know.” “But can you still talk?” And I’m like, “Yeah, yeah, yeah.” Sort of like (unclear 0:35:00), yeah. So, yeah, I could still carry on talking while I was biking and that. But there was lots of people… and they did weight lifting as well.

**INTERVIEWER 1: Yeah. That’s great.**

P18: I’ve never been a sprinter. But I’ve always been a… I can run for a long time without getting… you know, I can run on and on. I could before I had my knee replacement. They told me not to run on it now. But I don’t take any notice of what they tell you to do. I do what I want to do at the end of the day.

P13: [P18] and I were invited to a conference some years ago to the very first International Arts and Dementia Festival in London. And we got there the day before. And we were going for a short walk. And I didn't have the greatest shoes on. And [P18]… we must have walked for miles and I could hardly move the following day. And so, she can walk. She (unclear 0:36:01) swim, she can walk the feet off me as well.

P18: Yeah. And as I say, when we did the dementia run at (unclear 0:36:13) Park, I was first back. I was first back there and it was a ten-mile run and I was first back over. I was with another guy and he said… I said, “Oh, I might as well jog on with you then. It’s only me and you because all the others…” Maybe it wasn’t supposed to be a run. It was a walk. But I can't do anything at slow speed. I have to do everything at 100-mile an hour. So, this guy set of running, so I went running with him. We both crossed the line first. Because he said to me, “You need to go around again.” I said, “I’ve been around twice.” And he went, “Oh, oh, right.” So, I said, “No. I’ve been around twice.” So, yeah, but I enjoyed that as well. But it’s only supposed to be a walk. But I’m not into walking. I’m all right walking as long as I’m walking fast. I can’t be doing with this (unclear 0:37:12).

**INTERVIEWER 1: Yeah. You sound very active especially sporting, you know, with the swimming and walking and dog walking. That’s amazing.**

P18: I don’t do dog walking now. No. (Unclear 0:37:30) because it was –

P13: It’s a (unclear 0:37:33).

P18: It’s a (unclear 0:37:34).

P13: It’s a (unclear 0:37:35), so, yeah. That’s one of the –

INTERVIEWER 1: Sorry, it’s a what?

P13: It’s a (unclear 0:37:40). It’s like, as I said, a ramble rather than going at any speed. It’s for people of all abilities with dementia. They run a monthly walking group with our dogs around a local park. And it’s for people of all abilities. So, I would say it’s more of a gentle stroll around the park rather than going off at 50-miles an hour like [P18] tends to like to do. So, it didn’t really fit in with what [P18] likes to do.

**INTERVIEWER 1: Okay. So –**

P18: I haven’t got a dog anyway, have I?

P13: No.

P18: It didn’t matter that (unclear 0:38:16).

**INTERVIEWER 1: So, have you found a fast-walking group for yourself or are you doing walks by yourself?**

P18: No. I just walk by myself if I want. I mean, I just do what I want to do at my own speed now. So, you know.

P13: Best way.

P18: I don’t wait for nobody. You know, like (unclear 0:38:48). They like to stroll (unclear 0:38:51). I don’t (unclear 0:38:52). I just leave them and go on my own. Because I find it harder to walk slow.

**INTERVIEWER 1: Yeah, yes. It’s kind of harder to walk slow. Yes.**

P18: Especially along… I don’t know. (Unclear 0:39:12) just being slow, it just bore me. It’s boring walking slow really.

**INTERVIEWER 1: And I mean, you’ve been really quite active in finding things. I mean, obviously, COVID has made things much more difficult. But now that things are getting back to normal and also before, have you found that there were any difficulties in accessing things that you wanted to access? Or were there any things that you would have liked to see in terms of support that aren't available?**

P18: What when COVID was on? Well, there was nobody to give you any support was there. There wasn’t anyone around to give you any support. I think that [P13] and that, she was working in this place, weren’t you?

P13: Yeah.

P18: I mean, there was nobody. I mean, even going shopping wasn't a pleasure. Even just going to the shops. It was a mundane job going to the shop because you have to stand outside. It's all right in the summer when it's nice to walk but it's not nice standing out in the cold. And I don't do cold either. I can’t stand the cold, me. My body isn’t good in the cold. So, it wasn't nice. Just been going shopping (unclear 0:40:49). Shopping wasn't good in the COVID. And that was the only thing that I could pick and choose what I wanted. And it wasn't nice and I used to just write a list out and say to [MY DAUGHTER], “There you are. Go and get that for me.” Because it wasn't a nice pleasure going shopping. It was don't do this. Don't do that. Wear this. Do that. No, no. It’s not my idea of enjoyment that wasn’t. It’s got a little bit better I think. A little bit better. You don’t see them just being as aggressive in the shops as they were.

P13: The great toilet roll fight of 2020, when everyone was trying to grab the toilet rolls.

P18: And I could never understand that. You know, it’s a thing you don’t really need.

P13: I know, it’s bizarre.

P18: And people were running out. It was me and you, wasn’t it, in the shop.

P13: Can you remember that gentlemen with twenty –

P18: I don’t mean twenty toilet rolls.

P13: We counted how many he put in his boot.

P18: Twenty boxes of maybe eighteen toilet rolls.

**INTERVIEWER 1: And how people were stockpiling them. That was really funny. [laughter]**

P18: That was a good laugh that, that day.

P13: I take that as a leisure activity. The great toilet roll fight. [laughter]

P18: It was a good fight that.

P13: It was. (Unclear 0:42:19) anything with (unclear 0:42:21). But I undertook the role of… with my service, I was doing various different jobs with staff maybe shielding or couldn’t come into work. I worked a little bit on the frontline and also, I was working in the community and meeting the people recently diagnosed. And I would say that the vast majority of them were just going for a walk around the block, you know. Everyone I met (unclear 0:42:49) say that I’m trying to keep myself well. But it’s a short walk around the block. That’s as about as much as people were able to do. Because again, like [P18], they didn’t feel comfortable going to the shops. They felt quite nervous. They lost quite a lot of confidence. But mainly, it was just the walk around the local neighbourhood is the only type of outside exercise that people were managing to do.

P18: Well, I wasn't too bad really because if I went out through my back gate I was on [AN AREA OF SALFORD].

P13: You live in a lovely area, don’t you? (Unclear 0:43:22 - 0:43:24).

P18: I can’t go out through the back gate now because I’ve had it blocked off. But if I go around the (unclear 0:43:29) I can still get (unclear 0:43:31). But that’s a nice walk. But it’s all right in the summer, but in the winter because the rain gets into it and it's quite a bit hilly, isn’t it, I’m frightened of slipping into the river (unclear 0:43:45) because I don’t fancy swimming that. Because it’s like a deep ravine. So, it’s all right in the summer walking along there. But it's not good in the winter because it’s not safe. I don’t think it’s safe.

P13: I agree. I think that some of the footpaths are quite treacherous maybe.

P18: But that’s all right to do. That’s quite relaxing in the summer.

P13: But that’s one thing we were able to do, weren’t we? We were able to see one another in a sensible distance walk for a couple of hours, weren’t it, we went around.

P18: I did that with [MY DAUGHTER] and (unclear 0:44:24). We’d go for a run. We’d go for a run. I always get stones in my shoes though, when I run. I don’t know why.

INTERVIEWER 1: [laughter] Stones in your shoes, yeah.

P18: I always have to keep stopping and taking the stones out of my shoes. I don’t’ know why it happens. (Unclear 0:44:42) walk along one into the other, I don’t know. But that’s irritating when you’re running and you’ve got stones in your shoes. It’s like having an elephant under your foot, isn’t it?

**INTERVIEWER 1: I know, they always seem much bigger than they really are. [laughter]**

P18: They are. Especially if it’s in, like, the wet weather. You can’t just hang onto something to take it off. And you’re falling over. Your balance goes. And you try to get your shoe off and you don’t want to put your foot in the puddle and things like that. Yeah.

**INTERVIEWER 1: Yes, yeah, yeah. So, walking, obviously, has been something… being outdoors has been something that’s been quite good during the lockdown and (unclear 0:45:34) the weather’s been really good. But thinking ahead of, you know, things opening out again, are there any particular things that you look forward to that you might be wanting to do new or again.**

P18: Well, I'm hoping the groups get back again. But I went the other day, but it wasn't the same because they were restricted in people being together.

**INTERVIEWER 1: What groups are they?**

P18: Well, it was [P13]'s group, it was the café, wasn’t it? But where we would normally have about 30-odd or maybe more.

P13: More.

P18: Maybe 40 people. We only had fifteen. Well, when she spoke… when she sort of said a few words, she said everything really. There’s no… where if there’s a group of you on the table and your different conversations, you’re listening to different conversations. But when it’s just the same thing it got it got a little bit (unclear 0:46:38) on our table. And I don’t think (unclear 0:46:43) I will be going again until we’ve got the numbers back up, I don’t think.

P13: Okay. Yeah. So, normally, we’d have between 45 and 50 people attending and we’re all hoping we’re having that 21st of June opening. So, we’ve done everything we could to get these groups up and running because we (unclear 0:47:00) these people to come together. And then, unfortunately, we weren't able to do it as we wanted. So, we didn't want to cancel. We wanted to go ahead and at least it helps offer some support to some of our service users, established service users. And also, you know, we were very distant from one another. Normally the groups (unclear 0:47:19) eight people around a table but we couldn’t do that. So, it was very different. It was a bit cold really. We did our very best.

P18: But I tried my best.

P13: I know, it was definitely a little cold and it wasn’t very engaging. People aren't able to sort of walk around the room talking to different people. You had to sort of stay at your table. As a table’s normally for four people so people felt a bit distant. So, hopefully, we're coming out of that now. And we'll get back to having more people coming and back to doing what we normally do. But (unclear 0:47:54).

**INTERVIEWER 1: And what do you do in those groups?**

P13: Pardon?

**INTERVIEWER 1: What kind of activities or things do you do in those groups?**

P13: So, we do… (unclear 0:48:04) I’ll go through the different groups. We do the dog walking group. We started that because (unclear 0:48:10) another gentleman (unclear 0:48:12) was very keen on fitness and wellbeing intervention. He actually got a dog after his diagnosis to try and give him some form of responsibility to keep him active and engaged. And he would go out for long, long walks near where he lived. And he wanted to get people revitalised. And, you know, thinking about your health and wellbeing. And from a vascular dementia perspective, about getting people to think about their diet and healthy lifestyle. So, we started a dog walking group because of his dog and it got people together that maybe have a dog or don’t have a dog. And that’s quite interesting, that people maybe who used to have a dog would do a lot of reminiscence, (unclear 0:48:58) walk talk about some general dogs.

We also bring a lot of our hospital patients to the walk as well. So, that was really, really nice. They come along because they're on an assessment ward, and it's basically the only area they could get some proper exercise. And what would also happen there is, their loved ones would have met us in the park with their dog. So, the in-patients got to walk with their dog around the park, which was lovely to be able to do. So, we do that on a Monday morning. And it (unclear 0:49:32) really to go on a Monday morning. You know in all aspects of support, you'll find things are very much based on the Monday to Friday, 9:00 to 5:00 type, you know, support. So, we were trying to get a thing for people that had maybe a very long weekend of not being (unclear 0:49:48) and doing anything, that we revitalise them on a Monday morning. So, that’s the reason why we run our group on a Monday morning. And it really does actually… we were able to start that back up in early June. So, that worked really nicely for people to come together.

We run cafes. We run fortnightly groups. As mentioned, we see about 45 to 50 people come. And what we generally do there is have guest presenters that come in and give talks about what their service (unclear 0:50:19), helping to support people. For instance, things like (unclear 0:50:23), The Alzheimer’s Society. But we’re bringing lots of different practices in. We bring local history and (unclear 0:50:31) to talk about local history. That was always really well received because that’s a lot of reminiscences.

**INTERVIEWER 1: Do you ever ask the participants to maybe do a presentation or to do (unclear 0:50:44)?**

P13: We did. We had a gentleman who very sadly passed away during COVID. And he must have had a garage full of curiosity, shall we say. And he brought lots of various interesting gadgets and passed them around and explained them all. And he was also a very interesting gentleman because he was [PREVIOUS EMPLOYMENT HISTORY]. So, he would talk of some of his experience of being [A DECISION MAKER]. And he also worked for [ORGANISATION]. So, he’d talk about a lot of his life story which is something really interesting to people to share their life story. Also, it’s always very engaging then. It always goes down very well. So, we always ask our group members if they have anything they would like to share with the group they would be given time to do a presentation. So, on occasion that has happened. Yeah.

And we always have a multiple-choice quiz. That (unclear 0:51:35) I take some of the questions from The Chase because they give you three multiple choice answers. So, we don't ask the question if we don’t give a person at least the chance of getting that question right, really. And we play as a team as well on the tables, which is always very nice. It's a good way of people engaging together and making friends by doing these quizzes together. We used to do… which is probably good to share with you actually. We used to do… the last fifteen minutes we used to being physiotherapist down to do, like, a health and wellbeing exercise group. And they absolutely hate it. (Unclear 0:52:10) absolutely hated it.

P18: No, you've got it wrong there. One person we really enjoyed it. The other person, one of them did it to music that was like, good beat music. And the other one did it… I call it baby play. She treated us like babies catching a ball and moving it, you know. And on our table, we never participated with it because we felt she was humiliating us (unclear 0:52:52). In the way that she didn’t know… the girl from here did it. When the guy did it, we were all up because it was music and (unclear 0:53:02) and doing, you know, arms here and there. That was great. But then when you’re treating you like babies –

P13: That’s a point actually.

P18: It wasn’t good. And it stopped. Not because… it was the woman that come from the council she treated us like –

P13: There’s a Healthy (unclear 0:53:26) programme, (unclear 0:53:28) physiotherapist out and doing it. But it seemed to… I think maybe your table stopped so (unclear 0:53:36) across the room. Because –

P18: (Over-speaking 0:53:39 - 0:53:41) as soon as they said we were doing a keep fit, (unclear 0:53:41) all go. We were going now. And we all upped and went.

P13: I think exercise, to be honest, it was a lot of hand coordination and visual (unclear 0:53:53). So, there was a reason behind this type of exercise. But she did deliver some time to sort of nursery rhymes, you know.

P18: You know like, Incy Wincy Spider.

**INTERVIEWER 1: Oh, no. [laughter] Not quite the right thing to do.**

P18: We’re not children, you know. And I think that made us feel that we were being humiliated, I would say.

**INTERVIEWER 1: Yeah, quite.**

P18: So, as soon as… we started trying to do it at the beginning, didn’t we? We tried it.

P13: We tried everything. [laughter] (Unclear 0:54:29 - 0:54:30).

P18: If we knew it was coming at the beginning, we’d come a bit later. And if it was at the end, we were like, “Right, we’ve got a bus to catch or whatever.”

P13: So, we stopped… we did stop that, didn’t we?

P18: It would have been all right. It was all right when the girl from (unclear 0:54:49) because she did what we were doing in the gymnasium. They got the music on and they get them going. Not, you know, catching the ball and trying to catch it. And, you know, balance this on there and (unclear 0:55:06). No, I think that was… it was sort of, like, treating us… and when you’ve got dementia you don’t want to be treated like a baby. I wanted to be treated like a human being who’s got a mental… not a mental problem, a brain problem. You know, it’s not that we –

**INTERVIEWER 1: You want to be treated like the adult that you are, right?**

P18: I think so. Sorry?

**INTERVIEWER 1: You want to be treated like an adult as you are, right?**

P18: Yeah. That’s right.

**INTERVIEWER 1: Yeah. I would think that's the same, quite. Thank you.**

P13: Another group we run came from just a remark made at one of the cafes that they enjoy the reading of a good story, but felt unable to do that by themselves. And one lady said that she’s been part of a book club for many years and it felt very (unclear 0:56:02) to talk about her diagnosis. And the remark came from the group was, “Oh, what a shame you won’t be coming anymore.” Which I thought was really, very negative. So, as our service likes to try new things, we thought we would pilot for three months, a book club. So, our book club meets in the library, in the little room of the library. And we've been running it for nearly… well over eight years. So, that three-month pilot, that we extended and extended and extended. And it's lovely. We’re starting our first one tomorrow. And it's lovely. So, we all agree as a group, what story we're going to tackle next. We tackle books, we don't do short stories. WE tackle sometimes quite hard books and deep books.

P18: Lynda la Plante was good.

P13: Yeah. We’ve done all sorts. We really have gone through… we’ve not got one type of book. We’ve never done an autobiography. You’ve mentioned Cliff Richard. We’ve never done an autobiography. But we've done some gritty dramas and –

P18: Autobiography. It's quite personal, to the person. When I sort of listen to a bit of his autobiography and I think, “Oh, I never knew that.” You know, so that’s why I read it. But then I’ve got to start all over again because I’ve forgot what’s gone on. So, once my eyes are better, I will do. But now I can go to the book club, and I can do a bit of reading. But when they get back, I can just listen.

P13: So, we have two fantastic readers that read the story aloud. So, we have a copy in front of the participants. But sometimes they just want to sit and listen to the stories instead of reading along and it works perfectly really. We have a volunteer that can help support the person if, you know, they lose their track in the book. We can point them in the right direction and help them turn the page. It works very, very well.

In fact, it’s almost organically changed from the group participants because one gentleman came along and we always have a break in the middle for going (unclear 0:58:11) tea and coffee. And he brought a word… he had like a word game with his daughter in Scotland. And they would (unclear 0:58:20) to try and what this word means. It was maybe an old English word. And he would bring it on phone. And that started a conversation about, “Can I ask (unclear 0:58:31) what you think these words mean?” And all of a sudden, we found ourselves… that each group member would bring a word in for the halftime refreshments. And it all then sort of organically became this quiz that we continue to do now, help facilitate. So, we usually bring some words that people maybe don't understand what they mean.

Don’t know if you ever remember a programme called Call My Bluff. It’s probably before both your time, where you would bring a word and you were given three meanings to that word and then have to see, you know, which meaning fit that word. So, that’s kind of come from the group themselves. They sort of made this group their own. And we just do a synopsis at the beginning just so we can refresh our minds and recall where we're up to when we finish the group previously. We run it weekly because it works in the sense that people do recall. If you run it regularly and weekly, they do recall where they’re up to with that story. If you left it as a monthly book, it certainly wouldn’t work.

P18: It’s hard to remember everything in a week.

P13: Yeah. So, the continuity –

P18: So, longs they start telling you… once they start reminding you of it you go, “Oh, yeah. That’s right.” But you know, if you sort of (unclear 0:59:49 - 0:59:52) but if I’m reading it and I stop, I am going to have to start at the beginning because there’s nobody to remind you about where you’re up to or what happened. So, longs you can remember it, that’s great. They can remember it and that. I mean, we read quite a few books, but if you said to me, “What happened in such a book?” I wouldn’t remember it. When you tell me about it, it brings it back a bit but otherwise, it’s just… I can watch television, and I can watch the same programme on a Monday, Tuesday and Wednesday. And I don't know ever remember, “Oh, I watched this before.” I mean, on The Chase I can remember questions but I never remember the answers, like you say. It’s the same in the book club. I mean, if you sort of, like, read the book that we probably read last year, little bits of it would come back but the whole book wouldn’t. And I know that sounds –

P13: Do you remember that book we read called the Pilgrimage of Harold Fry. It was that gentleman that was walking the length of Britain to see his friend. And what was really nice about that is I actually brought a map of Great Britain, and the lay on table with a little figurine. And each week, [P18] or another gentleman would mark out the route this gentleman was taking in a highlighter pen (unclear 1:01:17) roadmap of Britain. So, it was really nice. A little bit different. But you know –

P18: We had a little Lego man, didn’t we?

P13: A little Lego man and we were sort of tracking the gentleman’s journey. So, it wasn’t just the story. It was a bit of engagement, which was really quite interesting really.

**INTERVIEWER 1: That’s lovely.**

P18: Because we didn’t know where this place was until we checked –

P13: We checked it on the map, didn’t we? (Over-speaking 1:01:41 - 1:01:46). I think another (unclear 1:01:48) that we no longer do, which is a shame, we’re hoping to get it running, we're hoping to get it running, was a young-onset dining group that we run monthly as well, where we felt it was important to have a social stimulation for people under the age of 65 that received a diagnosis. You know, (unclear 1:02:08) we are aware (unclear 1:02:09). We don’t do bingo. I won’t go down that route. But you know, sometimes, you know, if you're a younger person like [P18] and [MALE 1], you can (unclear 1:02:19). They don’t want to sometimes be engaged in these older groups. So, we run a number of set dining groups and we would meet in a different pub each month. And we were very lucky. It was quite well funded. We were able to pay for their meal. And it wasn’t for their loved ones. It was just for the person with dementia. And we would… we'd also sort of do that, with the understanding that wherever we went, we give some training to the establishment. So, they would become dementia friendly for the future. So, we would give them an idea of sort of (unclear 1:02:56) and things to consider in terms of a more dementia-friendly environment. And so, it worked really, really well.

The only reason it stopped really was because the other staff member left and I couldn't get anybody to run it with me. And that's the reason. So, we do hope that we will get that group up and running in the future. But that was a great social time, wasn’t it? And it was quite… it was quite (unclear 1:03:21) for me really because when we first joined this group, we sort of came with lots of reams of information and advice and information sheets and they said to me, “Put them away. We're here for the social time. We don't want to be talking about dementia. We don't want to be bombard with information. We want to do what anybody normally would do when they go out for a meal.” And we were absolutely fine with that. And that's what we did. We never brought information with us. It was just a really a lovely social engagement time.

P18: And we found that the worst places we went to were the posh places. Places that were like Weatherspoon's, fantastic Weatherspoon’s (unclear 1:04:07). You go to the… what’s that one on the –?

P13: [A LOCAL PUB]

P18: Go to [A LOCAL PUB] (unclear 1:04:15), they were the worst. We asked for a quiet area. We asked for disabled… to be near disabled toilets. And we ended up right near the front door. So, we couldn’t hear what was going on because all we could hear was the door banging. And they left us… all the meals that they gave us were all stone cold because they’d left them hanging around. And if you told them, it was cold, they didn’t like it. If I order a hot meal, I don’t want a cold meal if you know what I mean.

**INTERVIEWER 1: Yes. Absolutely.**

P18: So, to me it was like (unclear 1:04:59 - 1:05:03) and then said the bread will be here in a few minutes and it was ten minutes when the bread came for the soup. And then I just dipped it and I went, “This soup’s cold.” (Unclear 1:05:17), “If you brought bread at the same time as the soup, it wouldn’t be wrong.” Anyway, took it away and he put it in the microwave, I think. And it came back piping hot. And she must have thought I was going to turn around and say, “It’s too hot now.” And I went, “That is absolutely gorgeous now because I don’t like cold food when I want hot food, if you know what I mean. (Unclear 1:05:40) people see the disability and they think they can get away with anything. She probably would have done if we weren’t younger people who were able to stick up for ourselves still, you know. So, that’s a thing that people forget when they’ve got dementia. That, you know, we’ve got dementia, but we’re not at the end stages of it where you can just bombard us and tell us what we want. You know, we’ll tell you what we want. And then it’s up to you to accept it or don’t accept it. Do you know, I’ve never been… we went down to Salford uni as well. And (unclear 1:06:24) with the dementia group. And they treated us exactly the same as (unclear 1:06:28). Exactly the same. Just totally ignored us.

P13: Yeah. There was some really positive where the places were so engaged and really wanted to do their best to make it a really special time.

P18: Even the local chippy.

P13: Yeah. They had a little restaurant on the side. We went (ucnlear 1:06:50) fish and chips in newspaper.

P18: It was quite nice the little restaurant. And they couldn’t do enough for us.

P13: No. there was some really lovely places. I mean, it was interesting really. It was again, another learning curve of things that you need to do to put in action to help people feel at ease. So, we would meet with the establishment long before we actually went there. And we'd make sure we got the menus. And we would send the menus out to the person, so they could read it in leisure what the menu, you know, board is. So, they weren’t being rushed on the night to make a quite quick decision about what they wanted to eat. So, we would give them a menu choice booking form and they’d fill that in unless they’d forgot them. Quite a lot of times they do. But they’ve got a rough idea about what they wanted.

And then we also learnt that we would make a note of what person wanted to eat because sometimes if a menu… a waitress would come with, say, fish and chips and someone thinks that was their meal, and (unclear 1:07:49) that meal and actually, it wasn't the meal they ordered. So, we’d have to sort of make a note of the different meals that people had ordered. So, it was a real learning curve for us. But by the end, you know, before (unclear 1:07:59) stop this, which was January 2019 when stopped that, it worked really well. And what was also quite good about that was, if the restaurant was kind of big enough, (unclear 1:08:11) pub restaurant sometimes, the carers themselves, the family carers would sit separately together. So, they were also getting some support from one another and sharing a meal together as well. So, that worked very, very well.

P18: Yeah, it did. Yeah, I did.

**INTERVIEWER 1: That’s great.**

P18: They get things for us and then they disappear, you know.

**INTERVIEWER 1: Sorry?**

P18: They get things going that are good and then chucked away. And that’s the worst thing you can do to anybody, is to get some something going and people enjoy it and then take it away from them because they don’t trust people then after that.

**INTERVIEWER 1: Yeah.**

P18: You know, (unclear 1:08:56) was going, “You took it away.” Young-onset dining group and that went away. And (unclear 1:09:04) and then everything went when COVID drew its head up into the limelight. You know, we’ve become that way that you’re frightened really of getting involved with what’s going on because in case it’s took away.

P13: Yeah. I think in a sense with the research setting, we learnt a lot from people’s feedback and we did a long piece of research with [PROFESSOR] in the neighbourhoods and dementia. And what I was very keen to see make clear to our research group was it was a very engaging group. We were producing films and naturally, you know, making our own music. And it was very engaging. People loved coming to the research group. And what we didn't want to do was say, “Thank you Goodbye.” So, when we had finished that research and the researcher finished everything that we needed to do, we continued that really until it came to its natural conclusion.

But (unclear 1:10:09) we continued to do sort of reflections from being involved in (unclear 1:10:14). At the moment trying to produce what's called almost like a life story piece of work. A tangible book with photographs of people and sort of telling the stories about the journey through (unclear 1:10:28) take away from them. And I think we did that in (unclear 1:10:35). And we did actually run a (unclear 1:10:36) article on that really. But I think when you’re working with people with dementia, you don’t just sort of cut them out when you’ve got everything you need from them out of that research. That you continue to support them to the natural conclusion. I think that’s something that I personally felt very passionate about, and something that we were able to do in a nice way.

P18: Because in a lot of the university they use us but they never tell us what the outcome was. You know, like somebody’s doing… I don’t know what they call them. Is it a doctorate or something? We never get to know how they finish at the end. You know, the outcomes of what they’ve done.

P13: Just a hint. [laughter]

**INTERVIEWER 1: Yes, no, absolutely.**

P18: We’ve asked people, “Well, how did it end?” And they go, “Oh, you know, I don’t really know.” And you think, “Well, why ask for our opinions if then you don’t tell us how it becomes the norm.”

P13: I did exactly the same thing. I work with two researchers in the University of London who came and spent three days with me going to people’s houses and never heard back from them. And when I put it through our research and development, the person had gone and left. And nothing came back from it really. It’s a great deal of my time for nothing tangible at the end of it. So, yeah, we do an analysis and go along, don’t we?

P18: Yeah. I mean, I sometimes… I’m being honest with you now. They just use us to their own ends. You know, I mean, I know I’m part of that book, don't get me wrong, that book that we wrote with Salford University I'm (unclear 1:12:43) in that book. But I sometimes just think, they use us for their own end, you know.

P13: But I think there’s good ways of doing things and bad ways of doing (unclear 1:12:58). At the very most it should actually (unclear 1:13:02) of the person’s research, you know. (Over-speaking 1:13:06 - 1:13:07).

P18: What have you made out of… you know.

P13: Yeah. What findings have you found? What are you going to do to make things better for the (unclear 1:13:15)?

**INTERVIEWER 1: That’s really good to emphasise absolutely. I’m very mindful of time so I assume we have to wrap up. [laughter] Very lovely to listen to you and to everything that you’ve said.**

P18: You probably got about five minutes in all that gabbling that we’ve done. [laughter] for whatever you’re doing. You’ve got about five minutes in that hour and a bit or whatever (unclear 1:13:50).

**INTERVIEWER 1: So, this is the first stage of the project as perhaps you got from the information that [INTERVIEWER 2] sent off collecting, you know, experiences and information from people with dementia and carers and other stakeholders within Greater Manchester, to see what services are there and, you know, how do they work and perhaps what's missing, or, you know, do they need to be better connected or whatever it is. Because our previous project, sort of one of the key things that came out that there wasn't enough opportunity for initiative for people with dementia. So not just be passive participants, but actually to active. But it's really nice to see that, you know, in your group, clearly there's a lot of active stuff going on.**

**So, the next part of this project, so we'll collect all the information and try and see what pattern emerges from all the information that we've found. And then hopefully, we will do a feedback session for everybody that’s been involved, which then leads us into a co-creation or co-production session co-design session to think about what do the results tell us? And how do we want to take them forward? Can we improve something? Is there something that we can do better for Greater Manchester to help people with dementia? So as designers, we do the one thing that doctors usually don't do. They take the information and then they publish the information. But as designers, we try and actually figure out what needs to be done better, what can we do to help people change things from an existing to a better situation? So that's the idea so that we come up with some ideas. And then we see, depending on how big or small they are, whether we can actually implement, you know, a pilot study or something.**

P18: When you say that you design, like, we at Salford University designed the hub. I don’t know whether you’ve seen the hub itself (unclear 1:16:04). Have you seen the hub? The dementia hub at Salford University?

**INTERVIEWER 1: I haven’t personally seen it, but I have two colleagues who come from there from the dementia hub. So, they're already familiar with it.**

P18: Well, we designed that. As people with dementia and carers helped to design of that. And now, it's run its course. And now, it's not going to be called the dementia hub, I don’t think. It’s going to be called (unclear 1:16:33) such a thing, whatever now. So, we're getting pushed… I think we're getting a bit pushed out on that as well. I don't know. I don't know whether we are or not. We’ve served our purpose of making it one of these best places to go to with dementia and I think we’re just being… that’s another thing. I think we’re just being pushed out. And that’s with Salford University. I don’t know. I’d like to see who you’re in cahoots with, might be able to tell me more.

**INTERVIEWER 1: Yes. I shall have to ask my colleagues and see what they say.**

P18: Because it’s clearly something… it’s going to be changing its name anyway, I think.

**INTERVIEWER 1: Yes. So, hopefully, we’ll be… so, we aim to be in touch again with you if you're happy.**

P18: Yeah, okay.

**INTERVIEWER 1: To let you know when we have analysed the information when we have some… when we can provide an overview of our findings. And then we take steps from there.**

P18: Right, okay.

P13: Just to let you know, when we held our cafe, I did take some of your information and give it out to some of the group members. So, I'm hoping that you may get a nice response to (unclear 1:17:52).

**INTERVIEWER 2: Thank you.**

**INTERVIEWER 1: That’s really great. Thank you so much. [INTERVIEWER 2], have you got anything else you want to say?**

**INTERVIEWER 2: No, no. Thanks a lot for your support, it was really interesting and [P13], I will just write you an email about, you know, the voucher to know if you and [P18] prefer donation or voucher. But I will give you (unclear 1:18:15) explanation. So, it’s, you know, like, a thank you for your participation in the first one. And after, yeah, we will I’ve you feedback as [INTERVIEWER 1] said.**

P18: Yeah. And make sure you do.

**INTERVIEWER 2: Yeah, yeah. It’s a good point.**

P18: It does make us feel that we’re needed rather than used.

**INTERVIEWER 2: Yeah, yeah, absolutely.**

P18: Okay.

**INTERVIEWER 1: That’s brilliant. Thank you so much for your time.**

**INTERVIEWER 2: Thanks a lot.**

**INTERVIEWER 1: It’s been really fantastic talking to you. Bye. Bye.**

**INTERVIEWER 2: Thanks bye.**

P18: Bye.

**INTERVIEWER 2: Thanks. else you want to say? No, no,**

**[End of Recording]**