**WORK PACKAGE 1 – SESSION 3**

**Individual interview with stakeholder P3**

**26th March 2021**

Audio File Name: S3 - IDoService - Individual Interview - Other stakehoders - 26 march

Duration: 00:31:55

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

**R2: = Researcher (Interviewer in bold)**

P3: = Stakeholder

**R2: So, now I can ask you if you still consent to take part in this study?**

P3: Yes, absolutely, thank you.

**R2: Perfect, so yes, my questions, so the focus group, I think it was two months ago but the meaningful activities for people with early mild to moderate stage of dementia or even people with MCI and you mentioned maybe coordination or the differences between boroughs and conceal and these kinds of things, for you, it can be a problem or sometimes maybe something positive. So you could maybe speak a little bit more about that?**

P3: Sure, so within the ten boroughs of Greater Manchester, each one commissions memory services for itself and neurodegenerative diseases and dementia have a different priority within all of the ten different boroughs. There have been attempts to unify the priorities, but they haven’t been all that successful and different boroughs manage resource allocation within that very differently. So, for example, in Trafford, [PERSON ONE] runs Age UK services, so a third sector runs much of the quote, unquote “meaningful activity” for people with mild cognitive impairment and people with dementia.

So, its outsourced, whereas in Manchester footprint, as opposed to Greater Manchester, in the Manchester footprint, the NHS has developed a therapy hub which is a place where people with MCI can go and do these things. They have groups, support groups and all that kind of thing. In many of the boroughs, the CCG, the commissioners are content to allow the third sector to provide things like dementia cafes, to provide things like that and they don’t give them much support.

So, that’s a real problem for people, there’s an absolute postcode lottery in terms of what’s available. The other problem then is because the NHS is not the centre about which all these things revolve, communication of the existence of these activities to people living with cognitive impairment is very patchy indeed. So, some people who have very high educational attainment or occupational attainment background and have partners with high educational attainment and occupational attainment background know how to go out on the web and in the world and get all of the information, they create this little directory for themselves of all the things that they can have. They know all their rights; they know all of the funding that’s available and they also know how to contact other people for support and gain intelligence.

Whereas, on the average, that ability is not very good and for some people the ability to do that is very bad, so they don’t even know that there are specialist memory services, for example. So, there’s a whole spectrum in there but that patchiness means that planning services that could be rolled out at scale and could only be rolled out at scale, so for example, disease specific services. If you wanted to have something for people with early onset dementia, there would only be enough people in Greater Manchester to have a big service for those kinds of people because it’s rare and there’s not the coordination to do that, much as we might have tried.

So, that variation, some is warranted, in other words, the demographics are different from borough to borough to some extent. So, some of the variation is warranted but a lot of it is unwarranted variation and a lack of coordination, an accident of how services are funded and there’s a lot of talk about how Greater Manchester is supposed to be very joined up and we’re supposed to have devolved health and social care and we’re in charge of our own spending, but the practice is still very varied.

So, that’s one of the problems, I think one of the other barriers to access is deprivation, frankly. So, there’s two aspects to this, one is that people who are in lower socioeconomic groups present later, so they don’t notice, and nobody notices the cognitive decline until they’re at the middle stage of their Alzheimer’s disease. So, if you present with mild cognitive impairment, you’re more likely to be from a high socioeconomic group or from an area with a deprivation index which is quite low, and you may or may not be aware because it’s a quirk of the English data gathering but there’s lots of data on data.gov.uk about deprivation.

So the deprivation index is calculated from income deprivation, urbanicity, all these kinds of indexes, it was calculated in 2015, it was calculated again in 2019 and there’s quite a widespread in Greater Manchester of those deprivation indices. So, some areas like South Manchester have a very low deprivation index and some of them have quite high deprivation indices and in North Manchester or Central Manchester, for example, some of the highest in the country.

That’s something that doesn’t get factored into service provision. So, not only do these people present later, but they’ve less of that ability to access services because they don’t have the educational background to know and the culture is not that they have a right to access sit or something should be provided for them which people from higher socioeconomic groups say, if this service doesn’t exist, why doesn’t this service exist and if I get ten people together and we all write to our MP, maybe we’ll create a service. It’s just a very different way of approaching healthcare, it’s a more motivated way of approaching these things. So, we see that level of variation throughout Greater Manchester as well. Okay, ask me another question because I can talk for ages.

**R2: That’s really interesting but I think you are also involved in the Dementia United?**

P3: Yes, I have been, so the Dementia United was an attempt, it’s coming to an end, it was an attempt to unify some of the activity in Greater Manchester. To be diplomatic, it wasn’t clear what the targets were, in terms of project management, it may not have achieved all that it might have done because it tried to do everything, it’s tagline, it’s brief was to make Greater Manchester the best place in the world to live with dementia.

Now I don’t know what that means, nor did anybody else and so people came up with certain themes, some of the themes were easy to action and some of the themes were quite difficult to action and there was a lot of resistance, a lot of resistance at the level of the boroughs, at the locality level to standardisation because everybody was afraid, they were going to lose some of the resource they had.

**R2: Okay, so it was not really successful, in the end?**

P3: I feel it under-performed because it tried to do too much as a project. I strongly believe that the best results for people in healthcare, when you’re doing things that are almost Public Health but even your focus on meaningful activities for those living with mild cognitive impairment or early dementia, it is almost a Public Health intervention, the ideas that hopefully, number one, you improve quality of life but maybe, number two, you actually might have an effect on the progress of the disease or the experience of living with the disease.

That stuff has worked best, historically when it’s been from the ground up, when people have gone out and created things, from the bottom up, rather than having them imposed, partly because I know we’ve spoken a lot about variation, but people’s needs differ from area to area. So, in the South Asian community, there’s a huge need for education about mild cognitive impairment, about the fact that dementia is not normal aging, about the fact that there is a specialist service and a lot of stigma in the South Asian community about coming to a memory clinic which is situated in a mental hospital.

So, they don’t want to come because they don’t want to go to the mad house and be examined because they’re not mad, thank you very much, they’re just old and they just have memory problems. So, that pocket of work has to be done before we can get people together who are living with MCI and then in other areas like say, Didsbury or Chorlton in Manchester, where you’ve got a predominantly white, predominantly middle-class demographic, they’re pretty well educated and they present early and their question is, can I get access to research, can I get access to cognitive stimulation therapies. These kinds of things are meaningful for them if you like.

So, there is warranted variation, it’s not always geographical, the variation, I think that varies according to socioeconomic group and ethnicity and other things but there’s also unwarranted variation which we’ve spoken about. So, I think yes, Dementia United bit off more than it could chew, and I think there was … I’ll give you an example, so I’ve got a 75-hour work week roughly, every two hours of my day is planned. So, anything like this or anything with Dementia United is voluntary, essentially, I have to have make the time up somewhere else, which is fine because my whole life is doing this.

But there was no real realisation within Dementia United that anybody who attended, who was a doctor was going to have an extra hour or two or three, if the meeting went on for three hours at the other end of the day to catch up on everything that they had done. So, if there’s no realisation, then your engagement from clinicians is going to be low and the correct thing to do would have been to put aside some money to buy clinician’s time, so they could have some time backfilled, in other words, somebody would be covering for them on the wards. Then you could get clinician engagement from across the area, and you could also get engagement from broader community as well. But that wasn’t done. Anyway, in hindsight, everything is perfect in hindsight but yes, I wouldn’t have done it the same way.

**R2: It was a good try but not very successful or things to improve.**

P3: I think there were things to improve, yes.

**R2: So, it makes me think also about the dementia friendly access to activities can be linked to dementia friendliness, do you think … have you some idea how that can improve in Greater Manchester, some examples, things you see in other places or something you would like to see?**

P3: So, in terms of people living their everyday lives, what’s really important at the earlier stages is a good level of education amongst the general population about responding to people who have some cognitive impairment, so that if somebody is using public transport or they’re going to the hospital or they’re getting a taxi or they’re using a shop and somebody detects a level of cognitive impairment, that they’re educated enough to acknowledge that that is not normal aging, that it’s not enough to stigmatise it and being impatient and move on.

That’s a cultural change, so there are certain collectivist societies where older people are held in very high esteem, I’m thinking about Japanese society, for example, to some extent, I think the Scandinavian societies have a slightly better approach as well. I only have experience of Finnish friends, but they certainly say that the approach to older people is very different there. The UK is quite an individualistic society, and you may even detect that, coming from France.

It comes out of Thatcherism and it comes out of 40 years of there’s no such thing as society, I don’t know if you know, Margaret Thatcher said, there’s no such thing as society, there are only individuals and families and that become government policy for 40 years. The informal aspect of society is quite weak in the UK, the sense of a collective action, the sense of collective unity, union membership is very low, certainly compared to France.

So, there’s a number of cultural barriers to improving the lives of people with dementia and some of it is that actually people don’t care, they’ve been told … they don’t see the value maybe in being extra-patient, they don’t see the value in the older person when the older person has disease and really importantly, they don’t see themselves 40 years from now. They’re unable to project themselves 40 years from now which is a really important bit of working with these people because actually you’re working with yourself in 40 years’ time. Really, that’s the way I feel about it, I want things to be better because selfishly things are pretty rubbish now and I hope that I don’t end encounter that when it comes to me.

So, those barriers undoubtedly exist, what would I love to see? I’d love to see, in Greater Manchester, free transport for people with a diagnosis. When we diagnose people with dementia, we often take their car away and sometimes that’s right for safety and sometimes perhaps less. But they should have free public transport, there’s absolutely no doubt about that and some of them get it because they’re over 65 and they have access to a pensioner’s card and what not. But some of them don’t and I think the carers should have free access to public transport as well.

There needs to be, on a borough level, at least, so there needs to be at least ten in Greater Manchester, hubs, information hubs, where people can go and they should be outside of hospitals, where people can go for information, they can go for support and they can go for meaningful activity. So, in other words, we go together, my carer and I, I go and do my cognitive stimulation therapy or my dance class or my yoga or my tai chi or whatever it is that folks might do, and the carer goes into a support group for coffee and a moan and some networking and some advice.

I can imagine a place where I go and visit once a month and I recruit people to studies because they’re all collected in one place and it’s a centralised hub where people want to go. Now not everybody wants to be with other people who have dementia and we’ve mentioned some of the barriers before, didn’t we, fear about seeing people who are more impaired, all those kinds of things. But actually once you get them over the threshold of going, people generally have quite a good experience.

There are … within certain sectors of the Scandinavian society, I know that there are communities of people with dementia which are very different to what we would call a care home. So, in other words, people are intentionally at the early stages, given meaningful, paid jobs within the community, they are given … there’s a token economy, the place has its own currency, you know what I mean. Things are arranged as such that signage in the shops is explicit and clear and things are arranged logically in the shops, so people can maintain their independence.

How this thought, if you like, dementia of course, is when the cognitive impairment comes up against society, leading to a deterioration in independence and function. So, dementia occurs when you’re cognitive impairment is defeated by the microwave or is defeated by the remote control or is defeated by something else. The cognitive impairment in and of itself, might have been present for ten years, what we know about these diseases is they start in the fifties and if you test with hard enough tests, you’ll find cognitive impairment in these people at the very earliest stages.

But the dementia is a failure of the environment to accommodate that cognitive impairment. Now what I don’t want to communicate to you or anyone else is this soft idea which has crept in and some of the charities are to blame, that dementia is a journey and that it’s okay and that we should focus all our efforts on not defeating the diseases that cause it but accepting it as part of aging and I’m absolutely, obviously avidly opposed to that. These are fixable diseases, just as fixable as cancer, we haven’t got a cure for cancer but it’s much better to have it now than it was 50 years ago.

We’re, sort of, at that stage of dementia, we’re getting drugs through, we’ve got diagnostics and unfortunately, those are not being implemented as they might be. So, I think at every stage, from diagnosis to access to research, to treatment, to meaningful activity, to group support and education and information, dementia is under-served compared to cancer, compared to stoke, for example. If you’re diagnosed with cancer, you automatically have a charity, Macmillan, which is wedded to the NHS, which will provide you with dedicated nurses, there’s 24 hour a day phone lines, there’s all the information you can eat on the internet, in every digestible format, whether you’ve got a PhD or you’ve got very limited literacy, there’s videos, support groups, there are dedicated hospitals.

It's at a level of maturity in terms of service provision that I think we would really struggle to point to anywhere in the world for dementia, I just don’t think it exists and some people tell me that that’s because there’s a treatment for cancer but there’s no treatment for dementia. Well, there’s no pill that will stop it, there’s no pill that stops cancer either or if it does, it has pretty bad side-effects but there’s lots of stuff we can do for people with cognitive impairment, in terms of cognitive stimulation, alternative medications.

The finger study has demonstrated that they can be … you can reduce your risk of going from MCI to dementia by paying attention to blood pressure and exercise and all those kinds of things. So, there’s lots of stuff we can do but it doesn’t seem to have hooked into the healthcare service in the same way that cancer did, but maybe we’re just early on in that journey, I don’t know. Okay, ask me more questions Isobel because I’m rambling.

**R2: No, it’s so interesting but also you mentioned (unclear 00:23:38) thinks it but individualisation, sorry it’s difficult for me to say that, so you mentioned that ethnicities, social levels, or interest in activities and also you said the first step, okay I have my diagnosis, even the first step to have a diagnosis can be difficult but after that, to go, for example in Age UK or another service, to have information. So, have you some tips or ideas about how we can help people or individuals with these things or to have easier access to information?**

P3: Yes, so one of the things that we could do, if we’re talking about individualising information, is instead of trying to produce the Manchester booklet of information for dementia, you have a series of leaflets, if you like, which are lighter. So, you’ve got cognitive impairment in the memory domain is your piece of information on that, you’ve got cognitive impairment in the visual spatial domain because you’ve got Lewy Body disease, here’s your piece of paper on that. Here are the services that you can access in your locality.

So, that level, a directory really of individualised services and the people, I think might appreciate that a little bit more and maybe engage with that a little bit more. But it’s really back to commissioners, it’s really back to commissioners because quality service has to be paid for somewhere, whether that’s a yoga group or it’s a musical group, there’s only so much you can provide with volunteerism and community goodwill. Somebody has got to pay for the lighting, somebody has got to pay for the hall, somebody has to pay for the organisers.

It has been historically very, very difficult to get the commissioners to pay for those things from NHS funds, it’s not seen as a core health service duty to do those kinds of things and it’s probably outside of what social services think they should be doing because they’re putting out fires all over the place. So, maybe the third sector is the way but it’s not big enough to meet demand, is what I’m saying at the moment, not big enough to meet demand.

So, the MCI group in Trafford is tiny, it only accepts people from Trafford. Trafford is one of the areas of lowest need when you look at the demographics and the cases. So yes, I think we can make some efforts in terms of information provision to individualise what we’re doing, really, we want to be able to provide people with choice because if you say there’s a tai chi group, but I wouldn’t do tai chi if my life depended on it or there’s a yoga group, but I can’t touch my toes, then people are likely to not go.

Of course, age is a risk factor for dementia but people with dementia are 60-95 and if you think about that date of birth difference, it’s the difference between pre-war and baby boomers with very different cultures that they came from. These people were teenagers at very different stages, people I’m seeing now have life-long cannabis use and they started using it at Woodstock and it’s like a school, in the therapy hub, we have to stop them smoking cannabis in the toilets. Those are very different people from the 95-year-olds who you might find in a care home, who are mostly physically frail but are getting a bit of cognitive impairment and the ranges of needs is very, very different as well.

So, I think choice is really, really important, people have to be able to engage at their own level with what they want and what they’re able to engage with. That means providing services with some slack or adaptable services at the very least and that means resource again. I’m sorry to keep mentioning money but it really does mean resource and planning because otherwise you can provide something, and nobody will come, and things have happened like that. The dementia café where nobody turns up because nobody knew about it, it was uncoordinated, and people didn’t feel that it was organised enough to warrant going or anything like that.

So, I guess in that sense, the communication between the third sector and the NHS and the commissions could be significantly better across Greater Manchester because at least if we had that communication, we could find out what there is available to everybody and we might have some ideas about creating choice which as I said, to meet the needs of everybody who is living with early cognitive impairment, I think that’s important.

**R2: Great, I think we have already talked for 30 minutes, so I think I would like to go, it weas really, really informative, so thanks a lot and I will give you some updates by email about what we are doing in the project because according to the web page, it’s still not working and yes, thanks a lot. As you know, you can have a voucher, a £30.00 voucher but if you prefer, you can also have a donation for a charity.**

P3: Yes, I think a donation is more appropriate and yes, let me know how the research is going, let me know how the project is going and if, rather than being a subject, I can help as a colleague, I’m happy to do that, just let me know, whether that’s putting you in touch with groups or it’s putting you in touch with people within the unis.

**R2: Yes, it’s very nice.**

P3: I’ll bear you in mind when I’m having talks with other people, the uni is starting to come back to life a little bit, I think, so there may be more activity over the next few months.

**R2: Exactly, so I’m really looking forward to meeting you face-to-face, eventually, fingers crossed but yes, its very kind, so if you just … maybe you have an idea now of a charity or if you just want to send me an email later, when you have an idea.**

P3: Well, my standard one is Alzheimer’s Research UK, so that’s usually who I give to, from my speaker fees or anything like that.

**R2: Okay, right, so yes, we will let you know, when our service in the university are doing that, we will let you know. So, thanks a lot.**

P3: As they say, bon courage, keep going.

**R2: Thanks and yes, thank you for all this very interesting information and I hope your future health is good and hopefully we will be able to meet people soon.**

P3: Good stuff, well keep going, I’ll talk to you soon.

**R2: Yes, thanks, have a nice day.**

P3: All the best, bye now.

**R2: Yes, bye.**

**[End of Recording]**