**IDO SERVICE – WORK PACKAGE TWO**

**SESSION ONE IDOSERVICE: AGE UK SALFORD – CO-DESIGN GROUP**

**23 November 2021**

*These contemporaneous notes were written by the four Manchester Metropolitan University researchers present, made on afternoon 23/11/21 and then combined into one document.*

[preparation: materials prep, covid tests, screening questionnaire, wearing masks, bringing spare masks and hand sanitiser]

We arrived at Age UK for 11.30 to set up. [STAFF 1] from Age UK welcomed us, and [STAFF 2] joined us shortly after. We arranged tables for four groups, and put materials on the table, including post-its, pens, name labels, digital or instax cameras to take pictures as applicable later. [STAFF 1 & 2] laid out lunch and prepared the beverages. On hand was also a box with objects in case people had not brought anything.

People started arriving just before 12noon and clustered around three tables. There was one large group with 7 people (table 1, facilitator: Kristina, participants: 3 female, 4 male), another table (table 2) with 6 people (Facilitators: Isabelle, Steve, 1 female, 5 male), and a table with a smaller group of (4 people) which was also joined by the two colleagues from Age UK (table 3, facilitator: Laura, 3 female, 1 male). In total: 7 female, 10 male participants: being a mix of people diagnosed with dementia (6) and carers (6), some had been carers first, then stayed on after the death of a partner (4), or after being diagnosed themselves (1).

People had lunch, and towards the end of lunch time, we collected the consent sheets and offered replacements to those who had not brought them, which they signed helped by others in the group. People in the group had participated in research activities before and were familiar with signing consent forms. We answered any questions arising, which was mainly by one participant from table 2 regarding photos taken, because photographs taken at some previous activity for some other project had subsequently appeared ‘all over the internet’ and which he did not want to happen again. We reassured him that we would not take any photographs of him if he did not want to, and he decided that he did not want to appear in any photographs. Another participant in the same group decided the same. A third participant decided that he wanted to be anonymised if he appeared in any photographs.

When ready, Isabelle gave people the handouts for the introduction and made the introduction to the project. Kristina than took over explaining the importance and purpose of the co-design sessions for the whole project and the focus of the day’s session. Two participants offered comments that they had participated in co-design groups before and did not feel that results were effective or effectively communicate. They also voiced concern about services not being individualised enough, and Kristina explained that this is why we wanted to do this project so that we could develop a service where we can tailor activities to the individual.

The same participants also highlighted that being a carer was a day-by-day learning task, especially because all people and all dementia-related symptoms are different. They mentioned the difficulty to deal with the person they are caring for (but also with people around that might lack of understanding) and the resulting difficulty to find time and support to access support because it’s difficult to organise your day. They highlight the need to adjust and being flexible to take care of someone with dementia. This highlights the need to take into consideration the carer’s needs and experiences to offer an efficient service and reduce the risk of facing resistance (i.e., carers irritated by prescriptive attitudes and being “educated” about dementia and how to act).

The three groups then started working on the first task. Originally some feedback to the overall group was planned before a tea/coffee break, and then the second session following the same format before a final round-up of the session. However, the session worked rather more organically, and discussions merged with casual chat, supported by tea and coffee at around break time, and then moved into the second topic.

One issue that emerged during the discussions was that the masks the facilitators were wearing proved (not unexpectedly) cumbersome, especially for those hard of hearing who are dependent on lip-reading – a mix of mask wearing and social distancing to speak without masks was employed, but the originally considered clear masks would have been helpful and we will endeavour to get some for the next session if they are acceptable from a safety point of view.

When Isabelle took some photographs at the end of the workshop, she reassured the participants who did not want to be photographed that they would not be on them, and one of them replied then – contrary to at the beginning of the workshop – that he wouldn’t mind being on it, which may be seen as proof that he enjoyed the workshop.

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| GROUP ONE |
| [P23] (female, carer) |
| [P24] (male, dementia participant) |
| [P25] (male, dementia participant) |
| [P26] (male, former carer/dementia participant) |
| [P27] (male, former carer, now looks after [P26]) |
| [P28] (female, carer) |
| [P29] (female, carer) |
| GROUP TWO |
| [P30] (male, former carer) |
| [P31] (male, former carer) |
| [P32] (male, former carer) |
| [P33] (male,former carer) |
| [P34] (male, carer) |
| [P35] (female, dementia participant) |
| GROUP THREE |
| [P36] (female, carer) |
| [P37] (female, dementia participant) |
| [P38] (male, dementia participant) |
| [P39] (female, carer) |

**Group 1: (Kristina)**

Group one consisted of 7 participants, 3 female, 4 male and the facilitator. Two were current carers, other had been carers but now also had memory problems. All appeared to be in their seventies or older. All knew each other well and observed that they were very glad to be back and able to meet together in such a large group. When the group returned after the Covid restrictions were lifted, only groups of six participants were allowed.

**Task 1:**

Two of the seven participants had brought an object relating to an activity/skill they liked doing.

[P23] (carer) had made three round chocolate cakes. One resembles a Christmas bauble. Another one resembled a pinecone. The latter was made with chocolate buttons on the outside and a chocolate orange on the inside, situated on a chocolate coin. She learned cake decorating at night school and also had photos of birthday and weeding cakes she had decorated for her daughter and son, an activity she clearly loved and was proud of. She felt that she now had little time to pursue this and instead made mince pies and Christmas puddings.

[P24] was fond of refereeing. In the past he was a referee for football as well as rugby and he also liked playing cricket. He refereed mostly men’s matches at local leagues or for children’s matches. He mentioned refereeing in/for [SALFORD]. Later he also mentioned that he likes to read books.

[P25] chimed in that he was a [RUGBY PLAYER] for Salford. He also played the trumpet when he was in the [ARMED FORCES] in the … brigade. He also played in the rugby union. He was a swimmer and swimming coach.

[P26] (former carer) liked storytelling and dancing, and thought he could teach dancing.

[P27] (former carer, now helps look after [P26]) enjoys doing joinery. He had brought a pocket jointer and a piece to demonstrate pocket jointing. He had been an electrician and had worked at [A COMPANY] for 33 years.

[P28] (carer, hearing difficulties) plays the piano and likes reading. She also taught children swimming and was an international time keeper. She also likes computer games – crossword or cognitive games.

[P29] (carer) volunteers for Age UK. She loves being around people. She also looks after her family and does the school run for her grandchildren. She used to work in social services with terminally ill people. Together with [P27] she supports [P26]. She does not like the use of computers.

Kristina said she played the cello although not very much any longer and she had trained to be a jeweller.

The group mentioned dancing with dementia or something that tried but found it not very inclusive. They felt couples were not mixing and changing partners as they were meant to be. [P29] mentioned that it felt as if people with dementia had some sort of contagious disease.

They also mentioned singing with dementia. They felt that this was very good and helped people with their memories.

They also mentioned [A FEMALE] and remembered her neighbourhood project which they liked very much.

**Task 2:**

During task 2, which looked at activities that people either wanted to offer to others or receive help with, participants mentioned the following activities:

* Volunteering
* cake making
* Joinery
* Jewellery
* Swimming and timekeeping for swimming
* Playing rugby, football (for men and for children), cricket, refereeing for these
* Reading books
* Music making and listening
* Going to the theatre
* Watching rugby or old films

We also created a list of things people either wanted to learn or felt they could give help with or possibly had given help with previously in the past.

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| **Things I can help with…** | **Things I’d like help with…** |
| [P26] said he could help with teaching or coaching ballroom dancing. | Kristina said she would like to learn dancing |
| [P26] said he like to sit and talk about good memories because he could bring up things you had never thought about. | There was a suggestion that [P26] could talk to children or veterans about the past and his experiences. |
|  | [P26] would like to go parachuting because he had the training for it but never actually managed to do the jump. |
| [P25] used to be a swimming coach.  He didn't necessarily feel able to do this any longer but spoke fondly of his time doing it. | [P29] and [P23] said they wanted to learn swimming so they could join in. While they had taught their children they had never learned themselves and were afraid. |
|  | [P24] said he wanted to play rugby again |
|  | [P24] also said he wanted to referee for the England team - he didn’t mind whether it was football rugby or cricket. |
| The group determined that [P23] could help [P26] learn making meat pies. | [P26] wanted help with making a meat pie or pudding which [P23] could help him with |
| Participants in the group felt that everybody helped each other | [P27] mentioned that he liked doing social things as a group such as having a nice meal together or going to glassworks or similar excursions. Another thing was a long weekend together in Southend. He said age UK had organised such in the past for them. |
| One participant said they would like to offer help visiting people and talking to them ([P29]?) | [P24] said that he helped at home with the washing up. |
| [P28] said that she played the cornet and the piano  Kristina said she played the cello | There was a suggestion to make music together  Go to sing together. |
| Kristina said that she could teach jewellery making. | [P23] said that she would like to learn jewellery making. |
| There was a suggestion that university students could come and accompany a person from the group for a day to allow them to do something they could not do otherwise. |  |
| There was an observation that in the past they had bad experiences when people took their loved ones with dementia shopping because they might walk the aisles and take things on the shelves. And with staff had queried why the shopper brought the person with dementia with them or why at this time. – a suggestion might be to volunteer with shopping centres or supermarkets to raise awareness, help people understand, or support people with dementia and their carers in the task of shopping. – Perhaps work with dementia friends to create such a volunteer and awareness campaign. |  |

**Groups 2a,b (Steve, Isabelle)**:

Group 2 consisted of 6 people (5 male and 1 female) subdivided into two subgroups: a) [P30], [P31], and [P32] (facilitator: Steve) and b) [P33], [P34], and [P35] - [P34]’s wife (facilitator: Isabelle), with [P33] sometimes navigating from one subgroup to the other.

[P30], [P31], and [P32] are former carers, [P33] very recently lost his wife and [P34] is still taking care of [P35] – who has advanced dementia and speaks very little and only a few isolated words. At many occasion, they highlighted the importance of their friendship, mentioning it’s the only good thing that dementia offered them. They are very supportive friendships because with people that understand what they are living through and the impact of being a carer. [P33] expressed that from sharing their experiences, it was clear how there was no single way to care for loved ones with dementia, they each had to find their own way (subject to the individual conditions, personalities and contexts).

To quote [P30] (referring to his fellow carers and former carers): ‘Dementia brought us together..’

All 3 participants from subgroup B appear still quite young (no more than 65 years old). [P33] mentioned that his wife died before her 60th birthday. So she and [P35] had/has early-onset dementia that in some cases can be especially aggressive and fast to progress – making it harder for the carer/partner and giving less time to adapt. [P33] mentioned he had to stop working to take care of his wife.

All participants from subgroup A, whilst older (in their late 70’s), were each physically well. [P32] cycles for leisure and [P30] engages in ballroom dancing. [P31] recounted that the experience of caring for his wife had taken a physical toll on his health.

All of the group (2a & b) knew one another as a result of being part of the AgeUK carers group and engaging in the meet-ups and social activities. [P32] and [P30] showed a particularly strong social bond and on occasions connected outside of organised activities – pledging during the session to join one another in a new activity, signing up at a local gym.

**Task 1.**

*Group A (Steve): [P30], [P32] and [P31] each brought objects*

[P30] shared 2 objects, a music CD (musical theatre/ Westside Story) and a box set of conspiracy theory DVDs. Listening to music (particularly singing) calms [P30] down and he also shares a love of ballroom dancing as a pleasure. He likes to share his joy of music by lending CDs out to people.

[P30] has a curiosity around conspiracy, hence his box-set of DVDs. Rather than having a closed mindset, he and [P32] spoke of the ways in which conspiracy topics and historic news headlines (he has papers from the Falkland and Gulf wars), can offer a basis for (constructive) discussion and debate.

[P31] chose to share a novel (Magician, by Raymond E Feist), reflecting on his joy of escapism reading fantasy novels. Both [P31] and [P30] have been active members of Age UK’s book club.

[P32] brought memorabilia of his beloved sports of rugby and football a Manchester City book and a section of rugby shirts and the Manchester City football shirt he wore as a child. Beyond his love of the sports, he spoke of his efforts to stay fit, including regular cycle rides including a trip by the river, typically of 3-4 miles. He does like to treat this as a more leisurely pursuit, sometimes stopping for a pint on the return journey. At this point [P30] spoke of an over 70s membership offer at a local gym ([IN SALFORD]) which he and [P32] agreed to get together in joining.

Speaking further about hobbies and pursuits, [P32] reminisced of a hands-on craft kit to construct a barrel organ which he completed in his youth and he still has now and is very proud of, very keen to bring it with him to the next engagement session.

What became really apparent in ongoing discussion was how much engagement in social activity had been facilitated through the local group(s) including (pre-covid) organised trips such as pub lunches and memorable day trips, including Salford Quays and Blackpool.

As carers who had since lost their partners, the group spoke of their experiences caring for them and how peer support group made a significant difference. AgeUK had in the past provided a 6-week carers course (it wasn’t clear whether this was still provided). It clearly helped each carer that they were able to share experiences and learning and they highlighted that there was not one single way to provide care, influenced by the individual circumstances of their own contexts and conditions (type and behavioural effects of dementia, personality of the carer etc). Amongst their accounts of shared experiences, they talked of times they got frustrated, raised their voices with their partners ([P30] and [P32]) and felt bad about it afterwards. Ths really brought home the value of the peer support network.

The environment was key in their experience for newcomers joining the group(s), whereby the act of ‘making a cuppa’ was critical to making them feel welcome and relaxed.

Steve asked the question of the group of their knowledge of similar ‘connected’ groups for those with dementia and their carers elsewhere in Greater Manchester. From their knowledge, Salford appeared to be unique, citing Wigan as an example of a borough without such support.

*Group B (Isabelle): [P33] and [P34] had brought objects.*

[P33] showed his snooker cue. He really enjoys playing snooker and was part of a team but due to Covid, he had to stop it. It should start again very soon. He also mentioned cycling – he has a lot of bikes at home – but due to covid-19 he got less external support with his wife so had not the possibility to find time to cycle. His second object was a picture of him, his wife, and another family member taken during a cruise – one of his daughters works on a cruise for a long time and he and his wife really enjoyed cruises.

[P34] only brought one object – a notebook with some stories inside – he is part of a writing club (meeting one week online – the following one face-to-face – to adapt with covid and include everyone). He mentioned he and his wife enjoy(ed) travelling – [P35] was very keen to learn new languages – French, but also Italian and Spanish. She also really enjoyed musicals and still seem happy to listening to them.

Both [P33] and [P34] mentioned the importance of socialising/friendships and that some of them might change with the diagnose (some friends not being in touch anymore but some friendships becoming stronger) - but they didn't seem to mind the lack of support of some of them. They appreciate group days out, for example at Blackpool, for a lunch, etc. They highlighted the importance of some rituals such as regularly meeting friends at a pub for a chat. [P34] mentioned he enjoys cooking and inviting family/friends at home.

Regarding the interest of [P35] in activities, [P34] explained it’s difficult to know because he has no feedback. So “we do things we used to do… I don’t know because I have no feedback”. He also explained that he has now less time for his own activities due to his wife dementia.

[P34] mentioned he would like to try doing mosaics or related crafts to put outside, in the garden. He selected some material from the objects’ box to illustrate it.

He/they appreciate weekends away, walks – [P34] discussed with [P33] about the importance of accessible walks with clean paths to avoid falls and being accessible in a wheelchair – [P33]’s wife was in a wheelchair but he mentioned it was not a barrier to have access to activities outside of their home – it was really important for [P33] not staying inside and continue to have activities out of their home with his wife. [P34] mentioned that walks are the only one [P35] physical activity (she is not active at home – no activities even not chores or related). [P33] mentioned he enjoys camping – usually to be part of a beer festival – but he would like it for other activities too.

**Task 2.**

*Group A (Steve):*

The majority of the dialogue within the session related more to Task 1 as [P30], [P31] and [P32] spoke at length about the value of the group/network that exists and how these were forming lasting relationships between carers, beyond the lives of their partners.

In discussions around proposals for shared activities and initiatives for those with dementia (and their carers), the following were proposed and explored by the group:

Art and Craft: This was seen as a really engaging activity, which can be enjoyed without prior skill. With experience of previous classes, the group see this as being an activity which can be responsive, where activities and materials can be mixed. Additionally this is seen as a social activity, participants opening up to chat and share laughter. One member of the group (carer) shared that they had been able to stop using anti-depressants through participating in painting.

Walking: This is seen as a very accessible shared activity. Dog walking was discussed and whilst having a dog was seen as a barrier through additional responsibility, it was suggested that this is still possible through ‘others’ bringing their dogs along to the park for example.

Holidays/package deals and Cruises: building on successful days out in the past, this came as a suggestion (from [P34]) to tailor breaks for groups those with dementia and their carers.

*Group B (Isabelle).*

[P34] mentioned he would like to stick to his earlier idea about mosaics – it would bring colour to the rooms and be beautiful. When Isabelle asked if some external support or tips would be supportive, he mentioned he tends to do things on his own. When asking him more about how some support - and in which context/for which activities – might be useful to him and [P35], it mentioned he is receiving support from his relatives.

But after reflection, he mentioned he is not very keen on short drives (but doesn’t mind to drive longer distance), for example from home to a meeting place, so some support for it might be useful – including small buses to share with the other people involved in the activity (e.g., a walk around GM).

Isabelle asked if they would appreciate walks in nature led by someone giving nature or historical details about the place – he agreed he would appreciate it. Same for a language exchange – meeting someone willing to improve their English by speaking with native speakers and offering another language that [P35] was learning in return. He thinks that [P35] might have liked it when she was at an earlier stage of dementia. We discussed the importance of “dementia-friendly/inclusive” features – e.g., not too noisy, not too dark, disabled toilets, etc.

Isabelle suggested to [P34] to try to speak a little bit with his wife in French, it might trigger some memories and positive emotions – he speaks a little bit of French from their holiday in France. He said he will ask their daughter who is living in France and has a perfect command of French. He said some words in French and his wife reacted to them by standing up from her seat and pronouncing two inaudible sentences. It stayed isolated as she did not really react to more words in French, but [P34] seemed happy with her initial reaction because she is usually self-contained and not very interactive with people around – and mentioned he will definitively ask to their daughter to try it.

[P34] would enjoy more time in galleries and museums. Going there with his wife doesn’t seem a problem but he would be happy with support with planning (usually their relatives are doing it) – programme, tickets, transports, etc.

[P34] highlights that currently, it would be very difficult for him to find time to support/help someone else as he is dedicated to his wife. But [P34] think he might help someone with gardening – he has indeed in his friends network someone struggling with gardening – but they might need to adapt to find a way to support her while taking care of his wife.

* [P34] and [P33] appear to be very resilient and to have found a good organisation/balance between taking care of someone and staying mentally fine. [P34] mentioned he used to keep early morning hours for his own activities – when his wife is still sleeping. Despite his mourning, [P33] highlights the importance to keep going and having activities (again). So he is going on the cruise he had originally planned with his wife - he hesitated but his daughter did indeed insist that he must also take care of himself.

All participants highlighted the fact they are lucky to be in Salford as the place offered several opportunities and support orchestrated by Age UK Salford and the Reach Beyond & Open Doors Service. They are very aware of disparities around in other boroughs. During the short end-of-session debrief, Isabelle asked to participants how they felt about the session – if we might improve it and how to make it more pleasant for them. They unanimously reported they really enjoyed it and that would be very happy to be part of the next workshop.

Another remark (ethic): As [P35] is not very interactive (only some words and a face showing little emotions, it was difficult to know if she feels some discomfort being part of the workshop. But she grabbed some of the objects on the table – showing some interest? – and drank a cup of tea and had biscuits – and did not seem to want to leave the table during the workshop. [P34] has been very attentive as always, reassuring her by physical contact and never expressed she might feel some discomfort or impatience – at least not more than usual during the dementia café.

**Group 3: (Laura)**

Group three consisted of 4 participants, 3 female ([P39], [P36], [P37]), 1 male ([P38]) and the facilitator. (Two volunteers from Age UK also occasionally joined but were also occupied with hospitality for the room, so came and went.) Two were current carers and two were people with dementia. [P38] had mid staged dementia to the point that he was unable to communicate verbally, other than confirming his own name. He and his carer ([P39]) appeared in their 60s. The female with dementia ([P37]) was able to speak but was also largely silent and so her carer answered all questions for her. She appeared in her 80s and her carer is her daughter ([P36]). The carers knew each other well so the group appeared comfortable with each other and happy to chat.

**Task 1:**

Only one participant had brought one object.

[P36] had brought an art canvas and some stick-on jewels which were intended for her mother [P37] to be creative with. This sparked a conversation about all the arts and crafts things that [P37] does with assistance. The carer showed us multiple pictures on her phone of things that [P37] has done in the past couple of years. These included paper craft wreaths, a model witch for Halloween and art work using buttons. We discussed that before [P37]’s dementia had progressed, she was a keen and talented illustrator however she is no longer able to do this.

[P38] & [P39] had not brought any objects. [P39] stated that [P38] enjoyed walking, to which he nodded along in agreement. They used to regularly go on long walks together, for the enjoyment of the views and fresh air. [P38]’s dementia has progressed too far for this style of walking now.

The group then discussed the activities that [P37] currently participates in throughout the week. She has various clubs to attend – dancing for dementia, singing for dementia, armchair aerobics, dementia café.

The conversation then moved on to activities they used to enjoy, however both [P37] and [P38] had progressed too far, so these were no longer possible.

-Travel. All had been keen globetrotters but now, we discussed how even local travel is difficult as there is distress if unknown routes are taken or if the routine is broken.

- Squash, table tennis, curling, general sports. A couple of years ago [P38] and [P39] tried curling. However, it wasn’t a dementia specific session and they found it unenjoyable due to the lack of understanding from the ‘normal’ (their word) people attending.

**Task 2:**

Both people with dementia in this group were unable to offer any support to other people as their dementia is too progressed. However, [P37] would previously have been able to offer art and illustration skills and [P38] was previously a mechanic and loved engineering prior to his diagnosis.

When discussing what support was needed for them to do the activities that they enjoyed doing, there were no new activities that they wanted to try, but rather they just wanted more of what was already available, and help attending these. The main help that [P39] wanted was with transport. She doesn’t drive and so getting [P38] to various venues is a real struggle, preventing participation. Taxis are too expensive, ring and ride to unpredictable, public transport not an option and charities don’t have enough volunteer drivers or services.

Other things they wanted support with was something for the carers as a bit of respite while the people with dementia were doing an activity – something in tandem. [P36] and [P39] were in agreement that the activity was unimportant – it was the stimulation of any description that was important and just getting their loved ones out of the house.

[P38] began to get agitated by the length of time he had sat, so conversation then moved to general chit chat for the remaining time while his carer helped him calm. [P37] became animated for the first time telling a story about how her childhood house was bombed in the war and how she and her siblings were evacuated.

**Actions for next time (February):**

Clear masks

Feedback at the next session & what we have done with it

Taking more instant pictures to share/give to participants? [P32] took one himself and seemed very happy about it – it reminded him of the first polaroids and he hadn't used one for a long time – and happy too of keeping it.

