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Article

I Can Do: Co-Designing a Service with and for People with Dementia to Engage with Volunteering

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Abstract: This article reports on the co-development of the concept of a skills exchange service for people with early to mid-stage dementia. The service was co-designed with people with dementia, carers and professionals from the health, care and volunteer sectors in Greater Manchester, UK. The idea for the service arose from the recognition that it is important to people with dementia to be able to continue contributing to the life of others and to be valued for it, but that there is little support for people to do so. The initial data collection with stakeholders into opportunities and barriers in Greater Manchester provided key insights as a starting point for the service concept development. For its development, seven co-design workshops were held: two with people with dementia and five with carers and health, care and volunteer professionals. The outcome was the development of the concept and criteria of the *I Can Do Pathway* to support people with a dementia diagnosis in identifying their interests and strengths and to connect them with relevant volunteer opportunities. The article explains the transformative co-design process and its results, followed by a reflection of the insights of designing a new service within an existing service system.

Keywords: co-design; dementia; design concept; design development; service design; volunteer service; wellbeing

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1. Introduction and Key Concepts

The aim of the *IDoService* project was to develop a novel service with and for people with a recent diagnosis of dementia in Greater Manchester, UK to build confidence and self-value through connecting with and being able to contribute to the life of others. The research arose from the recognition that people with a dementia diagnosis often feel disempowered and lose their sense of self-value. This article reports on the co-design phase of the project, which researched and co-developed the service concept with stakeholders in Greater Manchester. We first discuss the key concepts and premises from dementia, service design and co-design that provide the basis for the development of the service. We then describe the methodology for the co-design phase before reporting on and discussing its results.

1.1. The Importance of Supporting People Diagnosed with Dementia in Accessing Social Activities

Dementia is one of the main societal challenges of the 21st century (WHO 2021). It is characterised by the progressive decline of cognitive, behavioural, social and emotional functions (Dening and Sandilyan 2014). With currently no cure, the focus for care is to improve quality of life. Much effort has been made on the later stages of dementia and care home provision. However, in England, 60% of people with dementia live at home (Clarkson et al. 2017). Therefore, more support is needed for people following the diagnosis of dementia, which is a key moment for people. While being able to explain memory and behavioural changes may come as a relief for some, being diagnosed is a difficult moment for most. It can leave people feeling helpless, anxious and alone (Low et al. 2018; Pratt and Wilkinson 2001; Roberts 2019); they may struggle with "self-identity, independence, control and status, activities, stigma, and how to view the future" (Low et al. 2018). This can cause depression and lead people even to consider suicide (Roberts 2019). However, with the right support, people with dementia can have fulfilling lives for many years.

A key to living well is keeping active and socially engaged (Fernández-Mayoralas et al. 2015). Participating in and contributing to social activities can provide a sense of agency or empowerment, which in turn promotes wellbeing (Niedderer et al. 2022b). However, people feel that there is not enough information and support following the diagnosis to achieve this (Low et al. 2018). The policy report from the Alzheimer's Society finds that "People affected by dementia value peer support and social contact" but their "survey found that one in five (21%) said they currently lack receiving peer support and almost one in three (31%) lack receiving support to maintain their social life" (Arblaster and Brennan 2022). This indicates a lack of support for accessing and participating in social activities. This particularly affects people at the early stages with a recent diagnosis: While people are looking for support with suitable social activities, dedicated dementia events that capture participants with mid-to-late-stage dementia may not offer the level and diversity of activities people look for and may be perceived as not suitable (Tournier et al. 2023). Furthermore, many people want to be able to make a contribution—however small—and to feel valued for it (Zanasi et al. 2023).

1.2. Co-Designing Services in the Dementia Care Context

To address this lack of support for people with a recent diagnosis of dementia (Arblaster and Brennan 2022; Wilson et al. 2023), the present research has investigated the development of a service that can help people to connect with and engage in social activities they feel are suitable and meaningful to them. Service design is playing an increasingly important role in the development and improvement of health and care services through its holistic and person-centred approach (Malmberg et al. 2019; Stickdorn and Schneider 2011). Such an approach needs to consider processes, components and environments as well as stakeholders involved in the service design to meet users' needs and expectations (Marquez and Downey 2015). To understand the different components of and participants involved in a particular service, co-design has become a key process within service design, which enables its holistic and person-centred aspirations (Steen et al. 2011).

Co-design came to prominence in 2008, with Sanders and Stappers' early publication on the topic (Sanders and Stappers 2008). Its recognition has since greatly developed, having become an established process both in service design and healthcare design because of its benefits to creating services that are fit for purpose. Co-design differs from public and patient involvement, which has been part of UK health and care policy since at least 1999 (Greenhalgh 2009), and includes participants usually through consultation and advisory functions. By contrast, co-design favours the participants' active engagement in the creative process of developing services or other design outcomes to ensure their relevance to the target group(s) (Wang et al. 2019).

Co-design has been recognised for the benefits it offers participants through involvement in the creative process. Using story-telling-focused co-design methods with family caregivers of people with dementia can enhance trust and empathy, and participants can benefit from the process itself as well as from the final outcome (Neuhoff et al. 2022). Rodgers (2018) has shown that people with dementia also can greatly benefit from involvement in the co-design process. Zeilig et al. (2019) have demonstrated that co-creativity can affect "experiences of well-being and agency of people with dementia and partners" because of its "inclusive and equalizing approach" as well as respectful sharing of stories, giving people a voice and nurturing trust, thus "increasing confidence and wellness" (p. 22). This is echoed by Rodgers (2018) with additional emphasis on the benefits of the social engagement ("being part of something") and of the satisfaction of achieving something (pp. 11–12).

However, co-design has been understood in a number of different ways. In line with prior research (Niedderer et al. 2022a), for the purposes of this study, we define co-design as "the methodological aspect of the collaborative and joint process of designing" (p. 3). Because of its creative nature, which requires defining the design problem before addressing it and developing a solution, it is important to include people with lived experience in the co-design from the beginning. This enables identifying relevant problems and developing suitable solutions for the targeted improvement of products, services or environments (McDougall 2012; Dening et al. 2020). In addition, we understand the related term of co-production as facilitating the collaborative space that enables successful co-design, while we use co-creation to refer to "the active participation of end users in [the] different phases of the creation process in general" (p. 4).

1.3. Co-Designing for the IDoService

In line with the above discussion, the research drew on a wide range of stakeholders to design the service, including people diagnosed with dementia, carers, dementia support workers, representatives from relevant charities as well as from health and care services in Greater Manchester. To include them throughout the project, it was structured into three phases: (1) Interviews and focus groups with stakeholders to understand barriers and opportunities for accessing and participating in social activities for people with dementia in Greater Manchester and which identified key insights for the service (Tournier et al. 2023); (2) the co-design phase to develop the service concept reported here; and (3) the implementation and evaluation of the service.

In the following, we describe the methodology for and delivery of Phase 2 and its results. We explain how the seven co-design workshops led to the development of the *I Can Do Pathway*, a guide and workbook for delivering the service to help people with dementia to identify their interests and strengths and to connect with relevant volunteer opportunities. We detail the design specification arising from the results, and we reflect on the transformative co-design process and insights of designing a new service in relation to an existing system.

2. Methodology

Phase 2 of the *IDoService* project consisted of seven co-design workshops with various stakeholders to co-develop the service concept. The aim was to develop a service for Greater Manchester that would support people with a recent dementia diagnosis in identifying their interests and strengths and to connect them with relevant volunteer opportunities. A key consideration was how the service could be made to fit within the existing service provision. It was therefore essential to include stakeholders from various existing services, including from health, care and voluntary organisations as well as people with dementia in the co-design.

2.1. The Workshop Design

The seven workshops were organised in an iterative set of events, whereby the first set (W1–4) explored the purpose of the *IDoService*, and the second set (W5–7) explored the content and format of the service and how it might be made to fit within the existing service landscape. Each set contained one face-to-face workshop with people with dementia and their support persons and three/two online workshops with stakeholders as set out in Table 1. The design of the workshops was based on prior research into co-design methods for use with people with dementia, especially within a service context (Niedderer et al. 2022a). Principally, methods chosen included: storytelling and prompts to facilitate storytelling related to the topics for discussion in each workshop, such as skills and experiences of people with dementia; and interactive prompts to facilitate discussion about the service pathway to help participant imagine what the service might entail and to solicit their responses and input. Methods and delivery format of the workshops were chosen to make them as accessible and engaging as possible, especially for those living with dementia, to allow them to share their insights and views fully.

Table 1. Overview and design of the co-design workshops (developed from Niedderer et al. 2022a).

Workshop No., Date & Mode	Content	Participants	Methods
Workshop 1 November 2021 Face-to-face	Explore meaningful/leisure activities and skills people like to do, like help with, or like to offer to others	People with dementia and care/partners 17 participants (6 people with dementia, 6 carers, 5 former carers)	Prompts (Garde et al. 2018): We asked people to bring objects that represented their favourite activities and/or skills. Storytelling (Ahmed 2015): We asked people to tell stories about their activities and skills important to them, using the objects they brought.
Workshops 2, 3 & 4 December 2021 Online via MS Teams	Explore services and opportunities based on identified skills and interests	Service providers 3, 6 and 5 participants, respectively	Online focus groups (Kort et al. 2019): For the workshops with service providers, we used a more traditional online focus group format, where we combined questions with storytelling to elicit relevant information about services and examples of their application.
Workshops 5 & 6 March 2022 Online via MS Teams	Explore and work out how the service could or should work	Service providers 7 and 5 participants, respectively	Service-pathway mapping using visual prompts and storytelling. All sessions followed the same pattern and were used to explore the proposed service pathway intervention—what to offer, how it might work, how to deliver it. A visual map with movable items was used to work imaginatively through what might be involved, and to solicit input and feedback on how a person might need to be supported to enable participation as a volunteer or participant.
Workshop 7 March 2022 Face-to-face	Explore and work out how the service could or should work	People with dementia and care/partners 21 participants (8 people with dementia, 8 carers, 5 former carers)	

2.2. Recruitment of Co-Design Participants and Workshop Settings

2.2.1. Stakeholder Recruitment and Online Setting

The results of the interviews and focus groups from Phase 1 (Tournier et al. 2023) were reported back to all participants in a series of online webinars in autumn 2021. These webinars were used to introduce the idea of and to invite stakeholders to participate in the forthcoming co-design workshops (Phase 2). A total of 26 participants (8 male, 18 female) were recruited from the following organisations:

- Age UK Salford;
- Age UK Stockport;
- Age UK Trafford;
- Alzheimer's Society;
- Caribbean African Health Network (CAHN);
- City of Trees;
- Dementia Carers;
- Dementia United;
- Global Brain Health Institute;
- GM Dementia Research Centre;
- Greater Sport (Active aging);
- Health Innovation Manchester;
- Health Watch Manchester;
- HMR Circle;
- Manchester Community Central;
- Manchester Metropolitan University;
- NHS Salford Clinical Commissioning Group;
- Reach Beyond & Open Doors Service, Salford;
- Social Sense;
- Springboard, Oldham;
- Together Dementia Support.

Participants were provided with information and consent forms one week in advance, and consent was confirmed verbally on the day. Workshops were held and recorded via MS Teams business accounts and subsequently transcribed. A PowerPoint presentation was used to provide an introduction and the questions for the workshop. Virtual working sheets with blank spaces were used to record participants' input on screen to support discussion in the session as well as in follow-on sessions.

2.2.2. Recruitment of People with Dementia and Workshop Setting

The co-design workshops with people with dementia were organized through Age UK Salford and held during their bi-monthly dementia cafés (November 2021, March 2022). Participants in this study were regular participants in the dementia cafe. They ranged from a recent diagnosis and admission by Age UK Salford to their dementia cafe (less than a year) to having attended as long as two to three years. All participants were informed of the event and provided with information and consent forms one week in advance, and consent was (re-)confirmed on the day. The group had already previously participated in research projects and were aware of the consent process. All individuals on the day were happy to participate but mentioned that they would like to be kept informed about the outcomes of the project.

The familiar social environment provided a supportive context for participating in the co-design activities and expressing their views. A pre-workshop lunch was held to allow participants and facilitators to become acquainted informally before starting the workshop. Making the participation in research enjoyable and meaningful for participants has a beneficial impact on the immediate quality of data collected, on participants' well-being and on the willingness to participate in the future (Rodgers 2018; Zeilig et al. 2019).

The project delivery also had to adapt to COVID-19 restrictions, including lockdown phases and safety requirements. Therefore, workshops with stakeholders were conducted online during lockdowns, whereas this mode was deemed not suitable for people with dementia. Hence, workshops with people with dementia were conducted face-to-face at times when this was possible, observing ethics guidelines and COVID-19 safety measures as applicable at the time of conducting the workshops, including COVID-19 screening questionnaire, COVID-19 tests, wearing masks or observing social distancing, providing spare masks and hand sanitizer.

Workshop 1 comprised a total of 17 participants (7 female, 10 male), which were a mix of people diagnosed with dementia (6), of carers (6), and of former carers who had stayed on (5). During the session, the group was looked after by two staff from Age UK.

Workshop 7 comprised a total of 21 participants (9 female, 12 male) of which 8 had been diagnosed with dementia, 8 identified as carers and 5 as former carers. During the session, the group was looked after by two staff from Age UK.

The workshops were run with four researcher-facilitators, including one psychologist and three designers—all with some experience in working with or caring for people with dementia or mental health issues. The group was split into three and four sub-groups for W1 and W7, respectively, led by one of the researchers each, because it is easier for people with dementia to work in smaller groups to avoid information overload. We asked participants to choose their own groups and participants they wanted to work with to make the sessions as comfortable and convivial as possible. The team met before the sessions to discuss and agree on the questions and objectives of the workshops as well as the co-design process, including ethics and safeguarding requirements. The purpose was to ensure the equitable and competent delivery by the different researchers across the different sub-groups. All researchers took notes as well as photographs of the objects brought along. They also encouraged participants to take photographs with the Instax cameras provided. Notes were written up by the four researchers after the workshops while they were fresh in mind and then amalgamated. We chose not to audio record the sessions. Because of the large group, this was deemed impractical (noise interference) and it was felt that it might make some of the participants uncomfortable. In addition, the co-design process did not necessitate a detailed thematic analysis, and hence a recording, as explained in the following.

2.3. Results Analysis, Consensus and Decisions Making

Since the results of the workshops had the purpose of the design concept development, a traditional systematic thematic or content analysis of the workshops by the researchers to achieve objectivity was not deemed appropriate. Rather, in line with the co-design ethos of the project, the development followed an iterative design process model based on idea generation and dialogic consensus as follows:

1. Within the workshops, ideas were openly discussed and, at relevant moments, researchers aimed at leading the discussion towards census relating to the key points discussed, loosely following the idea of the Delphi model (Toepoel and Emerson 2017).
2. A purposive review of the outcomes by the researchers after each workshop helped to synthesise key discussion points, ideas and points of consensus for use as source material and to build on in the following workshop(s). This is in line with the iterative nature of the design process. (Jonassen 2008; Sawyer 2021).
3. In the final stage, researchers reviewed all the information and outcomes from the workshops in the context of relevant psychosocial and design theory to draw up the specification for the service as a precursor for the design realisation and evaluation in the third phase of the project.

3. Outcomes of the Workshops and Concept Development

The aim of the seven co-design workshops was to develop the idea of the skills exchange service, which had emerged from Phase 1. In the following, we describe the workshops and their results and how their iterative sequencing enabled the development of the service concept from initial idea to tangible concept.

3.1. Co-Design Workshop 1: Understanding Experiences, Expertise and Interests

The purpose of **co-design workshop 1** was to understand people's experiences, abilities, skills and/or expertise as well as their interests of using them in the present, of learning something new, or to engage in meaningful social and creative activities. To start the discussion, we asked people to bring one or two objects along that represented (1) an activity they liked doing and (2) a skill important to them. About half of participants had brought objects to talk about, leading to a vivid discussion about their interests and skills, including sport, music, literature as well as craft skills, such as cake making or carpentry (Figures 1–4). Interests and skills were widely varied and included some predictable as well as some less common results:

- Sports and physical activities, such as walking, cycling, ball games, swimming, dancing, parachuting training and others.
- Arts and Crafts such as painting, illustration, making paper wreaths, mosaic laying, joinery and making a barrel organ.
- Other creative and leisure activities, such as reading, writing, storytelling, singing and playing music together, learning languages, cake making as well as playing various games.
- Leisure and travel activities, including days out, visiting museums or galleries, camping or holidays and weekends away.
- Socialising and friendships were important to people, such as regularly meeting friends at a pub, cooking and inviting family or friends at home, helping each other.

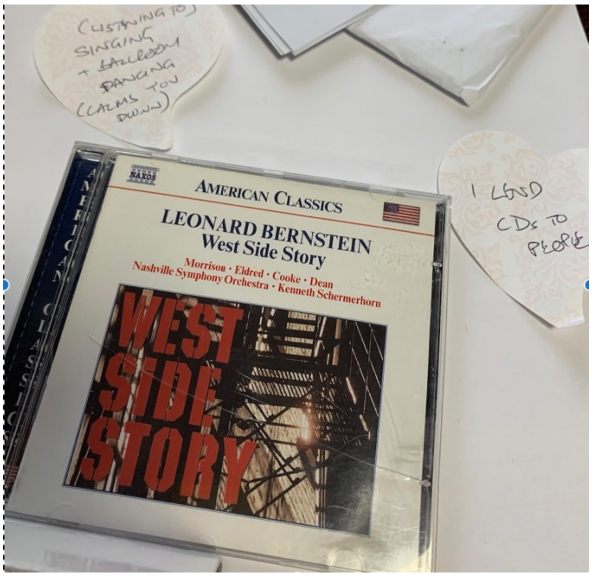


Figure 1. Music CD by one of the participants.

Figure 2. Signed memorabilia shirt by one of the participants.

Figure 3. Home-made cakes by one of the participants.

Figure 4. Demonstration of joinery tool by one of the participants.

The second half of the session looked at these interests and skills to find out what kinds of things people felt they could offer or help people with or, in turn, which they would want to learn or benefit from help with. When it came to helping others, some daily activities were mentioned, such as washing up. Other suggestions included: volunteering in supermarkets to raise awareness to make shopping for people with dementia easier; storytelling to make people think, refereeing for ball games, or being a swimming or dancing coach. Regarding needing help, support with travel to get to activities was a recurring theme. Other suggestions included learning to swim or dance or learning a foreign language. One participant suggested that he would like to go parachuting with someone experienced because he had the training for it but never actually got to do the jump (Orton et al. 2023, files 1. & 2.).

What emerged from the discussions of the workshop for the design of the service was that there was much interest, but that the service would have to be flexible to promote individual's interests outside of dedicated dementia activities and for activities not to be stigmatising or limiting. Also, support would have to be at hand for the persons with dementia to enable them to participate in or try new things without overloading carers and/or to give them respite time. These insights drove the presentation and questions for the workshops with service providers.

3.2. Co-Design Workshops 2, 3 and 4: Determining the Purpose of the IDoService in Relation to Existing Provisions

The **three workshops with stakeholders (W2, W3, W4)** from within Greater Manchester looked at what service provision there is already, what is missing, and how to connect people to (existing) opportunities to understand what the service needs to deliver and how it can be made to fit within the existing service landscape. The workshops started with a presentation of the outcomes and resulting key suggestions for the service from Phase 1, which comprised:

- Participating in 'usual' social and cultural activities;
- One-to-one support to help develop personal interests/activities;
- Opportunities and support for people to be able to volunteer.

The presentation then summarised the key findings from the first co-design workshop, which confirmed and elaborated on the Phase 1 results:

- To share skills and talents;
- To benefit from one-to-one support for personal activities (e.g., traveling, practice a sport);
- To support each other in reciprocity;
- To do/find existing activities in Greater Manchester with their (care) partners.

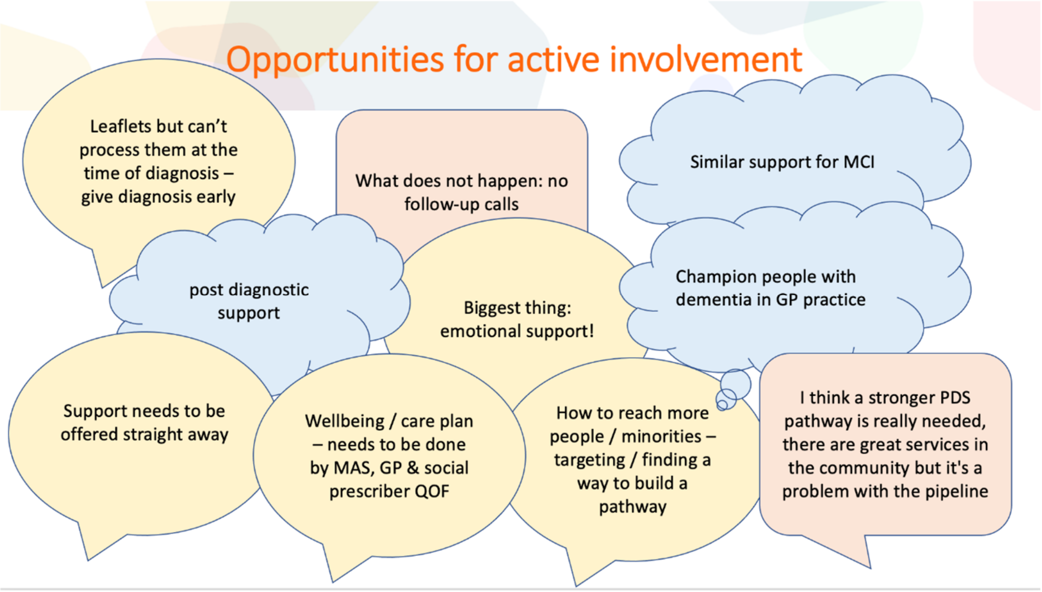
The participants were then invited to consider the following two workshop questions:

- What volunteering opportunities are there in GM for people living with dementia?
- How is it possible to connect people with relevant opportunities?

To provide the interactive co-design element in the online environment in a manner that would be accessible to all participants, a prepared slide with 'speech bubble post-its' was used to support the discussion. Researchers noted the key suggestions, concerns and considerations raised in the speech bubbles so that they were visible and open to further discussion by participants. The slides completed in workshops 2 and 3 were included in the presentation for discussion in workshops 3 and 4. All three workshops were also recorded, and recordings were transcribed and anonymised (Orton et al. 2023: files 3.–6.).

The discussion raised a number of different strands including needs, barriers, concerns and, most importantly, opportunities and solutions. There was a clear agreement among participants that people need support immediately after the diagnosis to feel safe and supported, and that, at present, this was often missing. While participants felt that there are great community services, they observed that there is "a problem with the pipeline" (Figure 5), and that a model is still missing that connects people with the support on offer following their diagnosis through memory assessment services (MAS).

In terms of key suggestions for what would be desirable, participants observed that the prospective service would need to build trust and provide emotional support and time for relationship building; that people want to be included in normal, existing activities; and that they need help finding out what is on offer and how to access relevant opportunities. Participants suggested that the service would need to start by talking to people shortly after their diagnosis about what they want, a strength-based conversation, or perhaps a kind of wellbeing plan that focuses on the person's ability or an "independent skills audit" (Figure 6). Participants suggested building relationships with organizations who can accompany people throughout the process. Some good opportunities for building on were mentioned, such as Social or Green Prescribing through GPs or MAS, dementia organisation support and programmes, and some volunteer centre offerings which are open to everybody over 50 including people with dementia. Focusing on volunteer opportunities and opening them up more widely to people with dementia was felt to be promising. Getting partners involved to have normal events for both was also considered important. One potential concern regarding volunteering for people with early onset dementia was that if they were to volunteer, they might potentially be seen as fit for work and lose their benefits. This concern was noted for further consideration later along the way. Overall, there was a consensus of the benefit of providing a service that would encourage people to explore their strengths and skills shortly after the diagnosis to help strengthen their self-confidence and social engagement.



Opportunities for active involvement

Leaflets but can't process them at the time of diagnosis – give diagnosis early

What does not happen: no follow-up calls

Similar support for MCI

post diagnostic support

Biggest thing: emotional support!

Champion people with dementia in GP practice

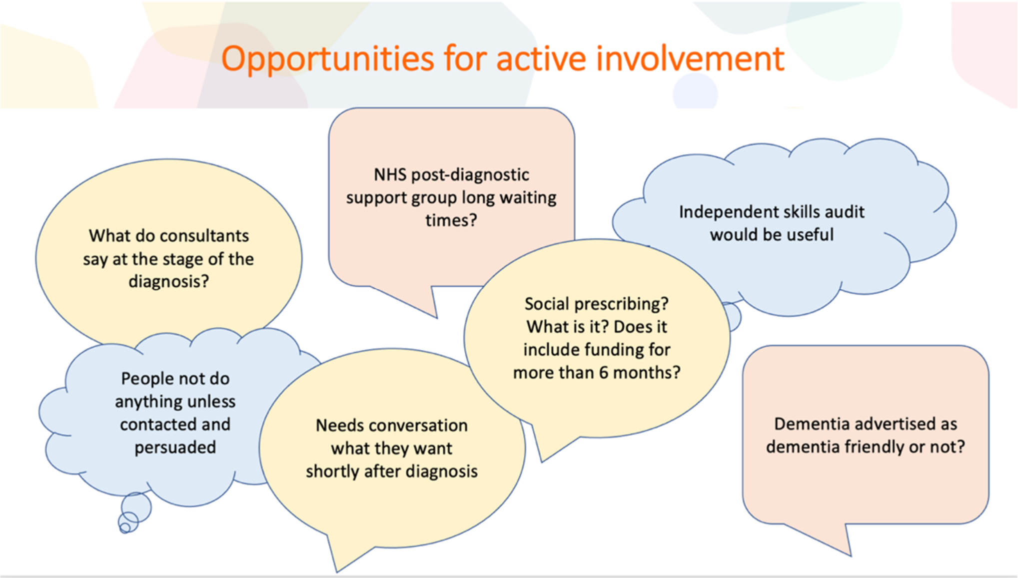
Support needs to be offered straight away

Wellbeing / care plan – needs to be done by MAS, GP & social prescriber QOF

How to reach more people / minorities – targeting / finding a way to build a pathway

I think a stronger PDS pathway is really needed, there are great services in the community but it's a problem with the pipeline

Figure 5. One of four slides filled with comments from the discussions in co-design workshop 4.



Opportunities for active involvement

What do consultants say at the stage of the diagnosis?

NHS post-diagnostic support group long waiting times?

Independent skills audit would be useful

Social prescribing? What is it? Does it include funding for more than 6 months?

People not do anything unless contacted and persuaded

Needs conversation what they want shortly after diagnosis

Dementia advertised as dementia friendly or not?

Figure 6. One of three slides filled with comments from the discussions in co-design workshop 3.

3.3. Co-Design Workshops 5, 6 and 7: Determining the Content and Delivery Format of the IDoService in Relation to Existing Services

Workshops 5 and 6 followed the same model as the previous three workshops, but explored the next set of questions to think about the content, shape and positioning of the service, now provisionally called 'Skills and Preferences Inventory' in line with suggestions from the previous workshops:

- Where and at which point should it be delivered?
- Who could or should deliver it?
- What should the content of the service be and how should it be delivered?

As an introduction, a summary of the results from workshops 2, 3 and 4 was provided. A visual representation of the service landscape of Greater Manchester (Figure 7) and a proposition for the service model (Figure 8) as prepared by the research team was then offered for discussion.

Considering existing services was deemed important because of the size and complex structure of health and care services in Greater Manchester. With ca. 2.8 million people (Office of National Statistics 2021), it is the biggest conurbation in the UK outside of London. It comprises 10 boroughs in which health care is provided by two National Health Service (NHS) Trusts: Greater Manchester Mental Health NHS Foundation Trust (Bolton, Salford, Manchester, Wigan and Trafford) and Pennine Care NHS Foundation Trust (Bury, Rochdale, Oldham, Tameside and Stockport). Within this system, the different boroughs offer different systems and levels of provision, with the approach and treatment of those with dementia differing according to local priorities. Nevertheless, there are some similarities. In general, the current pathway to a dementia diagnosis and treatment is to go to the GP who refers the person to the MAS[1]. Once the memory assessment is completed, the pathway diverges dependent upon location and other factors with referral back to the GP, to specialist NHS staff or to non-NHS organisations, such as social prescribers or dementia and volunteer organisations. Treatments offered vary and include medication, therapies and social activities.

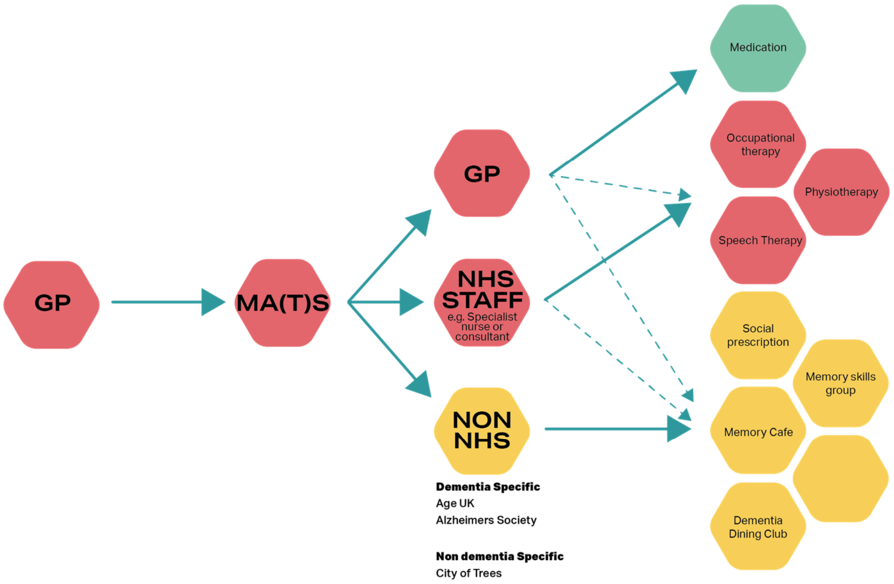


Figure 7. Route map for Greater Manchester residents facing symptoms of dementia.

In the workshops, the discussion about situating the service revolved around the gap between MAS and access to social activities and how it might build on and complement existing dementia care and wellbeing plans. This led to discussion about the current and potential role of GPs, social prescribers and dementia advisors in informing people about activities and linking them with suitable services as part of the *IDoService*. Participants also considered what exactly the service could provide to cater for the diverse interests and needs of people through linking with volunteer organisation programmes and the opportunities and challenges involved. One of the participants summed the discussion up with regard to the development of the service concept:

> *…obviously keep it simple when it comes to actually asking the questions, but I think it's something that you'll probably keep going back to. I'm just thinking. So, you'd have whether your wellbeing plan or some form of assessment and you'll look at what people's skills are and so on and then how they can develop those or volunteering and volunteer somewhere else. I think it is something that you'd keep going back to because people, as they get more confident, will want to do more so it's going to change as time goes on so there will be a lot of dipping in and out. […] I think if we had a specific toolkit so that we could explore it further where we could work either as a one to one or whether it would work within a group setting, I think that would be something we would use and would be helpful*. (W5, P8)

In workshop 6, a more developed model of the service (Figure 8) was presented and discussed, with responses highlighting the non-stigmatising approach and its potential for transferability:

> *I like the idea […] of it being at the point of a wellbeing mentor being the person that shares your inventory […] because it's not labelled as something for people living with dementia either because I was just thinking about your IDoService. I know obviously this project is specifically for people living with dementia but there could be people*

> *diagnosed with other health conditions that could equally benefit from the IDoService as well. If the implementation or sharing of what the inventory is and raising awareness sat with the wellbeing mentor, they could share it with more people, including people who have recently been diagnosed with dementia.* (W6, P9)

The discussion then went on to consider details to improve and refine the model, including the pathway, how it relates to existing services and its naming. Here, two examples of the discussion and how it moved the design on are shown:

> *P9: Although people most definitely need support when they've been through the memory assessment service and they get a diagnosis, they're going to be probably reeling from the news that's been delivered to them so to start saying straight away, for some people it might be important to hear, "Look, just because you've got this diagnosis, your life isn't over. You can still have a good quality of life for many, many years." I think it's important to hear that message at the memory clinic and signpost people to the wellbeing mentor for when they're ready.* (W6, P9)
>
> I2: *So we could in fact move that arrow, couldn't we, that blue arrow that goes from the GP to the wellbeing mentor potentially, from the MA(T)S to the wellbeing mentor or add an arrow anyway […] so it's the next step, once they've had their assessment they would meet this wellbeing mentor.* (W6, I2)
>
> *P9: Just another quick comment. Obviously, the service is called IDo and that's how you're funding for IDo but a very common phrase that we hear is 'can do', someone has got a 'can do' attitude. I really like the idea although obviously you'd have to ask people with dementia as well, if this pathway, this service was called Can Do, is getting the message over that you can still do things, your diagnosis doesn't have to get in the way.* (W6, P9)

Further suggestions related to creating a comfortable and encouraging service environment and delivery, including face-to-face introduction of people with dementia to volunteer staff, one-to-one and peer support, accessible venues, reducing stigma for certain communities, examples of people successfully engaging with volunteer and activity opportunities and ice-breaker activities to help people engage with the service (Orton et al. 2023: files 7.–11.).

These suggestions were used to refine the service concept and its presentation for the **final co-design workshop (W7)** with people with dementia and carers. Workshop 7 followed the same pattern as the first. It offered participants visual representations of the service in context, and of what the service should contain, and they were able to use post-its to make comments and add suggestions (Figures 9 and 10). The discussions largely confirmed the service model and added refinements for its delivery, such as a three-session pattern: starting with an individual talk with the wellbeing mentor to explore interests, followed by a peer session to explore activity and volunteer opportunities, and concluding with a one-to-one session to discuss how to realise individual interests (Orton et al. 2023: files 11.–13.).

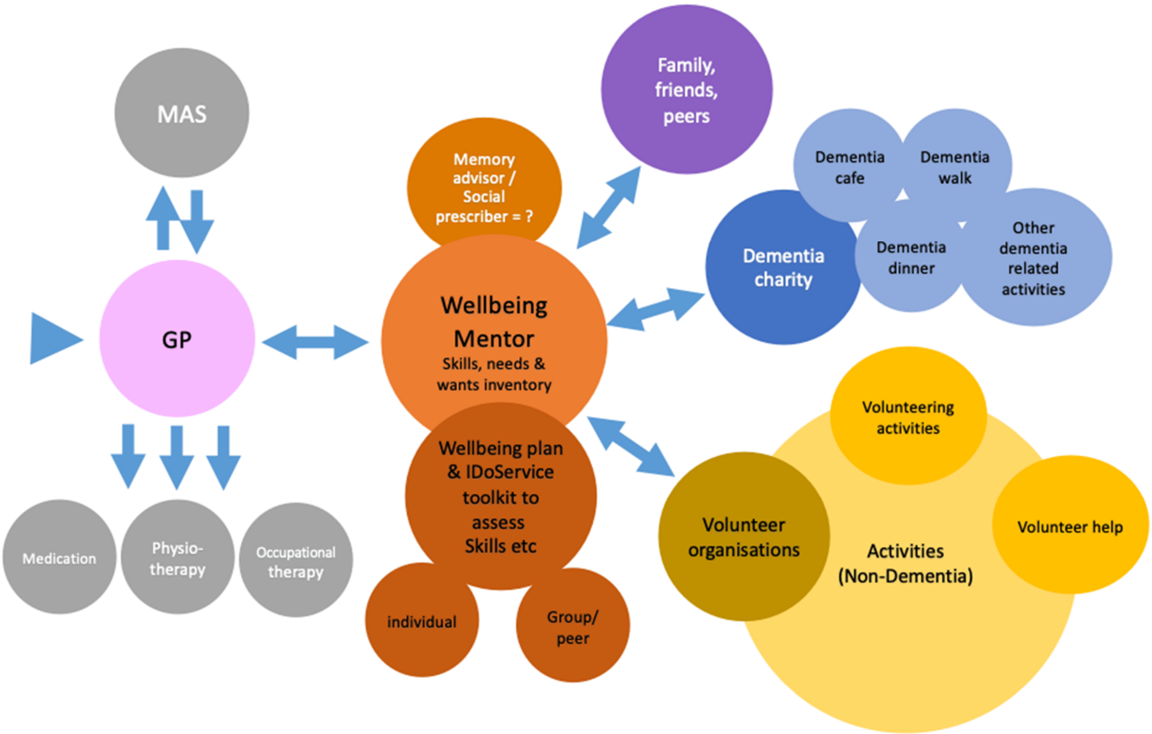


Figure 8. Service model and path presented in workshop 6, which was commented on by participants and subsequently developed as shown in Figure 9.

Figure 9. Feedback on the service model within the service pathway as presented in workshop 7.

Accompanying support for carers too otherwise they will feel isolated

A wellbeing mentor would be useful to find out what people might like to do

A mentor would be an ideal solution to navigate the system (blue badge, etc.) but more beneficial for caregivers than PWD

Need to be available 24/7 (pb by night)

Former carers have empathy and skills to volunteer (vs. "notebook")

Not enough info and there was nothing about confidence building – need to be something about encouraging people

Would be a nice idea and an efficient way to give info and tips to people

Everything in one place: Taxi vouchers, reduced council taxes, blue badge, carer budget, carer allowance, PIP, etc.

Vouchers for shops and restaurants would be great too: a good way to do something different

Never saw This Is Me or Wellbeing plan but it's a good idea

A game is overcomplicating something that should be just simple outright questions to a PWD

Didn't know these documents but find them useful – for medical appointments and family too

Would be nice having something similar focusing on activities / would be nice having a document or something to bring home

Happy with a taster session with volunteer services

Only for early dementia stages

Without early diagnosis skills exchange and volunteering are not a realistic proposition

Opportunities should be very local to be easy to access

A family-friendly / social event skills fair would be positive too – especially for family-oriented people

Would be more successful and relevant than group activity

Would enable a more detailed discussion about aspirations and needs regarding support

Good for people that are not "group people"

Like listening in groups but felt happy on an individual level also

Having a group session first with an individual session as a follow-up (as with Age UK Salford)

More likely to spark ideas

Would provide peer-support, ideas and confidence

Help them discover something new even things that they thought they never wanted to do

Could provide a more comfortable environment for wellbeing – making the environment more social and supportive than individual sessions

Group context better to draw attention to local activities and positive personal experiences

Group sessions would be nice too as they are a way to get info from other people and chat with someone knowing what you're dealing with

Figure 10. Comments and suggestions on the content, format and delivery of the wellbeing mentor sessions from workshop 7.

4. Discussion: Final Design Concept and Reflection

From the iterative process of the co-design workshops, the *I Can Do Pathway* evolved encompassing both the service concept (wellbeing mentor sessions) and the specification for its manifestation and means of delivery (guide- and workbook). We report on this first before concluding with some reflections on the value of the process for developing the service.

4.1. I Can Do Pathway Specification

The specification was derived from the key suggestions of the seven workshops, supported by recommendations from the literature on mindful co-design and from considerations on practicalities and feasibility. Key suggestions included in the specification are drawn from ideas put forward in the workshop discussions, which received a broad consensus, such as the name change from 'I Do' to 'I Can Do'. The literature on mindful co-design (Dening et al. 2020; Niedderer et al. 2022b) has provided guidance for the context, format and content of the wellbeing mentor sessions to facilitate a spirit of co-production and empowerment for people with dementia. Considerations of feasibility have considered the practical context and application, such as negotiating contradicting demands, or ideas that were interesting but not essential to the initial implementation of the service.

Contextual parameters for the *I Can Do pathway* include firstly that it should be situated between the medical diagnosis and treatment teams on the one hand and the dementia and volunteer organisations on the other. Principal implementation should be conducted through the latter organisations to bridge the gap, which was identified by the participants during the workshops, and to enhance the current provision in supporting people with a recent diagnosis of dementia (Figure 11). Secondly, it should be delivered by the wellbeing mentor who is envisaged to be an existing care professional, such as a dementia adviser, dementia support worker or social prescriber, who is already meeting people following their dementia diagnosis, and for whom the *I Can Do Pathway* provides an additional tool to support people with confidence-building, social engagement and self-realisation. In this way, it will allow the service to be integrated into existing service provision without the burden of having to develop an entirely new service.

Format specifications for the *I Can Do pathway* emerged from the second set of co-design sessions (W6, 7, and 8) as follows:

- Delivery through a baseline of three wellbeing mentor sessions, which can be repeated and revisited as required, including:
    - a 1:1 session with the wellbeing mentor to explore strengths and interests in an intimate setting;
    - a group session where between two and six people with dementia meet with local volunteer service representatives to find out what is on offer, and where people can discuss their interests within their peer support group. In this way, people can consider whether and what they might wish to do individually or together, since discussing and doing activities jointly can support confidence (Rodgers 2018);
    - a 1:1 session with the wellbeing mentor to work out details for realising one or two of the interests identified.
- Provide detailed information about the service to function as a guide for care professionals acting as wellbeing mentors in delivering the service.
- Provide detailed information about the service for people with dementia as well as spaces for notes to function as a workbook.
- Be designed engaging in terms of language, readability, the inclusion of images and other relevant materials to be appropriate and tailored to the cognitive and emotional needs of people with dementia (e.g., DEEP 2022).

Content specifications for developing the supporting *I Can Do pathway* documentation was developed based on relevant co-design guidelines. They should:

- Include a contents list for easy access and overview.
- Provide information on the content of each of the three sessions.
- Structure sessions inclusively and interactively to allow for co-production and provide participants with a sense of ownership and empowerment (Dening et al. 2020).

- Include relaxation and/or ice breaker exercises at the beginning of each session to enable people to mentally arrive and get comfortable (Niedderer et al. 2020).
- Include physical prompts as memory aids and inspiration and storytelling to allow for personal exploration (Ahmed 2015; Niedderer et al. 2020).
- Include spaces for notes to record e.g., interests, or choices agreed in the sessions.
- Include spaces for reflection on the sessions and feelings about them (Niedderer et al. 2020).

While we are aware that some of the methods recommended here are akin to therapies such as reminiscence and Cognitive Stimulation Therapy, the *I Can Do Pathway* is not intended to provide therapy sessions. Hence, we do not recommend therapy tools, but rather tools used to create dialogue and creative development.

The next step of the research is to design the booklet in collaboration with our wellbeing mentor, recruited from Age UK Salford, and to trial the service with people with dementia.

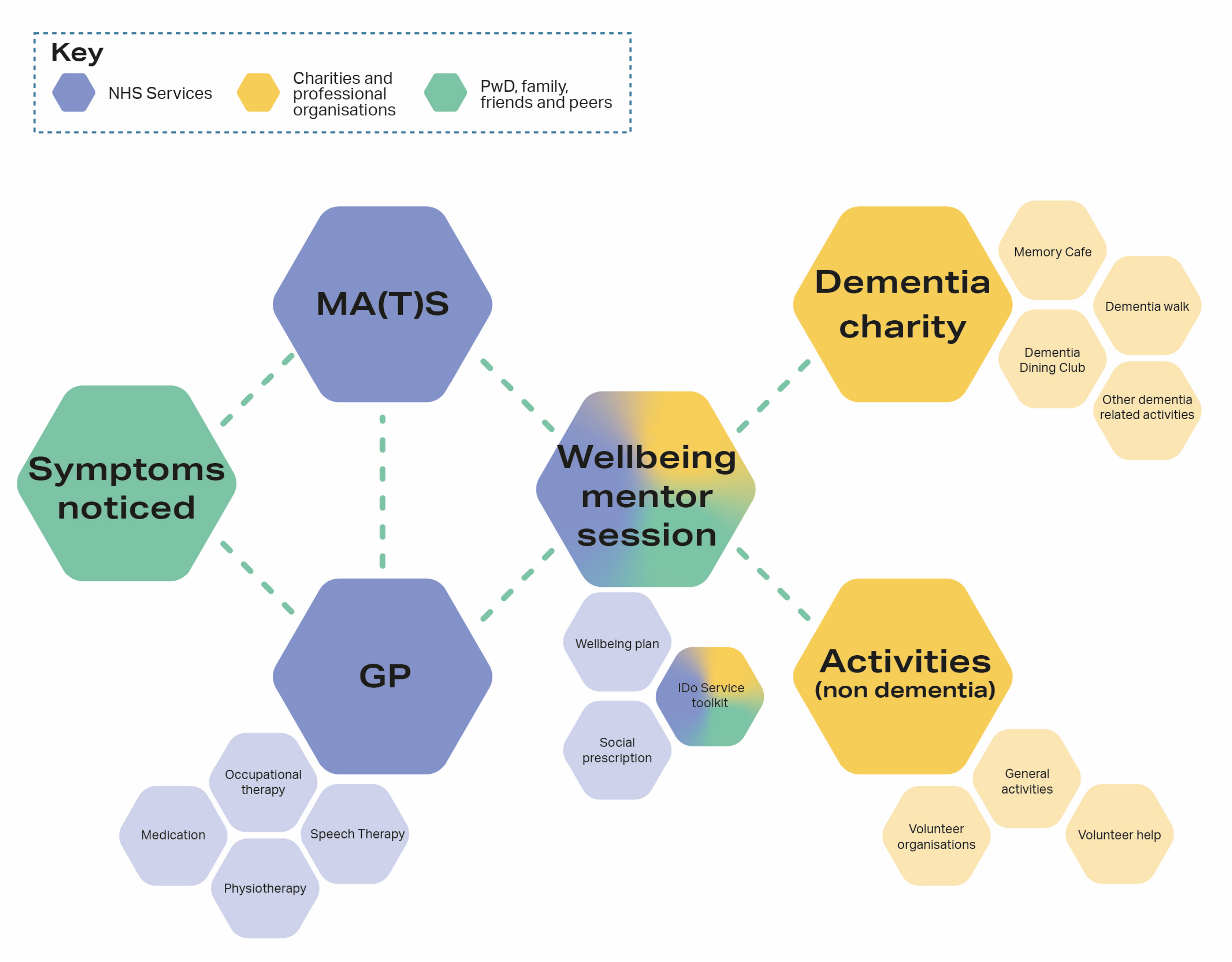


Figure 11. Route map for Greater Manchester residents experiencing symptoms of dementia: Situating the *IDoService* (wellbeing mentor sessions) within the existing service pathway.

4.2. Reflections on the Co-Design Process and Its Transformative Impact

The co-design workshops for the *IDoService* project has offered insights in two key areas:

Firstly, the co-design workshops have enabled developing the concept for the volunteer service for people with dementia. Through the iterative cycle and input from all stakeholders, including people with dementia, the concept of the wellbeing mentor sessions was developed. They offer working through the *I Can Do Pathway* to allow people to explore their strengths and interests, what activities or opportunities are on offer, and how they can realise their interests through connection with volunteer services and engagement with their local community. Through the co-design development, the original concept idea evolved from a standalone service to a service that can be seamlessly integrated within the existing service landscape and that makes use of existing facilities and expertise to deliver the service. In this way, working with community stakeholders in a truly collaborative effort has led to a practical service concept with a clear path to implementation, demonstrating the power of co-designing. At the same time, this has allowed bringing stakeholders from the different boroughs of Greater Manchester together to truly understand the existing service landscape, including some of the strengths as well as disparities in the existing service offer. The example of the *IDoService* shows how co-design can be used to develop existing services provision sensitively and efficiently through dialogue with, and creative input from, all stakeholders.

Secondly, reflecting on the methodology, while immensely rewarding, the design development through the workshops has shown that co-designing services is a complex and time-consuming process, which needs a lot of preparation as well as input and co-operation from all involved. There were particular challenges to this study, having to adjust to COVID-19 restrictions and, hence, to online delivery, which requires reconsidering the time and timing of workshops as well as materials and how to share them. While online delivery can reach a wider audience, its format makes interactions more structured and formal and less intimate and intuitive. Nevertheless, co-designing in whatever format offers great engagement with stakeholders. If well-delivered, everyone involved is generally forthcoming and happy to contribute, which provides great results, demonstrating the immense creativity that can arise out of such dialogue. Finally, one very important point stressed by the groups we were working with was the need to ensure continuity of communication and to keep co-designer participants informed of the outcomes and further developments to ensure they feel that their input is being valued.

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Note

[1] Also at times called MATS: Memory Assessment and Treatment Services.

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