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An overview of current practices and approaches to co-designing services with and for people with dementia towards developing a framework for best practice

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An overview of current practices and approaches to co-designing services with and for people with dementia towards developing a framework for best practice

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Abstract: The aim of this paper is to provide an overview of current practices and approaches to co-designing services with and for people living with early to mid-stage dementia to derive a set of principles and practices for application in the *IDoService* project. It explores the understanding of service design and of co-design for the purposes of this paper, and then uses a meta-review of co-design of services for people with dementia, underpinned by a selection of case studies from the literature to extract and collate a set of key principles of best practice. We then consider the application of these principles and practices for the development of the *IDoService* to discuss implications and benefits of this approach for designing services.

Keywords: dementia; co-design; co-production; service design

1. Introduction

The aim of this paper is to provide an overview of current practices and approaches to co-designing services with and for people living with early to mid-stage dementia to derive a set of principles and practices for application in the IDoService project and as guidance for others.

There is currently no known cure for dementia. Therefore, a focus on quality of life is essential. Quality of life includes here: subjective wellbeing, as the individual's perception of their emotional wellbeing, sense of purpose as well as being able to feel in charge of one's life (Zeilig et al., 2019). One key to living well is keeping active and socially engaged (Fernández-Mayoralas et al., 2015), for example through participating in 'meaningful activities', which are activities that provide a benefit such as pleasure, exercise, social connections and self-realisation (Dening, 2021). However, access to meaningful activities can be difficult for a number of reasons, including availability as well as accessibility. People with early-stage dementia often do not feel comfortable accessing dedicated 'dementia' activities and services because of the stigma or because of finding it daunting to see people at the more advanced stages. Therefore, a service is needed that provides a more individualised offer of participating in, initialising and contributing to or volunteering for meaningful activities.

Design can play an important role in supporting quality of life through providing strategies and services specifically designed to support people with dementia (Niedderer et al., 2020). With the IDoService, we aim to develop such a service. To do this, all stakeholders need to be involved in the design process. Within UK health and care services, involving target groups (stakeholders, persons with lived experience) has been part of policy since at least 1999, proposed and defined by Greenhalgh (2009) as Patient and Public Involvement (PPI). The involvement of stakeholders in the development of patient care and care services has become common since, usually through consultation and advisory functions. However, involvement of stakeholders in the creative process of developing such services to ensure their relevance to the target group(s) – i.e. in co-designing – is not yet the norm, even though co-design is by now a well-established methodology whose use is becoming more common in the health sector and also with people with dementia (Wang et al., 2019). Furthermore, Rodgers (2018) has emphasised that people with dementia have a lot to offer society, that they can do so through co-design, and that involvement in co-design activities can in turn help people with a diagnosis to stay socially connected and build self-esteem.

In order to develop the IDoService, we aim to utilise a comprehensive co-design methodology. The paper offers an overview of current approaches to co-designing services with and for people with dementia to inform the creation and implementation of the IDoService. It starts with a discussion of the background and concepts of service design and co-designing relating to application in the dementia context; followed by a meta review of current approaches to co-designing services with people with dementia, a discussion of best practice and the proposal of a tailored co-designing approach for developing the IDoService.

2. Background

Service design and co-designing are increasingly receiving attention, raising their importance in the improvement of services within the health and care context, including the dementia care context. In the following, we discuss and define the concepts and their uses for the purposes of this paper.

2.1 Service design in the health and dementia care context

Service design is playing an increasing role in health care, especially in its transition towards person-centered models of care (Malmberg et al., 2019). Service design is a holistic, co-creative, and person-centred approach to improve the quality of service provision (Stickdorn & Schneider, 2011). It takes a holistic view of the processes, components, environment and stakeholders involved in its design in order to meet user needs and expections (Marquez & Downey, 2015). Stickdorn et al. (2018) have identified six principles to characterise service design as: *human-centered*–the experience of everyone affected by the service;

collaborative–all relevant stakeholders should be engaged in the design process; *iterative*–taking an exploratory and adaptive approach; *sequential*–in the way a service's actions may be interrelated; *real*–in that it should be based on real needs, developed in real-world scenarios and made tangible through appropriate digital or physical means; *holistic*–considering all stakeholder's needs within the services and environments contexts.

By its nature, service design takes an interdisciplinary approach, drawing on methods and tools derived from different disciplines. Co-design has become a significant element in service design projects to enable their holistic and person-centered aspirations (Steen et al., 2011). For example, Neuhoff et al. (Accepted/In press - 2022) found that involving family caregivers of people with dementia in service design, using story telling methods, yielded positive results including "greater levels of trust, sensitivity and empathy in service design projects" (abstract). They found that the family caregivers benefited greatly from the process itself as well as the final service designed. People with dementia can equally benefit from involvement in the service design process.

2.2 Co-design in the health and dementia care context

Co-design is increasingly used within the health and care context, including for the development of services as well as with people living with dementia (Bate & Robert, 2006; Pearce et al., 2010; Steen et al., 2011). Co-design means the involvement of stakeholders in the process of developing novel products, services etc. to ensure their relevance to the target group(s) (Sanders & Stappers, 2008). Co-design includes working with people with lived experience from the outset, from identifying a problem to defining a solution (McDougall, 2012). One of its key feature and benefits is that the problem to be solved is not already pre-decided before stakeholders become part of the team (McDougall, 2012). Including stakeholders in the research and creative process gives them a voice in the development of solutions that are relevant, appropriate, and fit for purpose, to enable the targeted improvement of products, services or environments (Dening et al., 2020).

However, co-design is not a singular term or approach. It has many meanings and interpretations, for example, co-design by Sanders and Stappers (2008) is significantly different to that of experience-based co-design (EBCD), (The Point of Care Foundation, 2021). Whereas the former looks at including stakeholders in an open-ended creative process, the latter offers a strictly defined process of feedback around user experiences, but no specific involvement in the creative process. In addition, various terminology is in use, including participatory design, co-design, co-creation, co-production and others. These terms are often used interchangeably whereas they have overlapping but specific definitions, even if a clear consensus about them does not emerge yet (Sanders and Stappers, 2008, Dening et al., 2020). McDougall (2012), one of few authors to define all three terms, suggest that co-design is an attempt to define a problem and then define a solution; co-production comprises the way of facilitating co-design activity and working together, and co-creation is the process by which people do both. This view is still quite dominant (e.g. Malby, 2014). In line with this research, our paper takes co-design to pertains to the methodological aspect of the collaborative and joint process of designing, co-production to facilitating the collaborative space enabling successful co-design, and co-creation refers to the active participation of end users in difference phases of the creation process in general.

Involving people with dementia in co-design is receiving increasing interest across a range of topics. Much of the published literature concerns health care and environmental design, but topics such as empowerment, personhood or even creative contexts have been addressed, too (e.g. Bosco et al., 2019; McConnell et al., 2019; Parkinson et al., 2017). A recent scoping review with 26 studies involving people with dementia in design research suggests that the design process benefits from their involvement as do the persons with dementia (Wang et al., 2019). Especially, participation in co-designed activities and interventions helps people with a diagnosis build self-esteem, identity and dignity, and to stay connected to their community (Rodgers, 2018). People living with more advanced dementia can participate in and benefit from co-design too (e.g. Kenning, 2018). These studies also show that to achieve true co-design requires collaborative networks formed of clinicians, designers, academia, older people and industry across disciplinary and national boundaries (Niedderer et al., 2017).

In summary, although there are increasing examples of co-design activity including people with lived experience of dementia, *co-designing services*–especially with people with dementia–is not yet the norm. Examples are dispersed and there are many varying approaches, which make it difficult to know how and which approach(es) to choose. In the following, we have conducted a review of co-designing services with and for people with dementia to provide an overview of existing practices to establish a better understanding of this area.

3. Co-design approaches for developing services with people with dementia

In order to identify current practice in co-designing services with people with dementia, we have conducted a review of relevant review papers of co-design approaches in the area of service design with people with dementia.

3.1 Search criteria

Criteria for the literature search included a combination of parameters relating to co-design, service design and dementia with a focus on review papers. Google Scholar was searched using the terms "service design" AND dementia OR Alzheimer AND co-design OR "participatory design" OR co-production OR co-creation AND "scoping review" OR "narrative review" OR "systematic review" -"research design" -hospital -"care home" from any date before November 2021 when this review was conducted.

There were 115 results from this search and a preliminary review was conducted on these results, with the titles and abstracts read for each one. The results were further reduced by the following inclusion and exclusion criteria:

- Only papers that discussed a co-production activity with people with dementia were included.
- Those that worked exclusively with carers, family members or other professions were excluded.
- Those that only consulted with people with dementia in a final testing or market research phase were excluded.
- Papers that consisted of studies that were undertaking in hospital or care home settings were excluded, as these being not within the focus of this study and also often relate to later stages of disease progression.
- Papers not written in English were excluded.

3.2 Search results

Following exclusions, the search resulted in the inclusion of 5 papers broadly to be considered reviews, including an integrative review, two narrative reviews, and two papers reviewing and comparing a number of selected studies or projects (see table 1).

Table 1. Overview of the review studies

Author	Title	Studies	Aim/summary
Breuer et al. (2021)	Active inclusion of people living with dementia in planning for dementia care and services in low- and middle-income countries	Narrative review	Focusing on low and middle-income countries, Breuer et al. argue for the need to include people living with dementia in care and service planning at individual, community, and national levels, providing four principles for inclusion.
Davies et al. (2020)	Dementia enquirers: pioneering approaches to dementia research in UK	Review of 10 projects	Paper co-written by people with dementia which explores the barriers for people with dementia to participating in and leading research and ways forward.
Kort, Steunenberg & Hoof (2019)	Methods for Involving People Living with Dementia and Their Informal Carers as Co-Developers of Technological Solutions	5 studies	The authors argue that people living with dementia can very well contribute to developing solutions. To support self-management and daily living. They offer a number of co-design processes for doing so.
Lorentzon & Bryan (2007)	Respect for the person with dementia: fostering greater user involvement in service planning	Narrative review	Reviewing selected research publications and policy papers, Lorentzon and Bryan propose the inclusion of people with dementia in care service planning as part of person-centred care to promote respect, identifying a number of criteria for doing so.
Read et al. (2018)	The participation of people with dementia in the planning of their care and support: An integrative literature review	7 studies	Integrative review that demonstrates that people can and want to be involved in decision making around their care and in the development of services and that they do so through “attending education programme[s], setting goals in cognitive rehabilitation therapy and contributing to advance care planning."

3.3 Discussion of review studies

The five studies cover three key issues within the context of service design and planning: all studies make the argument for the inclusion of people with dementia in the co-design process; two studies discuss the barriers which people experience regarding inclusion in the research and design process as co-participants (Breuer et al., 2021; Davies et al., 2021), and all variously discuss opportunities or facilitators for successfully including people in the co-production process (Breuer et al., 2021; Davies et al., 2021; Lorentzon & Bryan, 2007; Read et al., 2018) or more specifically the co-design process (Kort et al., 2019).

The argument for including people with dementia in the co-production and/or co-design of services is not entirely new, but has been advanced over time, progressing from a user-centered focus to participatory design (Kort et al., 2019). Lorentzon & Bryan (2007) argue for including people with dementia in service planning as part of person-centred care to promote respect. They explain that people "want more power over decision-making concerning their lives and the services they need" (p.28) and that people want to be valued. This is echoed by Read et al. (2018) whose review demonstrates that people can and want to be involved in decision making around their care and in the development of services. Davies et al's paper (2021) is co-authored by people with dementia and makes the case for a rights-based approach, co-production approach as represented by DEEP. Breuer et al. (2021) promote care and service planning at individual, community, national and state levels to further the rights of people living with dementia and create a respectful and inclusive culture.

In terms of barriers, Read et al. (2018) quote historical assumptions of lack of capacity as one of the main reasons and the need to change cultural perceptions and related stigma (Breuer et al. 2021). Davies et al. (2021) mention exclusion from research as a result of such perceptions, tokenisms with topics being pre-determined by researchers as well as paternalism and bureaucracy in research ethics and related processes. In response, authors offer a range of guidance for including people with lived experience of dementia in the research and design process for the development of services and their own care. In Table 2, we collate this guidance to show overlaps and complementarities between the five papers. We have grouped the guidance into six categories, which have emerged during the analysis: Ways of involvement in existing care planning; (suggested) areas where people with dementia can be included; values for inclusion, aspects and methods of co-production; co-design methods in service design context, and generic co-design methods. We have included information from studies mentioned in the reviews where they add relevant further information, such as the DEEP (2020) criteria.

Table 2. Overview of categories of guidance for inclusion of people with dementia in the design and development of services

Categories		**Guidance (incl. activities, approaches and methods)**
1) Ways of planning / involvement in existing care services	Read et al. (2018)	• Attending education programme[s] • Setting goals in cognitive rehabilitation therapy

		• Contributing to advance care planning
2) Areas for inclusion	Breuer et al. (2021)	• Involve people living with dementia in service design and planning • Shared care plans at familial or service levels
	Davies et al. (2021)	• Involvement of people with dementia as co-researchers. • Co-development of technological solutions for service provision.
	Kort, Steunenberg & Hoof (2019)	• Fostering greater user involvement in service planning.
	Lorentzon & Bryan (2007)	Potential areas of involvement for people with dementia according to Alzheimer's Society Report 2003: • Presentation [of work of the society by people with dementia] • Collecting money for Alzheimer's Awareness Week • Video production (e.g. of people's lived experience) • Commenting on government legislation • Planning social activities • Recruiting new staff • Requesting a local support group • Website design • Developing information • Giving views on service • Sitting in on national board of trustees • Attending branch and national AGMs • Writing articles for newsletter
	Read et al. (2018)	Involvement of people with dementia with the planning of their care or support.
3) Values for inclusion of people with dementia in the research and development process	Breuer et al. (2021)	1. Respecting the rights of people living with dementia to self-determination. 2. Valuing people living with dementia's unique understanding of dementia. 3. Creating a culture of active inclusion which creates a space for people living with dementia to participate. 4. Ensuring appropriate accommodations are in place to maximise participation.
	Davies et al. (2021)	• People with dementia can conduct research • Mainstream research and research governance needs to adapt, if people with dementia are to be included. • People with dementia understand ethics and can come to considered judgements about capacity, consent and the risk of harm. • People with dementia may sometimes enjoy advantages in their ways of working
	Lorentzon & Bryan (2007)	Need to make people with dementia feel valued and involved. (From: carer's advice sheet, Alzheimer's Society, 2005).
4) Co-production aspects and methods for inclusion	Breuer et al. (2021)	Enabling factors

	(incl. suggestions by Lorentzon & Bryan, 2007)	• Create a role in the planning process for people with dementia to participate in local service development. • Ensure that people living with dementia are encouraged to speak for themselves, are actively and respectfully listened to, are able to influence decisions. • Offer or develop strategies to increase stakeholders' knowledge of dementia, decrease stigma, changing ways of working such as using disability supports. Communication • Prepare and share materials prior to the meeting • Materials should be in plain language, simple to understand and visually appealing with large font sizes (Northway et al., 2015; Goeman et al., 2019) • Pay attention and adapt materials to literacy and health literacy • Arrange a practice/ orientation session and follow up session for person living with dementia for important meetings • Have clear and simply communicated tasks and items on which decisions need to be made • Use clear language and avoid jargon (Abayneh et al., 2017; Lorentzon & Bryan, 2007) • Consider shorter but more frequent meetings • Ensure questions can be asked throughout – Check for understanding • Make allowance for 'wrong' ideas and words (Lorentzon & Bryan, 2007) • Use specific communication tools designed for people living with dementia (Wang et al., 2019) Physical environment • Ensure physically accessible location for persons with mobility restrictions • Ensure safe travel to venue available (and reimburse for travel) (Goeman et al., 2019) • Consider number of people in the room (Wang et al., 2019) • Keep noise levels down (Wang et al., 2019) • Ensure clear signage • Have a practice session for virtual meeting platforms with person with dementia Mental well-being • Ensure the person with dementia is comfortable (Lorentzon & Bryan, 2007) • Assign a psychologist or support person to the person living with dementia to monitor the needs, provide one on one support and answer questions for clarification Caregiver or care partner • Provide funding for a caregiver or care partner to travel with the person living with dementia • Allow opportunities to contribute without caregiver or care partner

		Continued engagement • Create a plan for continued engagement which takes into account disease progression (Whitfield & Wismer, 2006) • Be flexible with alternative options for engagement (e.g. Via phone call, individual meeting) and reschedule if necessary
	Davies et al. (2021)	Davies et al. (2021) quote the DEEP-Ethics Gold Standards for Dementia Research, (DEEP 2020). It highlights six principles: • Working in real partnership; • Respect and acknowledgment; • Safety and well-being; • Informed consent and capacity; • Confidentiality and anonymity; • Information that is simple, accessible and open.
	Lorentzon & Bryan (2007)	• Caring conversation • Use of images or prompts to support communication • Adjustment of research methods, consultative processes and ethics committee procedures • Flexibility in accommodating people's needs and wishes.
5) Co-design methods relates to service design development	Kort, Steunenberg & Hoof (2019)	• Observations • Consultations • Storytelling • Focus group sessions • Thinking-aloud Sessions (around mock-ups) • Photo-production with interviews • Visual-assessment (sensing) methods • Making mood boards • LEGO Serious Play method & storytelling
6) Co-design methods (generic)	Wang et al. (2019)	Co-design methods by dementia stage[1] **Mild** • Create scenarios • Make storyboards • Use visual prompts • Make vignettes • Use self-observation diary **Mild and moderate** • Use videos • Use external memory aids • Use environmental cues and triggers

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[1] We have deleted the co-production references from the list as most were covered in the relevant section in Table 2.

	• Use subtle physical prompts • Compartmentalize a main task into subtasks • Create a routine for a specific task • Plan tasks which are suitable for the educational level of pwd • Plan tasks to have a purpose **Mild, moderate and severe** • Use tangible materials • Use functional prototype • Apply Wizard-of-Oz method • Consider physical limitations (eyesight, hearing) • Let pwd tell their story as they wish to tell it, no matter if it is true or not • Personalize the final design (e.g. with pictures of pwd) **Moderate and severe** • Use auditory stimuli • Bring probes and observe the reactions of pwd towards these probes • Pay attention to facial expressions and body language • Choose activities that pwd are familiar with (e.g. drawing, make collages, reminiscence) • Plan activities based on hands-on daily tasks • Give physical instructions by touching and supported physical movements • Talk along and help pwd like a caregiver would do instead of taking notes • Let caregivers act as interpreter of the behaviors of pwd and be aware of the opinions of the caregivers involved **Severe** • Apply person-centered care principles

3.4 Insights and best practices for co-designing services with and for people with dementia

Our analysis of the studies has enabled us to distinguish six different categories of guidance in Table 2, column 1, including: Ways of involvement in existing care planning; (novel) areas of inclusion where people with dementia can make a contribution; values related to inclusion; aspects and methods of co-production; co-design methods in the service design context, and generic co-design methods. Within these six categories, we can further distinguish three types of guidance: activities (what to do), approaches (values-related suggestions) and methods (how to do things), see column 3. In favour of transparency, we have maintained a link to the source rather than separating the three aspects out, but broadly speaking, categories one and two relate to activities, and category 3 to value-based approaches.

Noteworthy is here that there are discrepancies in the understanding of what service design or development means. In some papers, it denotes the input of people with dementia into shaping their personal care pathway in a given system (e.g. Read et al., 2018). In others it actually means shaping the services available to work better for service users generally (e.g. Breuer et al., 2021, Kort, Steunenberg & Hoof, 2019). At present there are few areas for self-determination within the given system (Read et al., 2018) although there are suggestions within all five papers as to areas, roles and activities where people with dementia might contribute, including as co-researchers, co-designers or volunteers (see Table 2: Areas for inclusion), and there appears to be a consensus for involving people in the whole process from beginning to end. However, at present there is clearly a need for greater involvement in shaping available services, to ensure more self-determination within the care journey.

Category four (co-production), by its nature combines the three aspects in some of its guidance, but for the most part they are expressed in form of methods. Noticeably, the majority of guidance presented in the papers relates to co-production, including some consensus about the values for co-production as well as aspects and methods to enable inclusion. The review by Breuer et al. (2021) offers an extensive list, covering aspects of several of the other papers in our review, such as environment, communication, engagement, partnership and collaboration, wellbeing, values. What is noteworthy about co-production is that its sub-categories, such as physical environment, communication, wellbeing etc. could easily be mapped onto classification of personhood and fundamental human needs (e.g. Maslow, 1943, Mitchell & Agnelli). A systematic study to collate and synthesise the considerable literature and many aspects of co-production into a comprehensive yet concise and accessible guide could be a useful exercise to offer a better understanding and to ascertain any gaps.

Regarding categories five and six on co-design, actual guidance on co-design within the service design process is relatively scarce. Only Kort, Steunenberg & Hoof (2019) offer an explicit list of co-design methods. Breuer mentions a number of studies (Goeman et al., 2017; Wang, 2017) in this context. Wang offers a further set of co-design methods gathered from a review of the literature on co-designing with people with dementia, but not specific to service design, which we have added in Table 2 for completeness, although this list is, of course, not exclusive. Nevertheless, this list demonstrates that there are a wide variety of co-design methods, and that these are used with people at the different stages of dementia. They are used for different creative purposes to help people imagine novel situations in a tangible and often playful way. While there is inevitable overlap co-design methods related to service design and generic co-design methods, the latter appear more focused on the individual, whereas the former appear to put more emphasis on the group working aspect, including e.g. explicitly mention of focus group sessions and storytelling.

The list in Table 2, column 3, includes all of the examples mentioned in the papers reviewed. An extended review may be useful to collate a comprehensive list of co-design and co-production methods, values and approaches as a useful co-designers manual. Overall, co-design appears to be less commonly used and understood within the service design process than co-production, which relies more on consultation and advice. However, involving people in the creative process–beyond consultation and evaluation–is beneficial both for the process and as well as for everyone involved (Leorin et al., 2019). Doing so helps focus on people's abilities rather than deficits and this helps to promote and improve person-centered care (Geoman et al., 2017), both through direct input of people with dementia in the design process as well as by changing perceptions about their abilities.

We therefore argue that combining co-production approaches and co-design methods for service design is key to cover all user needs and aspects that need consideration in the service design process. If we follow the model by Stickdorn et al. (2018), which postulated six criteria for successful service design (human-centered, collaborative, holistic, iterative, sequential, real), we can see that the first three are likely covered by co-production whereas the latter three may are more likely addressed though the co-design process, although they may be overlapping with the process. Therefore, together, they will enable a comprehensive approach to designing services with and for people with dementia. Using the case study of the *IDoService* project, in the following, we explore the approach to the co-design sessions for the development of a skills-exchange service which this project seeks to co-design with people with dementia in Greater Manchester.

4. Proposing a tailored co-design approach for developing the IDoService

The *IDoService* project[2] aims to co-design a skills-exchange service to allow people with mild to moderate dementia to plan, connect with and participate in tailored opportunities to realise themselves and continue to be fully part of society. It is a follow up of the *MinD – Designing for dementia* project[3] in which participants with dementia emphasized their need for more activities and opportunities to realise themselves (Zanasi et al., Under review).

The *IDoService* project comprises three stages that inform the design of the service through insights and inputs from people with lived experience of dementia (i.e. people with mild to moderate dementia and support persons) or professional experience of it (e.g. third sector organisation staff, service providers). First, focus groups and interviews have been conducted to learn more about the preferences, barriers, facilitators, and potential improvement in accessing and fully participating in meaningful activities in Greater Manchester. This step enabled learning more about the variety of activities available, the emotional, creative, and intellectual stimulation they provide (Innes et al., 2016) and about people’s needs and preferences. It revealed that people are looking for more opportunities to participate in social and cultural activities and to share their skills by volunteering or benefiting from one-to-one support to enable personal projects. Based on these insights, the concept of a skills exchange service emerged and is being co-developed with participants through co-design

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[2] The *IDoService* project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 895620.

[3] The MinD project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 691001.

workshops to get views and input from all perspectives as to what the service should look like and how it could or should work. The third part will consist of evaluating the service concept in action with a small number of participants. This paper focuses on the development of the methodology for the second part, the co-design workshops, including some discusses of the co-production aspects.

The co-design workshops have been used to understand what activities or skills people do or have and they cherish; based on these, explore and bring already existing services and opportunities together; explore and work out how the service could or should work. The co-design workshops comprised 4-6 sessions in an iterative process, two of these with people with dementia and their support persons, four of these with relevant dementia organisations and service providers (Table 3).

Table 3. Overview of the Co-design workshops

	Content	Participants	Methods
Session 1, November 2021	activities, skills	People with dementia & care/partners	**Prompts** (Garde et al., 2018)– we asked people to bring objects that represented their favourite activities and skills. **Storytelling** (Ahmed, 2015) – we asked people to tell stories about their activities and skills important to the, using the objects they brought. This session was conducted face to face, observing ethics and COVID 19 safety requirements.
Session 2 & 3, December 2021	explore services and opportunities based on identified skills and interests	Service providers	**Online focus groups** (Kort, Steunenberg & Hoof, 2019) – For the sessions with service providers, we use a more traditional online focus group format, where we will combine questions with storytelling to elicit relevant information about services and examples of their application.
Session 4 & 5, March 2022	explore and work out how the service could or should work	Service providers	**Service-pathway mapping using visual prompts and storytelling.** Sessions 4 & 5 were once again conducted online, and session 6 face-to-face. All sessions followed the same pattern and were used to explore the proposed service pathway intervention-what it might offer, how it might work, and how it might be delivered. A visual map with movable items was used to work through imaginatively to gauge responses and solicit input into what might be involved, and how a person might need to be supported to enable participation as a volunteer or a participant.
Session 6, March 2022	explore and work out how the service could or should work	People with dementia & care/partners	

Specific aspects of this project method have been selected carefully to offer to participants with dementia the most convenient context to fully share their insights and views, embedded in the good practices enumerated in Table 2. In addition to dementia-related involvement aspects, this project also had to adapt to Covid-19 restrictions, including lockdowns phases and physical distancing requests. Especially, having no physical access to potential participants and having to conduct interviews online was a challenge to people with dementia involvement in the study. In this context, partnerships with local third sector organisations have been a great support. For example, some of our co-design workshops have been co-hosted by Age UK Salford during their bi-monthly dementia café. It was a great opportunity to meet people in a familiar environment, offering them a supportive context to express their views around people they feel comfortable with. For these co-design sessions, a pre-workshop lunch was organised to preserve the social aspect of the meetings and allow informal chat with workshop' facilitators and participants. Beyond the intrinsic relevance of making participation in research an enjoyable and meaningful moment for participants, it also has an impact on the quality of data collected as well as on the willingness of people to participate in future workshops and studies. A key is for people to feel that they make a real and valued contribution, and to keep them informed of developments beyond the immediate study.

5. Conclusion

In summary, while co-design of services with and for people with dementia is becoming more widely recognised, this is sometimes confused with service user involvement in their own care planning. The inclusion of people with dementia in the actual service design process is not yet very common. More common and developed is the use of co-production methods, but which may remain at the level of consultation. True input as well as involvement in the service design process has yet to become the norm. This has benefits for people with dementia, both, with regard to improving services as well as for their personal wellbeing through involvement in the process. Encouragingly, there are a number of co-design methods that are already used within service design, and a further thorough and comprehensive review of existing co-design methods, mapping them in relation to service design stages and requirements would be useful.

The review has also uncovered some barriers to both co-production and co-design implementation, such as the need of time and resources to facilitate the co-production and co-design work to ensure a person-centred approach, as well as (mis)perceptions of a lack of capacity and which may lead to tokenism, and which can lead to challenges regarding ethics and GDPR regulation. These challenges will have to be addressed at policy levels, but may also be addressed by researchers and lobby groups by pioneering and defining good practice within involvement to raise broader awareness and understanding.

Finally, a further challenge is the inclusion of minority groups as well as those at the very early stages of a dementia diagnosis as they often do not access existing services. We hope that the *IDoService,* once developed, will be able to offer a tailored service that can reach into these groups.

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