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8. Working with Experts with Experience: Charting co-production and co-design in the development of HCI based design

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Abstract

This chapter outlines the co-design process for the 'Let's meet up!' electronic system created to facilitate and maintain social engagement for people living with dementia. The system was developed by a multi-disciplinary team of researchers and people living with dementia using co-production methods.

'Let's meet up!' was created as part of the European MinD project 'Designing for people with Dementia'. It is a hybrid board and electronic system that allows people with dementia to stay in touch with their loved ones and to remain physically active by arranging joint activities through a simple, user-friendly tangible interface.

Co-design was used throughout the research and development process of - data collection, design idea development, decision making, design concept, and prototype development phases, to ensure the relevance and appropriateness of those ideas, concepts and prototypes for people with dementia. Within this process, co-production was increasingly used to enable groups of experts with experience (GEE) to co-host and co-curate the co-design sessions, and to take ownership of the process, which then allowed for instances of co-creation.

The chapter explains the integrated process of research and GEE activity evident within the design development through co-design and co-production, and draws out recommendations for this symbiotic way of working giving both its benefits and limitations.

Setting the Scene

The chapter discusses the design decision-making and development process undertaken for creating the Let's Meet Up system, and how this was interwoven with participant activities. The co-production events have informed the research and enabled co-design to occur, facilitating the effective design development and decision making with and for its users (Sanders & Stappers, 2014).

The rationale for this research was the understanding that people with dementia want and need to maintain social connections, interaction and physical activities and that these are important for maintaining cognitive abilities, emotional wellbeing, and quality of life (Mendes de Leon et al, 2003, Ylvisaker et al, 2005). Social connections become more challenging to maintain for people living with dementia because of a combination of functional issues (e.g. memory and attentional

problems), behavioural and psychological symptoms of dementia (e.g. depression, aggression), and social issues (e.g. perceived stigma of dementia) (Baddeley et al, 2002; Ylvisaker et al, 2005), which may lead to their withdrawal from social interaction. The lack of these abilities has a particular impact on the independence of people with early-mid stage dementia who wish to continue living at home for longer.

Common issues for people with dementia in this regard include mobility, where for instance driving and cycling may no longer be possible (e.g. Taylor & Tripodes, 2001), and orientation (e.g. Blackman et al 2003, Marquardt, 2011). The times and availability of a carer or other support person can also be problematic (e.g. Zwaanswijk, 2013). Mobility issues themselves are not necessarily caused by dementia, although dementia can compound them, for example it can make it more challenging to drive (Taylor & Tripodes, 2001). There are technological options available for orientation support such as using a Satnav when driving (Wallace, 2010), and when walking, there are digital devices available to help with wayfinding (Tchang, Tsai & Wang, 2008) and with safe keeping to track people in case they lose their way (e.g. Daniels, 2008). In the UK, the Dementia Dog scheme has been pioneered where trained dogs act as companions who can not only find their way around but can also remind their person when meal times are due (Design Council, 2012).

Social support is available in various formats and levels across different countries. In terms of social opportunities, in Germany, a person with dementia can apply for several hours of support per week for someone to spend time with and to accompany them on any activity including social and leisure activities (Bracke et al, 2016). In the UK, non-state-sponsored support includes Alzheimer's cafes and day care groups which provide opportunities for social interaction (Alzheimer Europe, 2013), as does the Humanitas scheme in the Netherlands – albeit not without criticism – where students with learning difficulties offer contact and support time to care home residents in return for free accommodation (Jansen, 2015).

In terms of making and maintaining social connections outside of such formalised support or social groups, Facetime and Skype are increasingly being used (e.g. Evans, Bray & Evans, 2015). In terms of Apps, as yet there are few available which are specifically developed for people with dementia (e.g. My House of Memories[1]), and even fewer that allow them to connect to others (e.g. Cuomo, Myinlife, Care and Connect: Dementia Friendly Places[2]). Most Apps are directed at carers, and those available are generally complex and can be a challenge to navigate even for people without dementia.

This brief overview of available support indicates two main issues: First, any personal social support is dependent on the country's national support system and its local organisations, which varies greatly from country to country. Second, problems with support are diverse and have to be solved on an individual basis. Key here is the availability of an individual's networks and facilitating them to keep connected in a sufficiently user-friendly way. As a means of addressing this second issue we have developed the 'Let's meet up!' electronic system in co-production with people with dementia. In the following section, we first describe the design development process including its different phases, co-production and co-design activities. We then provide a critical discussion about the inter-relationship of research, co-production and co-design processes, and draw out insights and recommendations for best practice.

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[1] Available on the APP store.
[2] All available on the APP store.

Research Process: Co-designing 'Let's meet up!'

The role of design is rarely acknowledged in the context of dementia support, even though many interventions utilise design. If acknowledged, it is usually under the label of 'assistive technology', addressing predominantly functional issues relating, for example, to stimulating memory, personal safety, enabling independence, and orientation (e.g. Guss et al, 2014). Furthermore, assistive technologies are often technology driven and developed with and for use by carers of people with dementia. Interventions are still rarely developed with and for people with dementia themselves. Hence there is a need for design-led interventions which involve people with dementia actively in the development process.

Our research process has taken a novel approach in that we have involved people with early to mid-stage dementia throughout the research process from beginning to end - from the data collection, scoping and decision-making phases right through to the design concept and prototype development. Methods have included interviews and focus groups as well as a one full-day consultation with the European Working Group of People with Dementia (EWGPWD), local work with GEE groups in the UK[3] and in Spain, at different points throughout the project. Altogether about 70 people with dementia participated in the study[4]. Our design research process can be broken down into four overlapping phases (Figure 1):

1) The Data collection with people with dementia which resulted in a number of 'MinD themes'.
2) The brainstorming and ideation phase where these themes were addressed by designers, and critically reviewed with a GEE representative. This led to the identification of 'Transition Areas'.
3) The idea development and decision-making for potential prototypes from the transition areas.
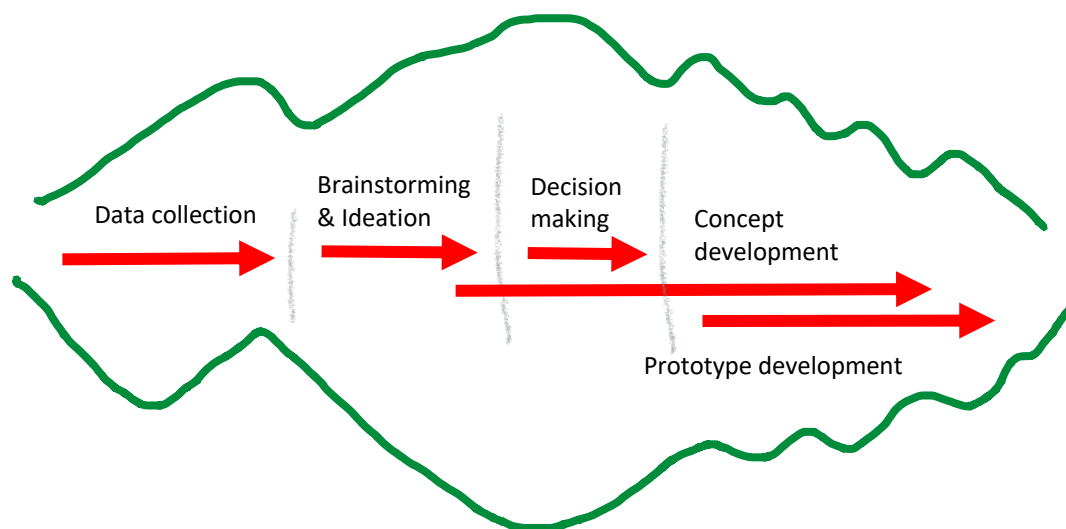4) Concept development, design specification and prototype development.

Figure 1: design research process in four overlapping phases

Phase 1 - Data Collection: Understanding what people with dementia want and need

The data collection, undertaken with people with dementia, sought to collect insights about their needs and wants concerning subjective wellbeing, self-empowerment and social engagement. The data collection methods were used to elicit issues and challenges of well-being and self-empowerment in everyday social contexts from the view of the person with dementia, with the aim of identifying situations for design innovation.

Data collection methods and instruments included qualitative interviews with individuals and focus groups using visual cards of daily activities to support discussion in the interviews, and visual probes – a design method used to collect visual and experiential information to complement the data collected through the interviews. Visual probes look at users' personal context including their social, aesthetic and cultural environment as well as needs, feelings and attitudes (Mattelmaki, 2006, Sanders & Stappers, 2014). The MinD probes included, for example, pop-up paper houses and Kilner storage jars, to support questions with visual metaphors designed to promote memory and initiate conversations about the everyday life and needs of a person with dementia (Figure 2). The MinD probes are more fully described in Garde, van der Voort and Niedderer (2018).

Groups of care professionals (psychiatrists, gerontologists, care workers and researchers) conducted the data collection and analysis with people with dementia and carers in Germany, The Netherlands, and Spain. The transcripts from the interviews were translated and passed to the designers as sets of themed quotes for them to work with. The analysis of the quotes revealed nine content related themes to focus the design innovations plus two generic themes (familiarity and continuity) to provide further guidance for designers (Figure 3). The nine content-related 'MinD themes' then provided the basis for the brainstorming and design ideation in the next phase.

Figure 2: visual probes to help with preserving important moments in people's lives.
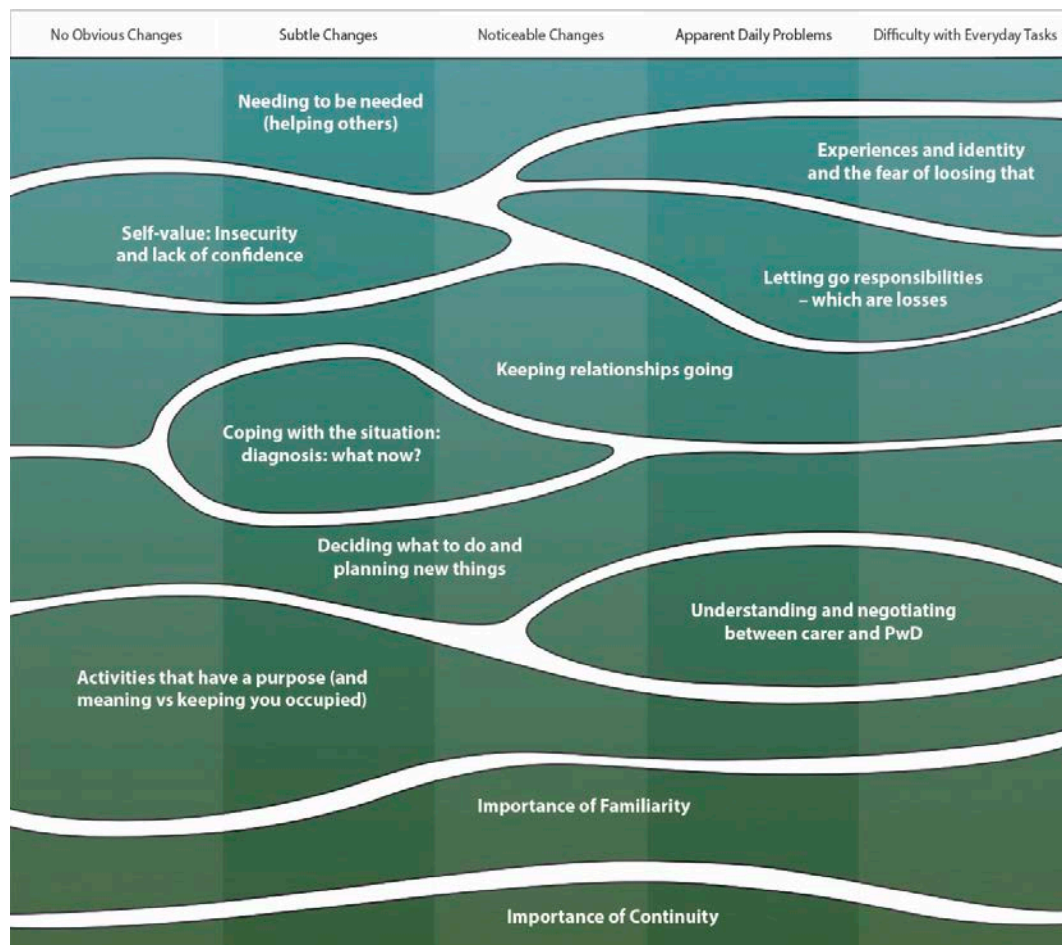
Figure 3: 9 + 2 MinD Themes

Phase 2 - Brainstorming and Design Ideation

Based on the 'MinD themes' from the data collection and informed by a context review, the designers began the ideation work with brainstorming and sketching. Each idea was then discussed by the team with GEE representation according to the criteria of mindfulness, functionality and feasibility, and positioned on a large-scale grid map as a data matrix. This matrix (Figure 4) was populated with images of existing designs, quotes from the data collection, and MinD design ideas, and highlighted particular areas of concern where support was needed for people with dementia but no existing items were available. These we identified as seven key 'Transition Areas' ripe for design intervention and acted as briefs for the development of the prototypes:

1. Coming to terms with the diagnosis: acceptance, self-value and identity
2. Feeling useful through helping others: sustaining self-worth and positive emotions
3. Self-realisation through purposeful activities: compensating for limitations with new activities
4. Coming to terms with emotions: defining and valuing yourself, in relation to others
5. Keeping relationships going: empathy in planning, decision-making and in negotiation with carers, friends and family
6. Maintaining social participation: autonomy in continuing relationships with carers, friends and family
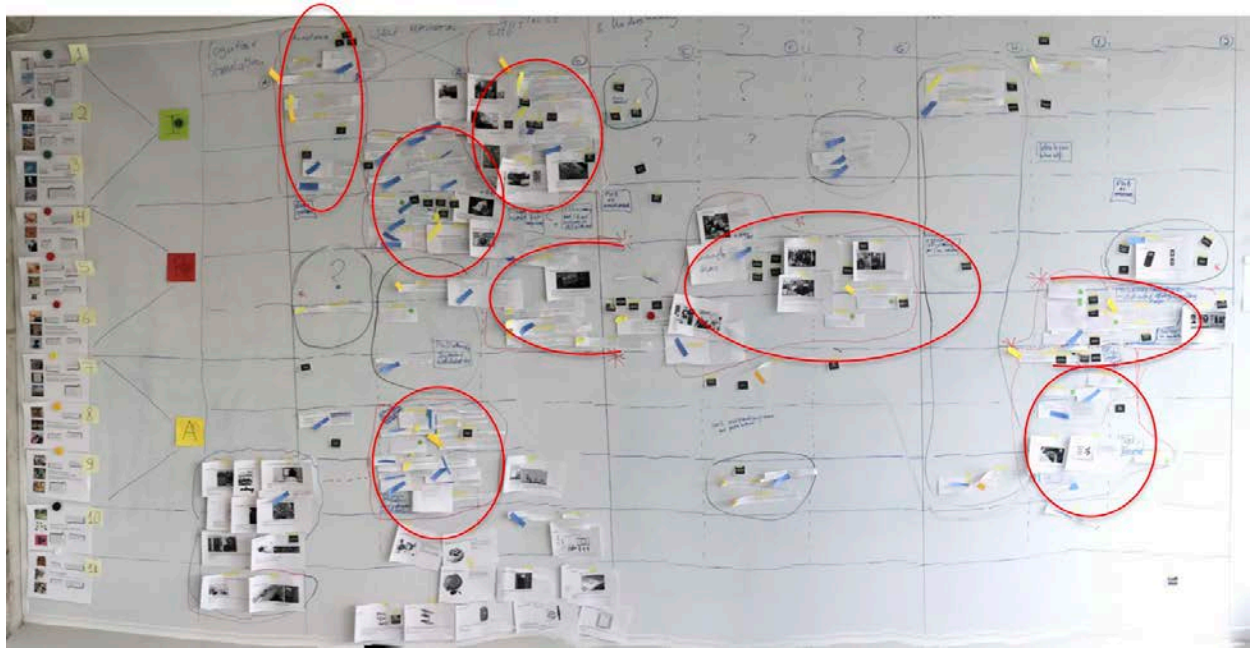7. Negotiation and communication: when planning activities

Figure 4: Map with Transition Areas. X-co-ordinate: MinD Themes; Y-coordinate: Design Themes; Content: existing designs, quotes from data collection, MinD design ideas.

Phase 3 - Idea Development and Decision Making

The initial design ideas were developed in more detail in relation to the transition areas as well as to personas and scenarios. Personas and scenarios are fictional entities based on real data from the data collection, they bring together typical characteristics to offer representative examples to work with (see Niedderer et al, 2017, Carroll, 2000, Williams et al, 2014). Ideas were then presented in short form (Figure 5) to different professional and user groups in Germany and Spain in an iterative process for feedback. Those judged to be useful, relevant and appropriate for taking forward were then presented to a group of people with dementia and carers in the UK, and one representative from the European Working Group of People with Dementia (EPWPWD) who joined via Skype. Overall, design ideas were discussed with a total of 26 MinD design and healthcare colleagues, external healthcare experts, carers and people with lived experience of dementia and memory problems to indicate, understand and acknowledge their preferences.

Based on the collated feedback, the MinD management group made decisions on which two design ideas to take forward for prototyping - a Good Life Kit and a form of Social Engagement Map. This paper reports on the latter, now designed as the 'Let's meet up!' system. The following section presents the prototype co-development activity leading to the creation of the system.

Figure 5: Social Engagement Map 'Let's meet up!' – short form presented for discussion

Phase 4 - Concept development, design specification and prototype development

This section provides an overview of the final design and the process by which it was derived. The section is organised in three parts: an overview of the design considerations and development, a brief description of the participatory co-design processes, and a summary of the final design.

'Let's meet up!' is a hybrid board and electronic system for social engagement that aims to empower people living with dementia. It encourages people with dementia to stay in touch with their loved ones and to remain physically active by arranging joint activities through a simple, user-friendly tangible interface. It seeks to empower people with dementia by helping them to plan and prepare for going out, giving them the confidence to initiate these activities.

After the decision-making was completed, the development process continued as an iterative process, which is a generally acknowledged characteristic of designing (Sanders & Stappers, 2014). The iterative nature was further promoted by the particular shape of the project conditioned by the grant scheme under which this project was funded[5]: Project work progressed during regular 2-week secondments, hosted by the different project partners, where different groups of visiting researchers worked first on the design concept development and later on the prototype development. In addition, GEE events were held (usually) during the secondments to facilitate consultation, feedback and co-creation opportunities (Figure 6).
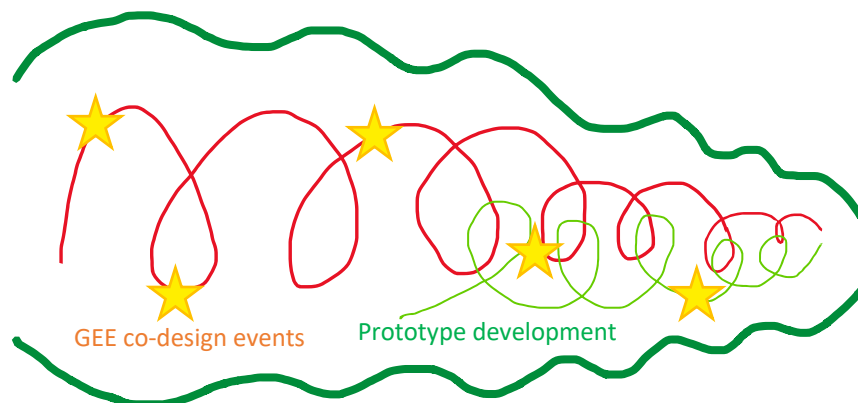

GEE co-design events   Prototype development

Figure 6: iterative design concept and prototype development process

Design considerations and development

For this prototype the designers were informed by transition areas 6 and 7 which indicated that it can be hard for people with dementia to keep relationships going, that friends and family may not always understand them that well, and that participating in group activities may become more difficult. Other design considerations related to the two generic MinD themes: the importance of a sense of continuation and familiarity, which could be attained through attending the same regular activity events, with the same people, or using familiar things. The data revealed that although people with dementia might be happy to let go of activities if they found them difficult, they would not be so willing to give up activities that they found pleasurable and that gave them a sense of independence, purpose or achievement, even if this caused anxieties for the carer who perceived those activities as a risk. Therefore, the design needed to offer ways of encouraging motivation and

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[5] The project was funded under the Horizon 2020, Marie Sklodowska Curie, Research Innovation and Staff Exchange grant, which seeks to promote staff upskilling through working on a collaborative research project.

confidence while offering new pastimes which might compensate for the necessary loss of some activities.

According to the MinD theme of familiarity, the team noted that there is currently a large number of those living with dementia who are not 'digital natives' having been born into an analogue generation. They are less familiar with new technological devices and find their interfaces somewhat complex. Cognitive simplicity was therefore essential for this prototype. Although there are a number of mobile phones and tablets with helpful Apps available, they are not necessarily the means of first choice, and users with dementia as well as carers usually need training to use them, which is possible but can also be difficult. Feedback from the GEE groups indicated people's varied preferences for paper diaries, email or iPad use for Skype, but for the electronic devices this also brought them difficulties with remembering, for example, passwords or the layered structure of Apps and Programmes. In bringing the two aspects of familiarity and cognitive simplicity together, the design developed an interactive format that offered a more simplistic interface than existing solutions, essentially in a 'hybrid' format integrating digital and analogue elements drawing on familiar concepts and processes.

For digital technologies, tangible counters for screen access can be easily manipulated without users having to learn or remember a new mechanism such as 'drag and drop' or tapping on a screen. Anyone who is able to physically manipulate those objects will perceive them as being graspable and moveable (Norman, 2013). There is evidence that using physical affordances such as these can make interfaces more intuitive for people living with dementia (ref chapter in this book Blackler, Chen, Desai and Astell). In addition, they have longevity in people's memories – common physical affordances are learnt in childhood and reinforced throughout the lifespan. So they are much more familiar and potentially more robust in the face of dementia than other interface features, especially newer features and conventions that many people in their 70s and older have limited familiarity with compared to younger people (Lawry, Popovic, Blackler and Thompson, 2019).

To meet these concerns the designers agreed on an electronic system in the form of an interactive map presented in the style of a board game with counters to move in order to play. The aim of the 'game' is to facilitate the person with dementia to connect, plan, support and visualize social participation. The social engagement electronic system 'Let's meet up!' is not an App or a Tablet, a Planner or a Diary, it is a means of keeping a person with dementia in touch with their family and friends and for continuing with their leisure activities for as long as possible. It is aimed at elderly persons with early stages dementia who find new technologies unfamiliar and challenging, and prefer not to use smart-phones or tablets. Let's meet up! instead takes the form of a flat board game with tangible pieces to move around on a horizontal electronic screen while the sophisticated technology driving the system remains hidden beneath the surface, invisible to the person using it. The system is played in real-time, is bespoke to that person and incorporates machine-learning so that it can adjust to suit them as their dementia advances.

'Let's meet Up!' Co-production, Co-design and Co-creation

In order to fully involve people with dementia as co-designers, some mutual capacity building was required to surmount common apprehensions and preconceptions and build confidence in working together within multidisciplinary teams in the co-design sessions. One way of achieving this was to begin each session with a joint convivial and creative social task loosely related to the session theme. These tasks allowed people to get to know each other, share feelings and experiences, and

celebrate common experiences as well as diversity. The sessions were then able to offer a safe space each time where participants were comfortable with each other, felt accepted, valued and able to speak up.

Two examples of these collaborative tasks are given below, the first focusses on developing shared experiences, the second concerns co-design working.

Example of developing a safe co-production space

This was an exercise around creative space where all participants were asked to pick an object of their choice from a 'magic suitcase' (Figure 7). Participants then worked in groups telling each other who they were and why they had selected 'their' object before working together to create a joint storyline in which all the objects were embedded. To create a convivial atmosphere, each group then told their story to the others, and finally, joined together to reflect on what they had learned about themselves, the other participants and about working together creatively.

Figure 7: Capacity building for creative partnerships in decision making

Example of developing co-design processes to facilitate moments of co-creation

During the design phase for 'Let's meet up!' one of the co-design workshops introduced a series of tasks around everyday objects, where all the participants were asked to bring along an object of their choice such as a diary, watch, map, tablet…. For these tasks, the participants worked in mixed groups to explore how we use the objects, how they help us organise and manage our everyday lives, and to see where they might not work so well, the space where new products could be envisaged. Based on the observations and insights from the tasks, participants were able to conceptualise what improvements or variations might be useful for 'Let's meet up!'. A large amount of material was gathered from these workshops which helped to inform the next iteration of the design process.

In the examples given, all participants shared personal information about themselves: people with dementia, carers, designers, and clinicians completed the tasks in groups with people with dementia. A redistribution of role and power was enabled along mutual mindful explorations of the personal worlds of others, as co-workers with and without dementia discovered how much they had in common and helped to create a team spirit where all felt included, enabled and empowered.

'Let's meet Up!' Design Specification and Prototype

The final system design is the output from the co-design process. It is intended to work from a single 40" screen placed on a (coffee) table where the person with dementia (player) will usually sit to rest and relax. Accompanying the screen is a round, transparent counter or 'puck' 8.5cm in diameter and an A4 sheet of instructions (Figure 8). The screen is activated by sensors which are triggered when the player sits down near the table. It then comes to life and shows a number of round images moving slowly around the screen, some are large and clear seemingly at the screen's surface others are smaller and faded as if below the surface. The images are that of either the face of a friend or family member with their name and relationship printed at the top, or an image of them with the person with dementia enjoying an activity together with the activity's name at the bottom. The 'face' images keep to the left-hand side of the screen, and the 'activity' images to the right. The large, clear images indicate who and what is available at that time. The screen of labelled faces and activities is to remind people of who they know and what they do. They can then follow through a small set of actions ending with a call to make an arrangement to meet and undertake an activity.

Figure 8: Trying out and evaluating the 'Let's meet up!' experiential prototype with GEE participants in Nottingham, UK

Using 'Let's meet up!' involves the following steps:

First select one of the large clear images by placing the 'puck' on it. This action sets the image by 'stamping' a coloured ring around it (Figure 9), holding it still while most of the other images fade and shrink in size leaving the next set of selection choices available to stamp (Figure 10).

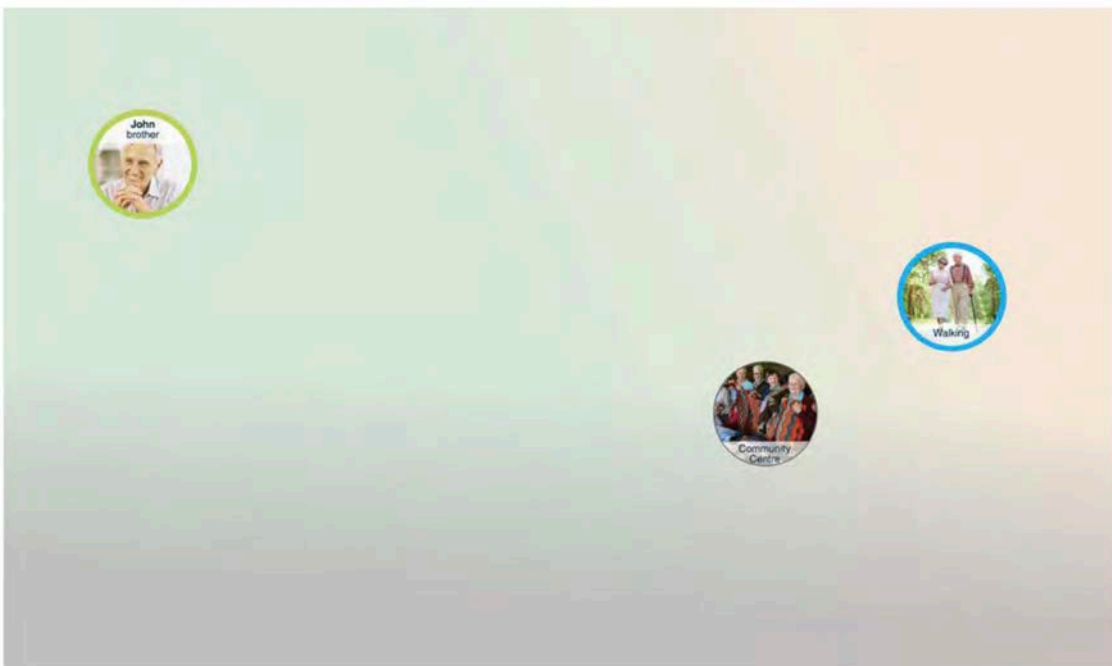Figure 9: 'Let's meet up!' – first 'entrance' screen

Figure 10: 'Let's meet up!' – second screen

The second stamped image (Figure 10) causes the others to fade as before, but also generates up to three information circles as conversation prompts at the bottom of the screen (Figure 11).
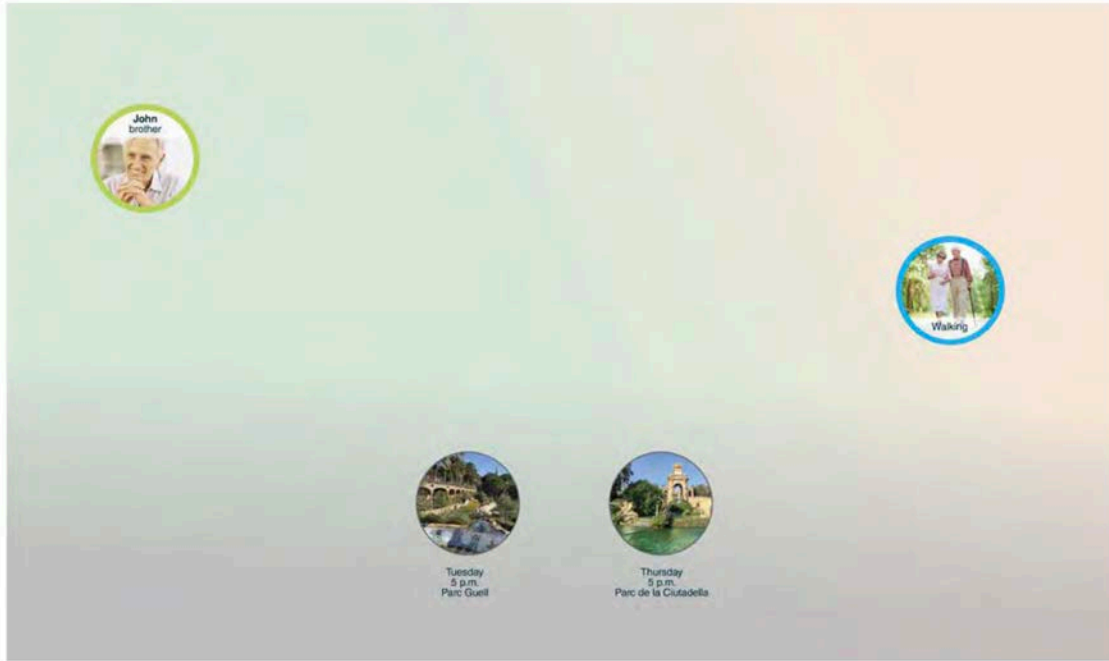
Figure 11: 'Let's meet up!' – third screen

At this point one of the two stamped and colour-ringed images (face/ activity) will then be circled by an animated ring, encouraging the player to place the puck on it for a second time (Figure 11). This action tells the system to call the chosen person directly and if it is a video call, the person phoned will appear in a central circle between the two face and activity images, with the three previously selected information circles visible below to act as conversation prompts (Figure 12).
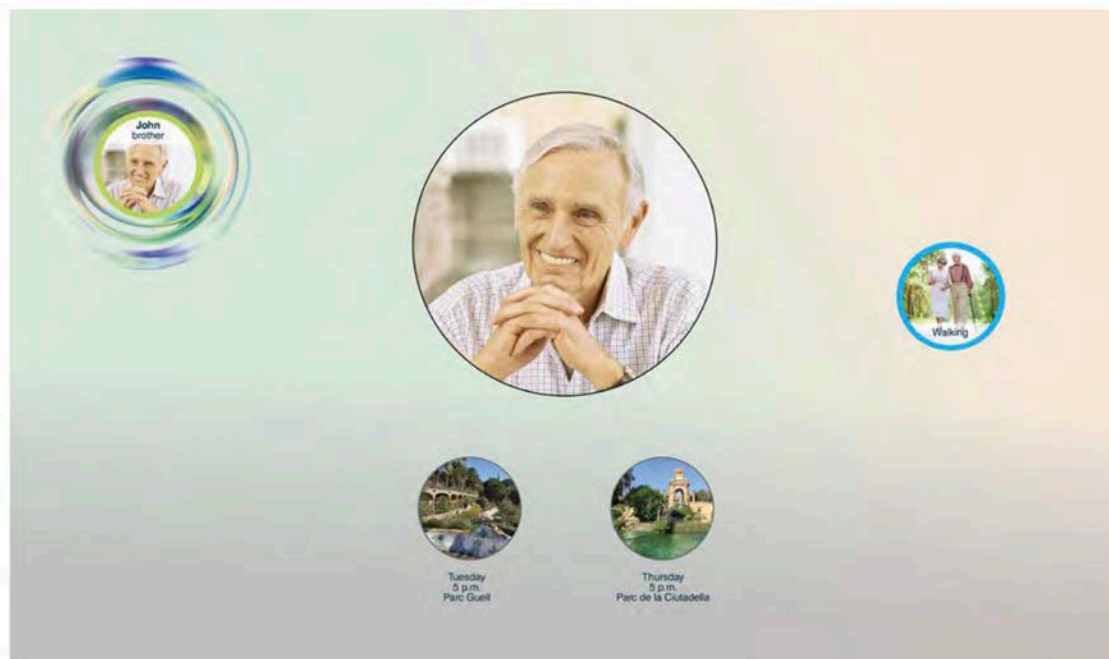

Figure 12: 'Let's meet up!' – fourth screen

When a meeting arrangement has been agreed and therefore which information circle is to be selected, the player moves the puck on to the information circle. This, along with the face and

activity circles, is now set in the system's memory so that all three will show again as a reminder to the player nearer the time. Once the last circle has been stamped, this completes the task and the puck is then moved off the screen and on to the table ending the call if the other person hasn't already ended it.

If the player has made an arrangement but forgotten about it and attempts to make another for the same time, the system will not offer any activity information circles which include that particular time. Instead it will offer alternative times available at the time of access.

Should the player changes their mind at any of the three selection levels, they move the puck off the board and place it on the table, the system then reverts to the previous selection level so that the following choice can be re-taken. The only exception to this being where the final information circle is selected and may then need to be changed, in this instance the puck can be placed instantly on to another information circle taking the orange ring with it (without the need to move the puck off the screen and on to the table first). When all is finally selected, moving the puck off the screen and on to the table will then set the arrangement and end the call.

There is also the potential for the system to enable members of the support team to call the person with dementia to invite them out. At present, this extra facility was not deemed necessary as the purpose of the electronic system is to empower the person with dementia by allowing them to take control and initiate the conversations to arrange their outings. Whether this feature should be developed will be decided following the evaluation of the system's prototype with users.

In technical terms, the system is activated by the person with dementia but runs on a database built on information supplied by their support team of friends and family who will have previously agreed to supply their data for this. The support team members will need to input personal details such as names, relation to the person with dementia, time-slots when they are available to be called, face and activity images etc. through a separate form. They will also be able to edit their data if, for example, they need to change their face image or their availability slots. The support team needs to ensure that between them there is always someone available in the daytime time-slots. It is likely that none of them will want to be available during the night so there would be no large clear images available to the player during those hours. The player simply moves the puck and selects the clear circular images, other than that the programmed system and database is invisible to them.

The system is designed to appear as being quite simplistic and easy to play in that there are only three levels to it and never more than three options for the player to choose from on each level. The aim is to enable the person with dementia to use the device on their own, as their carer may not always be at hand, and promotes maintaining autonomy for as long as possible. The prototype created exists in its most basic form of contact and engagement, and other affordances can be programmed in as required such as a means of recording the event for memory enhancement and savouring pleasant moments, or linking to a wearable tracking device. Each system is uniquely bespoke for its owner and may begin with a much wider social sphere than the one demonstrated in the prototype, however as the dementia sets in the machine-learning aspect of the system will work with the user and reduce the scale of the social sphere accordingly.

Conclusion & Recommendations

In this chapter, we have discussed the development of the 'Let's meet up!' electronic system designed with and for people with early to mid-stage dementia. In response to data collected at the start of the project, the system was developed as a means of enabling people living with dementia to stay active and socially engaged.

A key aspect of this design project has been putting people with dementia at the centre of an open-ended design process, not predefined by technology. It was therefore essential to involve people with dementia at all stages of the research and design process. This engagement has taken different forms through the different phases of the project, and for different purposes. For both the data collection and the evaluation stages, traditional interview and focus group techniques were used, while for the iterative design process, the GEE was seminal in getting people with dementia to share their experiences and offer valuable feedback and input. The GEE was also essential when helping to devise and review the research tools using appropriate formats, content and language.

The co-design process made it clear that it is paramount that designers work directly with that user group in order to better understand the feelings and lived experiences of people with dementia and to provide efficient and appropriate designs as helpmeets. Key to this process is the recognition of what form of involvement would be most useful, and at what point. This means designers moving away from consultation and advice, to co-design and co-creation where they can ensure that people with dementia can make a real contribution. This was also appreciated by the people we were working with as different to their usual forms of GEE engagement.

While very successful, this kind of working needs careful consideration with regards to communication and feedback to those involved, researchers, designers, health-care workers… as well as to the people with dementia. When working with a large group of people on a design project like that of MinD, which included well over 50 researchers and participants, it needs to be understood that decisions have to be made and that these cannot be made by everyone. Even though an individual's contribution may have been crucial to the development of the design, their ideas and voice will not be explicitly visible in the end result. Therefore, it is advantageous to stress and communicate to everyone involved in the project that their input has been hugely important and highly valued, no matter at what point it was contributed.

Central insights and recommendations from our work concerning participatory research include:

- Be aware of different types of participation from advice to co-research;
- Different phases require different methods: consider using different types of participation at different times for different purposes - what is appropriate when and for what purpose?
- Be aware of conditions and constraints (e.g. funder regulations) and how to make the best of the resources available (staffing, time, money);
- Be clear about the different roles, aims and expectations of the collaborators: equity does not mean that all participants are involved in everything;
- Consider communication and feedback: when, by whom and to whom.

Central insights and recommendations from our work concerning co-production include:

- Plan for capacity building to enable co-production: allow sufficient time to plan events where people can get familiar and comfortable with each other for the work ahead;

- Allow for activities that will develop a shared language, shared understandings and shared work ethics;
- Together: consider when and how to plan and shape co-production events; work on developing co-production and co-design tools; implement co-production events as a forum for facilitating co-design & co-creation.

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