



designing for people with dementia  
mindful self-empowerment & social engagement

# **Guidelines for Designing with and for People with Dementia**

January 2020



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Further project information:  
[www.designingfordementia.eu](http://www.designingfordementia.eu)

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# Executive Summary

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## 1. INTRODUCTION TO THE MIND PROJECT: ORIGINS AND AIMS OF MIND

Dementia can affect all aspects of a person's life, including how they spend their time, their feelings about themselves, their relationships with other people and their social life and interactions. Using design and mindfulness, the MinD project 'Designing for People with Dementia' aims to help people with early to mid-stage dementia engage in social contexts and meaningful activity to improve psychosocial wellbeing. The project has brought together 18 partners with different types of expertise, including lived experience with dementia, from 8 countries. It has developed partnership with Groups of Experts by Experience (GEE), to centre on the lived-in worlds of people affected by dementia. Our experts have worked together on identifying and developing design solutions that can help people with dementia manage, enjoy and make the most of their daily lives. Here, we set out what we have learned about good design with people with dementia, based on our work and that of others. This document is aimed at a professional design audience as well as interdisciplinary research teams. We plan to develop an accessible version aimed at people with dementia, their families and those closest to them, and other relevant audiences.

## 2. BACKGROUND: LITERATURE AND THEORY

In developing the frameworks and methodology for MinD, we have drawn on published literature and relevant concepts. These include:

**Personal design:** Design is ubiquitous and is found in every area of life. Increasingly, the emphasis is on user-led or person-centred design, with greater involvement of users and aimed at the potential of increasing empowerment or maintaining independence. Much of the existing literature on technology and dementia concerns assistive technology. This has several limitations from our

perspective, as it is often focused on more severe dementia; its use is often focused on functional aspects and applied for or on people with dementia rather than by or with them; and its design is rarely participatory.

**Personhood:** Person-centred care is a widely-used model but it has limitations since it can overlook or ignore the social and relational aspects of life with dementia. MinD looks beyond a merely person-centred focus and places the social world of the person with dementia at the forefront to enable a more holistic view and approach.

**Mindfulness:** With its focus on 'in the moment', mindfulness can help mitigate the disadvantages caused by memory problems, and this gives it great potential in working with people with dementia. Mindful design has been used in other contexts to promote reflection, choice and responsibility. Embedding mindful choices and reflection into the items designed was an attractive starting point for the MinD project.

**Co-design, co-production, co-creation:** These terms have varied and often overlapping definitions, or are used interchangeably or alongside other terms such as 'participatory design'. In this report, we use the term co-design to describe work involving people with lived experience of dementia in the design process. We regard co-production as the process that facilitates partnership for and within co-design to happen; and we have tried to avoid the use of co-creation, which is generally used as a broader term covering any part of the collaborative process – unless it is explicitly used in the literature. Use of these terms is discussed in more detail in section 2.5.

### **3. THE MIND FRAMEWORK**

MinD is a diverse interdisciplinary and international group of researchers and professionals with experience in, for example, clinical practice, design, architecture, partnered with a cohort of lived experience that included researchers, who were themselves living with mental wellbeing, memory or cognitive challenges, and who participated as equal partners in secondments, contributing on all levels, co-ordinating much of the GEE and participatory development work and contributing significantly to innovative co-design activity.

To facilitate this diverse project team and its ambition to integrate mindfulness in people's lives through design, a strong framework had to be created to enable both the collaborative journey and the implementation of the project's aims. For this purpose, the team developed a framework for using mindful design in the dementia context with regard to both design as a process and an outcome, and which has been used to facilitate the MinD journey.

### **4. METHODS AND PROCESSES: AN OVERVIEW OF THE MIND JOURNEY**

A key feature of MinD has been lived experience collaboration from the outset. This has included traditional methods (interviews and focus groups) as well as a one full-day consultation with the European Working Group of People with Dementia (EWGPWD) and local participatory development and co-design work in the UK and Spain, at key points throughout the project. Altogether about 70 people with dementia collaborated in the study. Another meeting with the EWGPWD will provide feedback at the end of the process. Lived experience and GEE input, including innovative co-design activity, has directly influenced the different solutions designed by the project.

Qualitative research conducted in different countries (Spain, Germany, Netherlands, UK), in phases 1 and 3, collected data to understand the main needs and challenges faced by people with dementia and carers in their lives, together with their aspirations. Different approaches were used to suit the different settings and needs of people with dementia and carers in the different countries. This work included focus groups, completion of design probes and one-to-one interviews. Ethical requirements such as informed consent, voluntariness, privacy and confidentiality were addressed. The materials were developed jointly by professional partners with expertise in research, design and dementia. The data collected were analysed and used to derive 'MinD themes' for further work within MinD.

The main issues addressed in the GEE and participatory development workshops included: identification and verification of the needs to be worked upon; involvement in data collection; choosing which concepts should progress to the design stage; and providing feedback at various stages of concept and prototype development. Attention was also paid to developing a strong co-design culture based on mutuality and respect for everyone's contributions that ran through the entire partnership and project activities. Establishing meaningful lived experience collaboration requires attention to how and why people are approached in the first instance; the invitation that is made to them as experts for consultation and creative input based on their lived experience; observing relevant rights, permissions and consent; creating an equitable and inclusive partnership environment; using accessible communications and participatory activities that include everyone.

## **5. KEY INSIGHTS AND OUTCOMES: MIND DESIGN GUIDELINES**

The MinD project has collaboratively developed four design ideas incorporated into two prototypes: the Good Life Kit (This is Me, Living the Life, You & Me) and the Social Engagement Map 'Let's Meet Up!'. Evaluation of designs have focused on usability and user experience. Alongside the tangible design outcomes and evaluation, the MinD project has developed processes and practices of co-design and co-production, and undertaken research in partnership to obtain evidence of lived experience directly from people with dementia. The insights from the process of developing these designs in partnership have been a key part of our work. In this report, we offer our insights and recommendations from the MinD project, divided into guidance for:

- Multi-disciplinarity and inclusion in participatory (design) research projects
- Mindful partnership and co-production processes and values
- Mindful partnership, co-production and co-design: language and communication
- Mindful co-/design processes with and for people with dementia

## **6. CONCLUSION**

From our experience in the MinD project, there are different types of findings that can be useful for other researchers, designers and people with lived experience who may want to co-develop future studies involving design with and for people with dementia. This report offers the theoretical background and framework as well as insights and recommendations to support others who wish to follow a mindful design and co-design process in participation with people with dementia.



# 1. Introduction to the MinD Project: origins and aims of MinD

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The MinD project – Designing for People with Dementia: Designing for mindful self-empowerment and social engagement – arose from the wish to support people with dementia through design. On the one hand, with no cure in sight, focus on quality of life is a key. This includes subjective wellbeing (the individual’s perception of their emotional wellbeing, sense of purpose and meaning of life) and social connectedness as well as being able to feel in charge of one’s life. On the other hand, design offers the interface between technology and human interaction. This is often overlooked in the traditional focus on AT.

This four-year project (March 2016 – February 2020) has therefore sought to bring together designers, healthcare professional, technologists and people with dementia to work jointly on identifying and developing design solutions that can help people with dementia manage, enjoy and get the most out of their daily lives. The project has included 18 partners from 8 European and international countries, and partner groups with lived experience of dementia, working together. A key aim was to develop a mindful design and co-design approach to enable the collaborative development of design ideas and prototypes from start to end.

This addressed the following MinD Research & Innovation Objectives:

- 1) To investigate the challenges and opportunities of increasing subjective wellbeing and social engagement for people with dementia through design from a mindfulness perspective;
- 2) To develop mindful co-design approaches to empower people with dementia to express their needs and challenges with social engagement during the design process;
- 3) To develop a mindful design approach to developing design product solutions to empower people with dementia to engage in social contexts;
- 4) To investigate and test the conceptual and technical development of tangible mindful design solutions, both personal and environmental, supportive of personal well-being and social inclusion within a dementia care context.

This report focuses on the insights learned from the design process. It offers a description and analysis of the process, and concludes with a summary of the key findings in form of design guidelines. The guidelines are offered as an aid for designers, care professionals and interdisciplinary research teams who aim to develop designs (or other interventions) based on participant engagement and co-production.

## 2. Background: literature and theory

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This section provides an overview of key approaches and developments dealing with the processes and products of designing with and for people with dementia, including personal design, environment design, lifestyle support, personhood and co-design. It looks at principles and guidance for design and co-design processes to provide an overview of the basis from which the MinD project developed its holistic co-design and co-production approaches, and against which design guidelines are developed within this report.

### 2.1. PERSONAL DESIGN

Design is ubiquitous and acts upon many aspects of everyday life for all of us. Design affects our mental states and behaviours in the course of a whole range of tasks and activities. Design may influence how and whether we are able to open a kettle to make tea or coffee, what food or cloths we buy, or whether we take the stairs or the lift, the train, bus or car. In short, design affects all aspects of our lives. Normally we do not think about this, but it can be helpful to be aware of the influences and to be able to reflect on them. Design can embed mindfulness in various ways to promote mindful awareness and reflection (Niedderer, 2014, Niedderer, Clune & Ludden, 2017). A personal approach to design can help realise the potential of mindful design to enhance well-being and self-empowerment in people with dementia.

The earliest application of person-centred design in dementia was probably in the area of assistive technology (AT), for example the EU-funded ASTRID project (A Social and Technological Response to meeting the needs of Individuals with Dementia and their carers; Marshall, 2000). ASTRID produced a guide in order to provide a framework for assessing the needs and identifying appropriate technological solutions for potential users of assistive technologies. Anticipated users were people with dementia and their carers, the health and social services and other organisations that work with older people, and suppliers of AT. As observed by Innes and McCabe (Innes & McCabe, 2007), ASTRID was explicitly founded on the principle that the primary concern must be the views and wishes of the person themselves and improvement of their quality of life.

Another EU project, TED (Technology Ethics and Dementia; Bjørneby, Topo, & Holthe, 1999), sought to 'marry the new with the familiar' when developing and introducing new technology to people with dementia and their carers. It focussed on quality of life, facilitating independent living of people with early dementia and promoting wellbeing through access to enabling systems and products. 'Pleasure, memory support, entertainment and own activity' were identified as key words in the project. A third EU project, ENABLE (Enabling products for people with dementia, <http://www.enableproject.org>), produced an assessment report on assistive technologies with useful observations about process as well as design guidance (Holthe, 2004).

These projects focussed on assistive technologies and the methods used were not particularly participatory but they did reveal some important aspects of collaborating on technology design with people living with dementia and carers. Cahill, Macijauskiene, Nygard, Faulkner, and Hagen (2007) summarised the 'Design for All' principles of ENABLE, which included: giving the feeling of independence; support of the person in making choices; having a positive impact on life; supporting and maintaining skills rather than emphasising lost skills; not to focus on the disability but support self-image; reminders of existing solutions; and making information about a product's use visible at all times. Ethical aspects of the three projects were also highlighted (Bjørneby et al., 2004).

Although the above shows an advance in promoting a user-centred approach to design, a decade later, Gibson et al. (2016) found that assistive technologies could be readily categorised as being used 'by', 'with' and 'on' people with dementia, with many solutions still being about their use 'on' people, which is not very empowering. De Filippis et al. (2014) further observed that most assistive solutions focus on the lower levels of Maslow's Hierarchy of Needs, addressing physiological and safety needs, such that more aspirational needs are not well addressed. Meiland et al. (2017) reviewed the literature concerning development of assistive technology for community-dwelling persons with dementia, and found that the user group were often not involved in development or evaluation of technologies and that although ethical issues were often mentioned they were not often explored.

Assistive technology, however, forms only one area of design relevant to people living with dementia. There has been relatively little research on design specifically aimed at promoting well-being, independence and empowerment. More recently, researchers such as van der Cammen et al. (2017) have described how applications of design and technology can contribute to 'autonomous ageing', for example, independent living and life style support, and can compensate for functional deficits associated with ageing. So far, what is missing is research on how design can help people with dementia in a more aspirational way: in other words, moving from a preconception of their needs to more active consideration of their wishes and hopes. Mindful design, focusing on abilities and self-value seems like a promising way forward (Niedderer, Tournier & Coleston-Shields, under review).

## **2.2. ENVIRONMENT DESIGN**

The ASTRID project (Marshall, 2000) also led to a good deal of useful design guidance in the area of environmental design which continued through one of its co-investigators, Mary Marshall, who has most recently produced guidance on Dementia Friendly Design through the Australian charity HammondCare (O'Connor et al, 2019). Guidance on design of buildings, rooms, equipment, furniture and outside spaces in care homes and community housing includes overcoming the difficulties a person with dementia may have with flooring and bathroom equipment (toilets, taps), designing for familiarity, as well features of ageing such as visual and auditory impairment which may compound memory problems. Solutions include greater use of glazed doors and interfaces and attention to spatial organisation of the physical environment to aid memory, and generally avoiding clutter.

Halsall and MacDonald (2015) have produced a two-volume guide 'Design for Dementia', which is freely available, on architectural (buildings) design and the lived environment. The guide emphasises 'liveability' and 'joy' for buildings and environment including broader notions of 'familiarity' (use of local landmarks etc.), 'distinctiveness' (Sense of place etc.), 'legibility', 'accessibility', 'comfort', 'stimulation' and 'safety'. It also offers an approach to design which is 'experiential' (using all of the senses) and 'responsive' (safe and secure and conducive to community life) to be achieved by working with end users and communities from the outset, empowerment of local groups, involvement of academic and healthcare experts, and an interdisciplinary design effort. With specific regard to hospital design, Bueter & Marquardt (2019) have brought together insights about sensitively designing for people with dementia in an architectural context to enable mobility, activity and independence. Van Rompay, Ludden, Tournier & Niedderer (2019) have looked at the use of environmental design from a different angle to create mindfulness-state-supporting environments through 'soft fascination' related to nature imagery to

support effortless attention and relaxation. All approaches stress the importance of working with people with dementia during the design process.

## **2.3 MAINTAINING PERSONHOOD**

The current importance attributed to personhood and to person-centred care in dementia owes much to the work of Tom Kitwood (1997). Kitwood identified and operationalised a set of psychological needs, including comfort, attachment, occupation, identity, inclusion, and love. He also described how malignant social psychology in care settings could reduce the personhood of individuals with dementia, leading to negative changes in their behaviour. These insights have revolutionised modern approaches to dementia, with increasing focus on behaviour as being a form of communication.

Closely related, 'person-centred care' seeks to elicit individuals' values and preferences which, once expressed, guide all aspects of their health care, supporting their health and life goals (American Geriatrics Society Expert Panel, 2016). Person-centred care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires.

However, the concepts of personhood and person-centred care have limitations since, if the focus is limited to the person, it can overlook or ignore the social and relational aspects of life with dementia (Nolan et al., 2006). Personhood has also been criticised for being too abstract and ambiguous (Higgs and Gilleard, 2016) and therefore we should look at more positive aspects, such as people's capabilities, while minimising the harmful consequences of any incapacities. In keeping with these views, MinD therefore looks beyond a merely person-centred focus and places the social world of the person with dementia at the forefront.

## **2.4. PUBLIC INVOLVEMENT**

Public involvement in fields such as healthcare or design has received increasing attention over the last two decades. This has also led to a variety of terms that are used to describe various ways in which members of the public, consumers or people with lived experience (of a health or social condition) may contribute to activities such as research and design.

Within healthcare, involving patients has been part of UK policy since at least 1999, with the publication of a document called Patient and Public Involvement. This term has remained popular and is widely familiar as its abbreviation, PPI. In relation to health conditions, especially long-term health conditions, PPI can include several dimensions, including self-management by the individual, coping with the illness, engaging with local services, and contributing at a wider level to critical public health (Greenhalgh 2009). The preferred European term is Groups of Experts by Experience (GEE) and that is used in this report as (a) this is a European collaboration and (b) GEE avoids the reference to Patients that is part of the term PPI thereby implying health care settings and related unequivocal relationships.

Involvement of the public and of people with lived experience in research is now widely advocated and indeed evidence of GEE activity is required for most grant funding applications. NIHR Involve offers a set of online resources to promote GEE in research (NIHR, 2019). Involve defines public involvement in research as research that is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them, being rooted in the civil rights movements best defined as 'nothing about us without us.'. This specifically excludes awareness raising, recruitment to studies, or

dissemination of research findings to the public. Rather it includes a spectrum of activities from consultation to co-production, which closely aligns with co-design approaches which advocate the inclusion of users into the design process, not just for consultation but for involvement from the beginning to the end.

Involve uses the following terms: Involvement, where members of the public are actively involved in research projects and research organisations, e.g. as joint grant holders or co-applicants, as members of project advisory or steering groups, or directly carrying out the research (such as interviewing participants). Participation, where people take part in a study, e.g. being recruited to a clinical trial, completing questionnaires, or being in focus groups. Engagement, where information and knowledge about research is provided and disseminated. Other terms used in other (groups of) countries: citizen involvement and citizen science (EU); patient partnerships and patient-centred outcomes (US and Canada); consumer and community involvement/participation (Australia) (Hoddinott et al., 2018).

There are two main arguments for GEE in research. One of these is ethical, about the rights of people to participate, and the other is the assumption that it may improve the quality, relevance and uptake of research. The second argument requires evaluation (Boivin et al., 2018). There is certainly evidence for the growth of GEE though it is patchily applied across different studies (Mathie et al., 2014). A review suggested that GEE has positive effects on the quality and appropriateness of research (Brett et al., 2012) but the quality of the evidence is often weak and there is likely to be a reporting bias too.

The design field has also seen a growth in consumer input into the design process, referred to variously as user-centred, participatory or co-design. Research suggests that co-design leads to design solutions that score higher on user benefit and novelty but maybe less feasible. Also, good results are dependent on a well-functioning team (Trischler et al., 2018).

MinD has employed various forms of public involvement at different stages and these will be described in following sections. From an early stage, there has been a member of one of the MinD groups with lived experience, whose insights have been invaluable in several of the activities within the programme. Members of the public, including several people living with a diagnosis of dementia, have contributed to focus groups, design sessions and evaluation. Most MinD participants were community residents and not recruited through clinics, so GEE is a preferable term to PPI in relation to MinD.

## **2.5. CO-DESIGN, CO-PRODUCTION AND CO-CREATION**

These terms are frequently used but may have varied and overlapping definitions. There are also other terms with similar meanings, such as participatory design (e.g. Sanders 2002). Many other designers and researchers since have followed demonstrating that user or participant inclusion is desirable, even when access to user groups is not always easy. Different names and understandings for participatory and co-design processes, co-production and co-creation have emerged (see SCIE, 2019, Skills for Health, 2019, Think Local Act Personal, 2011, Tseklevs et al., 2018). The published literature contains a degree of consensus although a lack of clarity remains and these terms are not often used together, authors tending to use any two of them rather than all three simultaneously. Therefore, in view of the high level of lived experience involvement in MinD, it is important to be clear about the terms we use and what we mean by them in this document.

McDougall (2012) is one of few authors to define all three terms and, although this publication is

on a webpage not in a peer-reviewed journal, it has clearly been influential (e.g. Malby, 2014). For McDougall, co-design is an attempt to define a problem and then define a solution; co-production is the attempt to implement the proposed solution; and co-creation is the process by which people do both. Alternative views of co-creation exist; for example, Zwass (2010) defined it as the creation of value by consumers, which could be either 'sponsored' (at the behest of an organisation) or 'autonomous' (taking place outside of any established organisation); and Greenhalgh et al. (2016) defined co-creation in terms of knowledge generation by academics working alongside other stakeholders.

Sanders and Stappers (2008) described an increasingly complex world of human-centred design research, and a lack of agreed definitions for the key terms of co-creation and co-design. They describe co-creation as any act of collective creativity, which could occur in a wide range of applications, some of them well beyond simple product design. Co-design is the collective creativity across the whole range of the design process, the combined creativity of designers and people not trained in design working together (Sanders & Stappers, 2008).

In this sense, while co-design emphasises the aspect of the collaborative and joint process of designing, co-creation can be considered as a broader term that includes many of the concepts that maintain dignity at the same time as engaging creative inputs in a flexible and inclusive manner, such as playfulness. In a good example, thinking more broadly about participation in design, Treadaway, Taylor & Fennell (2019) write about compassion as a key aspect of relating to people with more advanced dementia where designers are motivated to be involved with relieving suffering.

Co-production is usually used as a broader term, to describe the process of facilitating co-design, i.e. providing and facilitating the setting and conditions of working together, though an alternative meaning is for it to refer to implementing the solutions that have been generated by the design process. Co-creation is probably the most confusing of the three terms. It can have a similar overall meaning to co-production, that is, referring to participation in the whole journey of design and implementation. However, it may also be used to refer to flashes of creativity within a participative setting.

Therefore, in this report, we use co-design to mean the process of working together to develop design ideas, make design decisions, and develop workable products. Co-production is used in its broad sense to refer to the way in which co-design is facilitated; and we have attempted avoid the use of co-creation, unless it is specifically referred to in a cited paper.

## **2.6. CO-DESIGN AND DEMENTIA**

Guidance for designing for and with people living with dementia is often informed by a combination of person-centred care, as developed by Kitwood (Fazio, Pace, Flinner, & Kallmyer, 2018) and participatory design (Smith, Bossen, & Kanstrup, 2017). Co-design involving people with dementia has received increasing recent interest across a range of topics. Much of the published literature concerns health care and environmental design, much of which relates to residential facilities. However, other issues where co-design (or co-production) has featured include the promotion of personhood (Bosco et al, 2019), developing a shared definition of empowerment (McConnell et al, 2019), participatory data analysis (Clarke et al, 2018), and other creative contexts, such as art, music etc. For example, the Dementia and Imagination partnership (Parkinson & Taylor, 2017) produced a guide about a person-centred approach to involving people with dementia in the visual

arts with an emphasis on maintaining personhood. A recent scoping review (Wang et al 2019) found 26 studies involving people with dementia in design research, and in addition the evidence suggests that there are mutual benefits for the persons with dementia and for the design process (Leorin et al, 2019; Wang et al, 2019). Alongside the possible benefits, there are also issues of possible exploitation, ownership of intellectual property and copyright that are not often considered but merit more attention (Swaffer, 2016).

Van der Cammen et al. (2017) used the concept of 'autonomous ageing' to promote independent living and to compensate for functional deficits due to ageing.

Rodgers (2018) emphasised that people with dementia have a lot to offer society after diagnosis and that co-designed activities and interventions will help people with a diagnosis to build self-esteem, identity and dignity, and stay connected to their community. Their Disrupting Dementia tartan project showed how people with memory problems were able to be creative and gain much satisfaction from doing so, whilst producing a genuinely useful product, prompting ongoing engagement with art-based activities and community events. This is an example of people with dementia being fully engaged in the design process and its outputs, but not in the decision-making phase about what is to be designed.

Use of design tools has also been a feature of recent research. Wintermans, Brankaert, and Lu (2017) worked with people with dementia to co-design a communication device based on a familiar device (an old-style radio) obtained using design probes in the home, by means of the collection of stories of couples situated in their own homes. Imamogullari and Biamonti (2017) described their experience of a 'designerly' way of engaging people with dementia.

It is also clear that people living with advanced dementia can participate in co-design, as demonstrated for example by Kenning (2018) in a project with residential care facilities. Treadaway, Fennell, Taylor & Kenning (2019), in the appropriately named LAUGH project, emphasised the importance of playfulness and compassion in achieving positive outcomes for both the participants and for care staff.

These approaches show that design can be used in a range of ways to achieve a variety of purposes and different types of support. They also show that to achieve true co-design requires collaborative networks to be formed of clinicians, designers, academia, older people and industry across disciplinary and national boundaries. This has formed the basis for the MinD approach (Niedderer et al., 2017).

## 3. The MinD Framework

### 3.1 AN OVERVIEW OF THE MIND JOURNEY

As a four-year long project, the MinD project has undergone a transformative journey in a number of ways. Being interdisciplinary and intercultural, it has brought together a large range of researchers, professionals and participants from a range of cultures and backgrounds. This has required colleagues and participants to engage with knowledge and experiences outside of their usual spheres and has facilitated a fruitful knowledge exchange and growing together. Further, as is the nature of design, processes are developmental and cannot be predicted from the beginning in their entirety. This always provides an aspect of uncertainty but which – when embraced – offers the potential for opportunities beyond initial expectations. This can also be said for the MinD project in that it has shifted its focus from designing ‘for’ to designing ‘with and for’ people with dementia. and, thanks to intense user-participant engagement and co-production, has changed the insight and views of all participants, in terms of understanding the matters at hand, the design process as well as the designs developed thanks to intense user-participant engagement. Conceived as a traditional 3-phase research project, MinD had three distinct phases (Figure 3.1).



Figure 3.1: Three Phase of the MinD Research Process

#### Phase 1: Data collection

The first stage comprised data collection from people with dementia about their needs and wants concerning subjective wellbeing, self-empowerment and social engagement. This included the development of data collection instruments tailored and appropriate to the nature of the design research project. For example, we used qualitative interview scripts, visual cards of daily activities to support discussion in the interviews, and visual probes – a method from design to collect visual and experiential information to complement the data collected through the interviews. Instruments were developed with feedback from GEE consultees to ensure appropriate language and presentation. The data were subsequently analysed and synthesised into nine ‘MinD themes’ which were key in informing and providing a basis for the design phase.

## Phase 2: Design Development

The design development comprised a number of steps, including brainstorming and ideation based on the MinD themes, the initial design concept development and decision-making about which design solutions to take forward to realisation, then the full concept development of the selected ideas, and finally the prototype development. The input from Groups of Experts by Experience (GEE) has been an important part of the design development and decision making in all these stages.

## Phase 3: Design Evaluation

Finally, mindful evaluation instruments were collaboratively developed, and the designs were evaluated with participants through interviews and focus groups with regard to usability and user experience (feasibility evaluation).

The development of the three phases of the research were underpinned by the development of relevant conceptual frameworks including:

- The mindful design framework for application in the dementia context;
- Based on the MinD themes, the AIR (activities, internal world, relationships) model was developed as a tool to explain the human social and environment relationships within the MinD themes;
- A co-design model for application in the context of the MinD project.

In the following section, we expand on the concept development before detailing the design research process of the MinD project.

## 3.2 MIND CONCEPTS AND FRAMEWORK DEVELOPMENT

Three frameworks have guided the MinD project. First, the mindful design framework, which has provided the basis for the project in bringing mindfulness thinking and practice into people's lives through design in order to help with subjective wellbeing and self-empowerment in social contexts. Second, the AIR model was developed and has helped to understand parameters and relationships of people with dementia with regard to their personal understanding (identity) as well as social and environmental contexts. Third, the co-design framework has provided essential guidance in working together with people with dementia, carers and healthcare professionals within the design process.

### 3.2.1. MINDFULNESS AND DESIGN

Mindfulness has been introduced in the MinD project as a concept that can help enhance perceptions of personhood and that can be embedded in people's lives through design (Niedderer, 2014; Niedderer, Tournier & Coleston-Shields, under review). A summary is provided below.

Kabat-Zinn (2003) defines mindfulness as 'the awareness that emerges through paying attention on purpose, in the present moment.' Langer (1990, 2010) demonstrates that mindful awareness can help draw novel perspectives. Focusing on 'being-in-the-moment' – as it does not require 'memory' – can offer empowerment to people with dementia. 'Developing a Mindful Interdisciplinary Design Methodology' (Niedderer et al., 2017) explores the application of mindfulness to mindful design in relation to improving the lives of people living with dementia.

Design can support or prompt activities and raise awareness, for example, of our state of health or the need to exercise, stand up, or breathe mindfully. Design can be a powerful tool for changing behaviour (Niedderer et al., 2017) and even embedding mindfulness thinking and practices in

everyday life (Niedderer, 2014). A small number of studies support the beneficial impacts of mindfulness through design. Although many do not mention mindfulness explicitly, they draw on criteria related to mindfulness. From these studies, five different approaches to mindfulness can be distinguished, as follows.

These design approaches which allow for reflection, choice and responsibility, and which promote subjective wellbeing, self-empowerment and meaningful social engagement, may be summarised as follows:

- **Mindful design approach 1:**

Environment design for improving relaxation and mood through 'soft fascination' or multisensory stimulation (artificial or natural) e.g. landscape views, gardening or snoezelen environments (Ozdemir & Akdemir, 2009).

- **Mindful design approach 2:**

Mindfulness practices in therapeutic contexts e.g. interactive handheld light globe to support mindfulness practice in mental health/depression (Thieme et al., 2013).

- **Mindful design approach 3:**

Delivers mindfulness training through design, e.g. Apps such as the thought-distancing training AEON which allows the user to visualise their thoughts as imaginary ink on parchment placed under water. By touching the screen, the user can produce waves which progressively dissolve each written thought (Chittaro & Vianello, 2014).

- **Mindful design approach 4:**

Creates self-awareness to initiate mindfulness practice in everyday e.g. the health feature in the Apple watch 'taps' the user on the wrist to prompt breathing or exercise.

- **Mindful design approach 5:**

Activates mindful awareness and directs reflection to social and environmental issues, values and beliefs, expectations or preconceptions in every day actions and social interactions through mindful choices embedded in the design (Niedderer, 2014).

To enable the development of mindful design, in the MinD project, the natural affinity of co-design and mindfulness has been fused into a mindful design methodology. This integrates traditional participant and GEE involvement for the different stages and aspects of the project, through design methods that create awareness of their role and requirements in the process and the designs, such as Mindful Scenario Task Analysis (MSTA), Design Ideation (persona development), and a framework for GEE-based co-design. The application of mindfulness through design in the MinD project will be discussed further in the description of the MinD method story and its participatory processes.

### 3.2.2 THE AIR MODEL: MOVING TOWARDS A VISION OF CO-DESIGN AND CO-PRODUCTION

The initial period of data collection led to the development of nine MinD themes, along with the two continuous themes of familiarity and continuity.

#### MinD themes identified from the data collection:

- 1) Coping with the situation: After diagnosis: what now?
- 2) Self-value: Insecurity and lack of confidence
- 3) Experiences and identity and the fear of losing it
- 4) Deciding what to do and planning new things
- 5) Needing to be needed (helping others vs. feeling useless)
- 6) Keeping relationships going
- 7) Understanding and negotiating between carer and people with dementia
- 8) Activities that have a purpose (and have meaning vs simply keeping you occupied)
- 9) Letting go of responsibilities (these may be losses as well as bringing relief)

These themes are important at different parts of the dementia journey. The nine themes were grouped by their affinity to three key concepts: the individual and their internal world, their relationships, and their activities to develop the AIR model:

#### A – Activities

#### I – Internal world

#### R – Relationships

Figure 3.2 shows how the nine MinD themes become grouped under the elements of AIR. After all, AIR is something we all need. What is meant by activities and relationships is fairly straightforward. By internal world, we mean the subjective perspective: the feelings, emotions, and mental state of the person living with dementia. This includes their self-perception, their confidence, what they want to do, and the choices they want to make.

The three components of AIR are closely inter-related and we have represented these inter-relationships in Figure 3.3: A lack of activities can have detrimental effects on both the internal world and on the relationships of a person. Turmoil or distress in the internal world can prevent someone participating in enjoyable activities and over time can harm relationships. Negative forces are symbolised by red arrows. Conversely, the green arrows indicate that events or interventions can act positively on any component of AIR and thus benefit the whole system. The most obvious intervention is providing a new activity, but other things can be done to help improve relationships or enhance the internal world of a person with dementia.

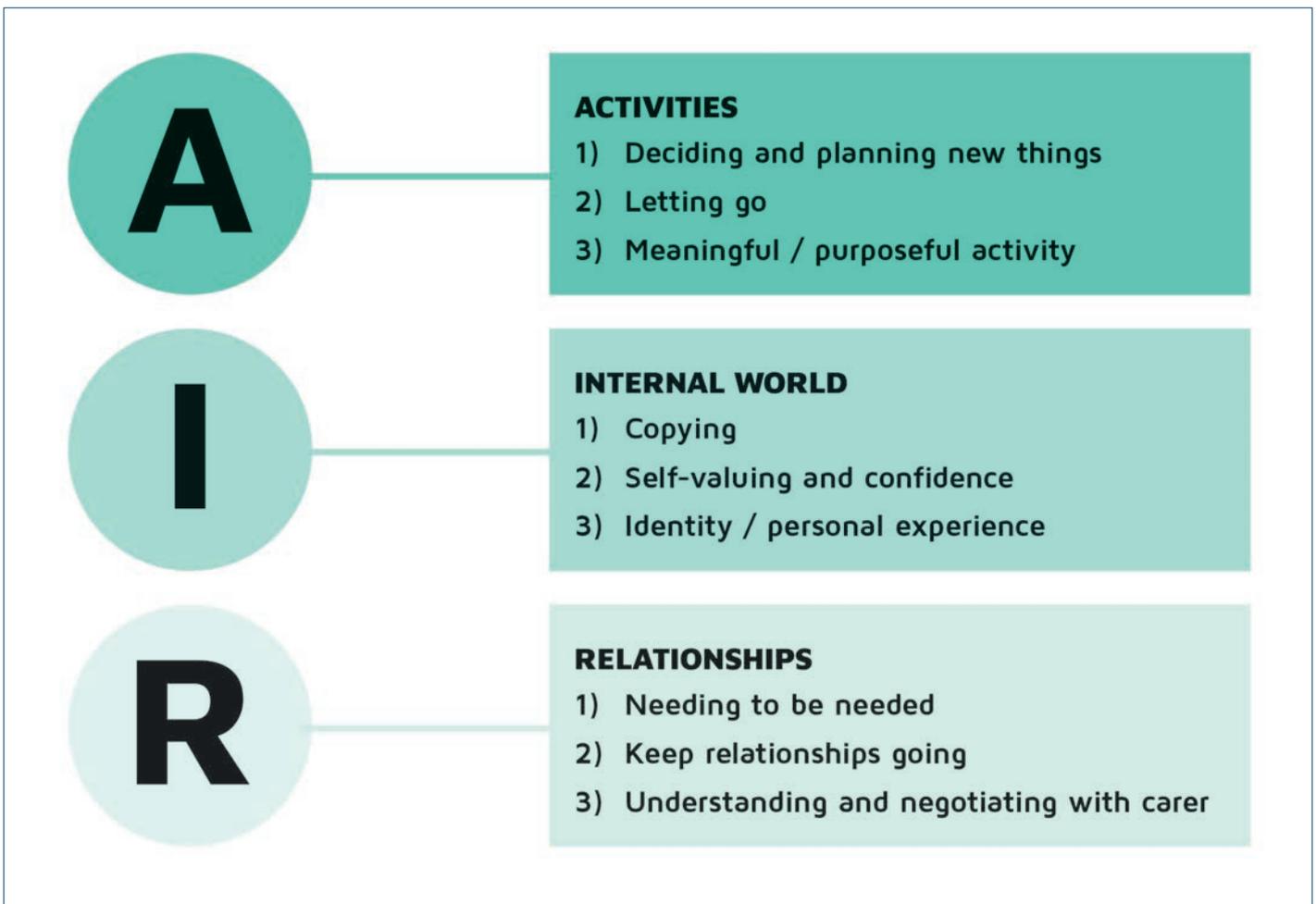


Figure 3.2: MinD themes grouped into Activities, Internal world and Relationships (AIR)

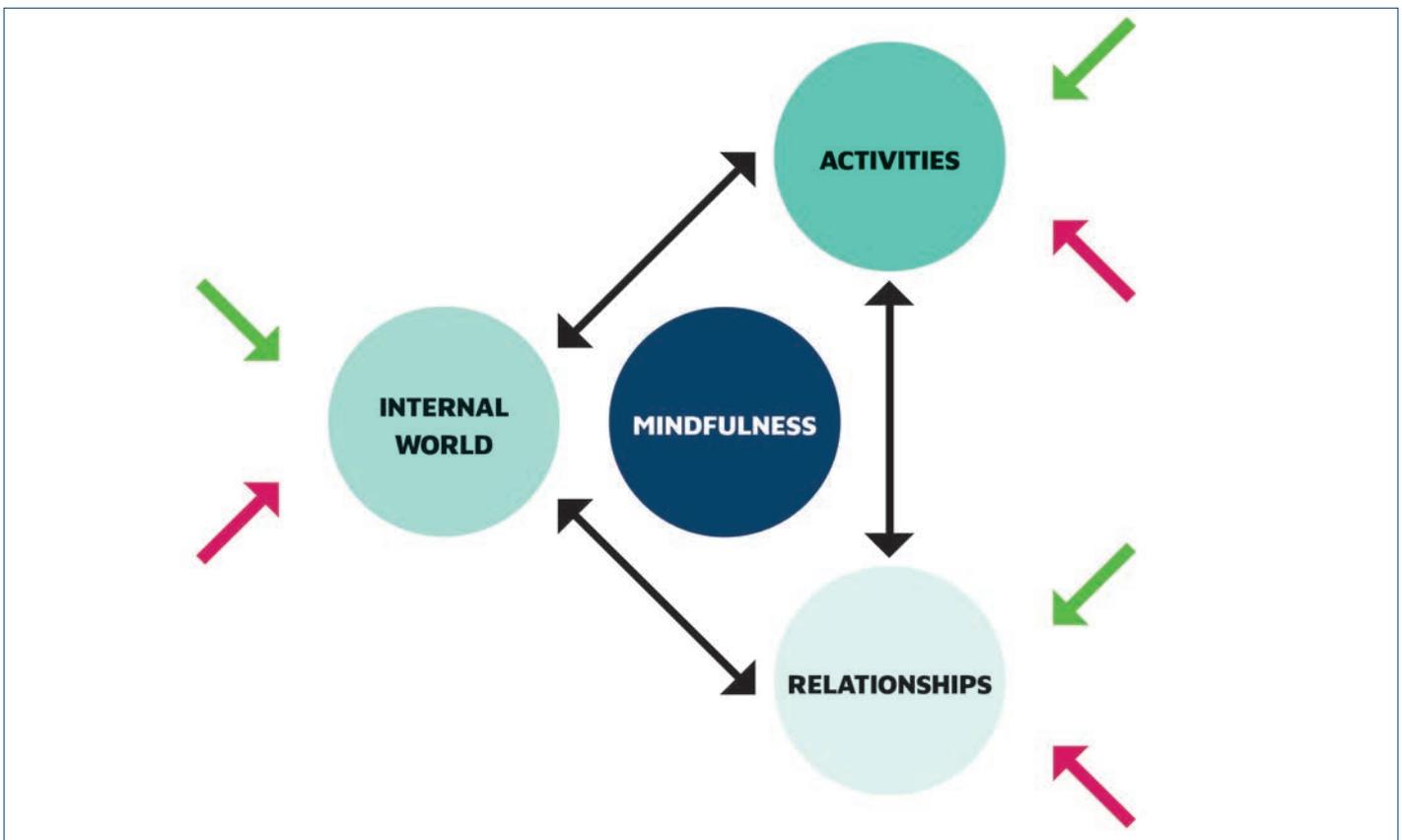


Figure 3.3: The interacting components of the AIR model

This model can help in three ways (Gosling et al., 2019):

1. **Mindfulness.** The AIR model is consistent with a mindful approach to design. It reminds us of the importance of bringing the internal and external worlds together and, as there is no specific dimension of time, it rests in the moment.
2. **Design.** In designing for dementia, we can consider all three components specifically. We may for instance use a design focused on one component, such as activities, but in thinking about how the design may work we can take into account the likely impacts on relationships and on the internal world. Or a design can be targeted at either of the other two components. In practice, it may be a combination of targets, and we can be deliberate in our intentions if we think about all 3 parts of AIR simultaneously.
3. **Evaluation.** Our evaluation stage will examine how suitable our prototype designs are for people living with dementia (and their families) and the three components of AIR give us a framework that will be useful in assessing not just whether something is effective but also how it has that effect. Or, if it doesn't work, why not, and that will give us a handle on how to improve it.

It is worth noting that the AIR model has some similarities to the Compassionate Design model of Treadaway, Fennell, Prytherch, et al. (2018), where three components of personalisation, sensory stimulation and connecting with others and the world cluster around a core of loving kindness for the person with dementia. Compassionate Design was however developed for work with advanced dementia and does not have the visible links to enablers and obstacles that the AIR model does. Perhaps because of the severe dementia context too, the core of Compassionate Design is more passive than the more active mindfulness of the AIR model.

### **3.2.3 PARTICIPATION IN MIND: PRINCIPLES OF CO-DESIGN AND CO-PRODUCTION**

As discussed in section 2.6 above, partnering with people with dementia in the research and design process within MinD has been essential in order to develop relevant and appropriate solutions. In the following, we discuss how the MinD project understands and has applied co-design (and its derivative terms) in the practice of our project.

Participation, involvement and partnership, usually in the context of health or social care, pertain to the facilitating of joint processes and the principles by which such processes are done. There is no single formula, partly because of the diversity of views and partly because each instance, initiative or situation has to be considered for its own merits. However, there are some key principles that should be present in co-production initiatives. These include:

- defining people who use services as assets with skills;
- breaking down barriers between people who use services and professionals who deliver them;
- building on people's capabilities;
- reciprocity – where people get something back for doing something for others;
- mutuality – people working together to achieve their shared interests;
- peer and personal support networks working alongside professional networks;
- facilitate services by helping organisations to become agents for change rather than just being service providers (SCIE, 2019).

Similar principles have previously been proposed by Hendriks, Slegers, & Duysburgh (2015: 79-80), specifically for an inclusion focussed approach to co-design:

- “The positioning of the participants’ impairment in the project.” This deals with the perspective of other partners, how impairment is addressed in project interactions, and the extent of the involvement throughout the design process.
- “The aim for equivalence” relates to “how equal contributions and collaboration are supported”, the development of a shared language, and whether involvement offers participants with impairments a valuable and meaningful experience.
- “The balancing of viewpoints”, relates to how different perspectives between participants with and without impairments are managed, and whether researchers’ limited knowledge of an impairment affects the process.
- “Dealing with ethical challenges” concerns how any practical and legal challenges, are dealt with, including e.g. informed consent, unanticipated issues, and the impact of participation on all involved.
- “The adjustment of co-design techniques” concerns the particulars of the project as well as of participants; how they are taken into account; what adjustments work well or fail (and why); and levels of flexibility to approach and materials.
- “The data collection, analysis and interpretation” concerns data collected, method of collection, ways in which data differ from those researchers / designers usually work with, challenges encountered and adjustments in analysis and interpretation of data.

Hendriks et al’s (2015) points of co-design have guided MinD co-design processes to enable the international, multi-disciplinary knowledge exchange between researchers with and without problems of memory and/or thought processing, different types of participants and levels of participation.

The multi-participatory nature of MinD has engendered the adoption of further general participatory principles as demonstrated within the joint actions of all MinD activities, including planning, data collection, design, evaluation, co-research, co-designing, knowledge exchange, etc. Principles important to MinD were:

- respect for diverse understandings and ways of working;
- shared responsibilities, tasks and acknowledgments;
- equitable distribution of power where applicable to create participatory spaces;
- a collective voice and genuine inclusion of less powerful voices.

In addition to co-production and co-design principles, these general principles were used to facilitate partnership with people with a diagnosis or lived experience of dementia and/or other problems of memory and cognition, which are often seen as presenting specific challenges, and to avoid tokenism or exploitation.

## 4. MinD Methods and Processes

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This section discusses the practical application of participation, co-design methods and processes in the three phases of the MinD project and draws out key insights, which are subsequently reframed and presented in the summary of design guidelines in section 5.

### 4.1 DATA COLLECTION WITHIN MIND: TRADITIONAL AND NOVEL

The data collection with people with dementia sought to collect insights about their needs and wants concerning subjective wellbeing, self-empowerment and social engagement. Data collection instruments included qualitative interview scripts, visual cards of daily activities to support discussion in the interviews, and visual probes – a method from design to collect visual and experiential information to complement the data collected through the interviews. The design research tools that were developed are described in the following.

#### 4.1.1 PARTICIPATORY PROCESSES IN MIND

Within MinD, lived experience partnership and GEE processes related both to participation in the traditional sense as research subjects as well as to more innovative involvement as co-researchers and co-designers through the mechanisms of mutual and equitable activities with other MinD partners.

Traditional types of research participation included MinD focus groups and individual interviews to elicit issues and challenges of well-being and self-empowerment in everyday social contexts from the view of the person with dementia, with an aim to identify situations for design innovation. Focus groups were used to elicit different views and facilitate discussion through dialogue while individual semi-structured interviews offered deeper understandings. These traditional research tools were supported and complemented by two design tools (which are described in more detail in section 3.2.1):

- visual cards, developed as prompts, memory aids and discussion points for use during the interviews, and
- diary probes to focus more strongly on values and feelings, and to collect visual evidence from research participant diaries.

Traditional approaches were complemented by participatory approaches to research and design wherein GEE-based co-production and co-design approaches invited mutual decision making and actions. MinD aimed towards a meaningful element of co-production in order to influence the values, process and content of the research. It sought to ensure that researchers with domain experience and design or clinical expertise and lay participants worked equitably, and that preconceptions on both sides were challenged, including professional assumptions e.g. regarding the needs and desires of people with cognitive impairment or their attitudes and capabilities regarding technologies as well as GEE 'lived experience' perceptions around the authority or authenticity of academic 'learned experience.'

Participation in MinD was enhanced by the input of colleagues with experience of GEE working, to plan activities through on-going consultation with both researchers with domain experience and service users and carers. MinD appointed peer researchers with lived experience and participant volunteer co-workers whose expenses were fully reimbursed, following volunteer recruitment,

engagement and support. In working with GEE co-researchers, while it is recognised that everyone has needs when co-working in meetings and workshops, practical challenges that can arise for researchers with healthcare needs or care responsibilities have required appropriate consideration including timings, venues, travel, flexibility and sensitivity towards health or care requirements.

#### **4.1.2 DESIGNING MINDFUL DATA COLLECTION TOOLS**

For the data collection, two tools were developed to support and complement the individual and focus group interviews with people with dementia and their carers: Firstly, a set of visual cards depicting daily, leisure and social activities for use in the interviews as prompts or memory aids. Secondly, a visual diary has been developed to complement the interviews to collect visual and written information about personal values, objects used, etc.

##### **Visual Cards**

The idea to use a set of visual cards (Figure 4.1) emerged from the discussion about the interviews and focus groups. The question was how best to communicate with participants, how to help them maintain their attention and to remember e.g. tasks and situations of daily living, during the interviews. The aim was to provide support, both, for the interviewer and interviewee during the interview through being:

- usable as a prompt and memory aid;
- easy to understand because of offering a visual and written dimension.

Cards to support interviews have already been used successfully by other researchers, e.g. Casais, Mugge & Desmet (2016). The MinD team reviewed existing cards as well as approaches of appropriate visualisation. This resulted in a decision to use illustration to visualise the activities in order to reduce them to the key characteristics and keep them visually simple and clear for easy recognition, following guidance for designing for elderly people (Marshall, 2016). The cards were designed to cover four areas of activities and daily life in line with the mindfulness framework of the project, and the focus of the interview schedules, covering:

- activities of daily living
- leisure activities
- social activities

As part of the development process, different options for the cards were presented to all members of the team as well as experts with lived experience to comment on. In this way, the cards were gradually refined in terms of the chosen activities, figurative representations (e.g. age, gender, ethnic diversity), visual readability, and aesthetics.

The Visual Cards have been used, and their use observed, in eight interviews with people with dementia, to evaluate their role in supporting the interview process. They proved to be especially supportive as conversation starters in situations where participants did not directly know what to answer. Additionally, as a physical reminder, they helped the interviewers to cover all of the interview topics in the semi-structured interviews.



Figure 4.1: MinD Visual Cards, developed to support interviews with people with dementia

### Visual Probes – Do Books

As a complement to the interviews and focus groups, design probes in the format of a 'do book' was used to obtain richer contextual information about the life of people with dementia. The 'do book' allowed for more active participation of people with dementia through self-documentation. Probes look at users' personal context, including social, aesthetic and cultural environment as well as needs, feelings and attitudes (Mattelmäki, 2006).

The do books that were developed for the Mind project sought to collect data on two general topics: (1) personal information about e.g., goals, attitudes, experiences, motivation, capabilities, and social context, that could be used to develop rich personas (Figure 4.2), and (2) information about areas of change and needs for preservation in peoples life with respect to activities of daily living, leisure activities, social engagement and wellbeing, in order to identify areas for design interventions (Figure 4.3).

**If you could capture anything (for instance any moment, sound, song, smell, view, object, place...) and preserve it in this jar for you to relive what would you choose?**  
Please use the stickers to describe it and place them on the jars.



Figure 4.2: 'Do books' exercise about preserving important moments in people's lives

**Please take 3 photographs of the things you tend to take with you when you go out of the house.**

**Why do you like to take them?**

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Figure 4.3: 'Do book' exercise about personal things people with dementia take when going out

The design of the do books consisted of an A4 folder with loose leaves that could be worked on separately in the order of choice. To cater for personal preferences of participants and to generate additional visual information about their life context in addition to the verbal information from the interviews, the activities of the do books allowed for various ways of expression such as writing, drawing, photographing and crafting.

Furthermore, to make the probes accessible for participants, the activities were of varying difficulty, did not require learning and were designed to be gender neutral. A few of the probes were based on the artful work of Wallace, Wright, et al. (2013) who used probes to get insight into personhood in dementia. Fifteen do books were distributed over three countries, Germany, the Netherlands and Spain. They remained the property of the participants but anonymized pictures were taken of the results for analysis. Results offered valuable insights into decision making, values and attitudes of people with dementia. The methodology was described in detail by Garde, Voort and Niedderer (2018).

#### **4.1.3 DATA COLLECTION PROCESS: PARTICIPATION DURING THE DATA COLLECTION PHASE**

While the level of participation with people living with dementia during the data collection for the most part followed a traditional model, with people with dementia and carers providing information to researchers based on the pre-designed interview scripts and design probes, the data collection tools (interview scripts, visual cards and design probes) were designed with some input from people with lived experience.

The development of the data collection tools was an iterative learning process for the interdisciplinary research team. It firstly brought together design and health disciplines and their methodologies to expand traditional interview and focus group methods by adding the visual cards and the design probes tools to allow for visual and experiential stimulation and data collection. The cards and probes were then developed by design researchers informed by relevant prior research. Prototypes and draft scripts were shared either with individual people with dementia from the EWGPWD or presented in a relatively standard workshop format to participants from the GEE group in Nottingham for comment and improvement.

Feedback included issues around wording, readability, and diversity. Interview schedules were reframed and reworded as and where suggested to ask questions in the most appropriate way. In relation to the visual cards, the feedback highlighted differences between the cultures of nationalities represented and researched in the MinD project. For example, cards for the UK had to represent a wider variety of visible ethnicities, cultures or other diversities than those for Germany or the Netherlands where in turn such variety would have been alienating. The changes were subsequently implemented for individual card sets as required.

In the actual data collection process, people with dementia contributed in the traditional role of 'research subjects'. Settings differed between different countries, including day care groups as well as home visits. Participants offered insights into their lives through the interviews and through completion of the 'home tasks' associated with the visual probes. Where possible, at the end of the interviews, participants were able to comment on their experience with the research process in which they participated.

Partly because of the learning process, and partly because of the restrictive remit of the grant under which the MinD project is funded, people with dementia were not involved as facilitators, or in deciding settings or formats for the data collection.

#### **4.1.4 DATA COLLECTION RESULTS: THE MIND THEMES**

The MinD themes (Figure 4.4) emerged from the analysis of the data gathered through the interviews and design probes with people living with dementia and their caregivers. Nine content-related themes were identified: three sets of three themes as represented in the AIR model, and two supporting themes offering general design guidance.

##### **Themes relating to the internal world (self/identity):**

- Coping with the situation: diagnosis: what now?
- Self-value: Insecurity and lack of confidence
- Experiences, Identity and the fear of losing that

##### **Themes relating to relationships:**

- Keeping relationships going
- Needing to be needed. Helping others
- Understanding and negotiating between carer and person with dementia

##### **Themes relating to activities:**

- Purposeful activity (real purpose and meaning vs keeping you occupied)
- Letting go responsibilities - which are losses?
- Deciding what to do and planning new things

##### **Supporting themes providing additional information and guidance for designers in thinking about and designing for the above nine themes:**

- Importance of familiarity
- Importance of continuity

These themes were underpinned with quotes, descriptions and visual materials from the data collection to illustrate their meaning to the design team and the research team as a whole. They provided in a nutshell the starting point for the design phase. They indicated the key concerns of people with dementia with regard to subjective well-being, self-empowerment and social engagement in a number of areas. They included both examples of successful practice as well as gaps and challenges that people with dementia face in everyday and social contexts. The themes thus provided both the starting point and important experiential information for designers to start thinking about possible ideas and solutions.

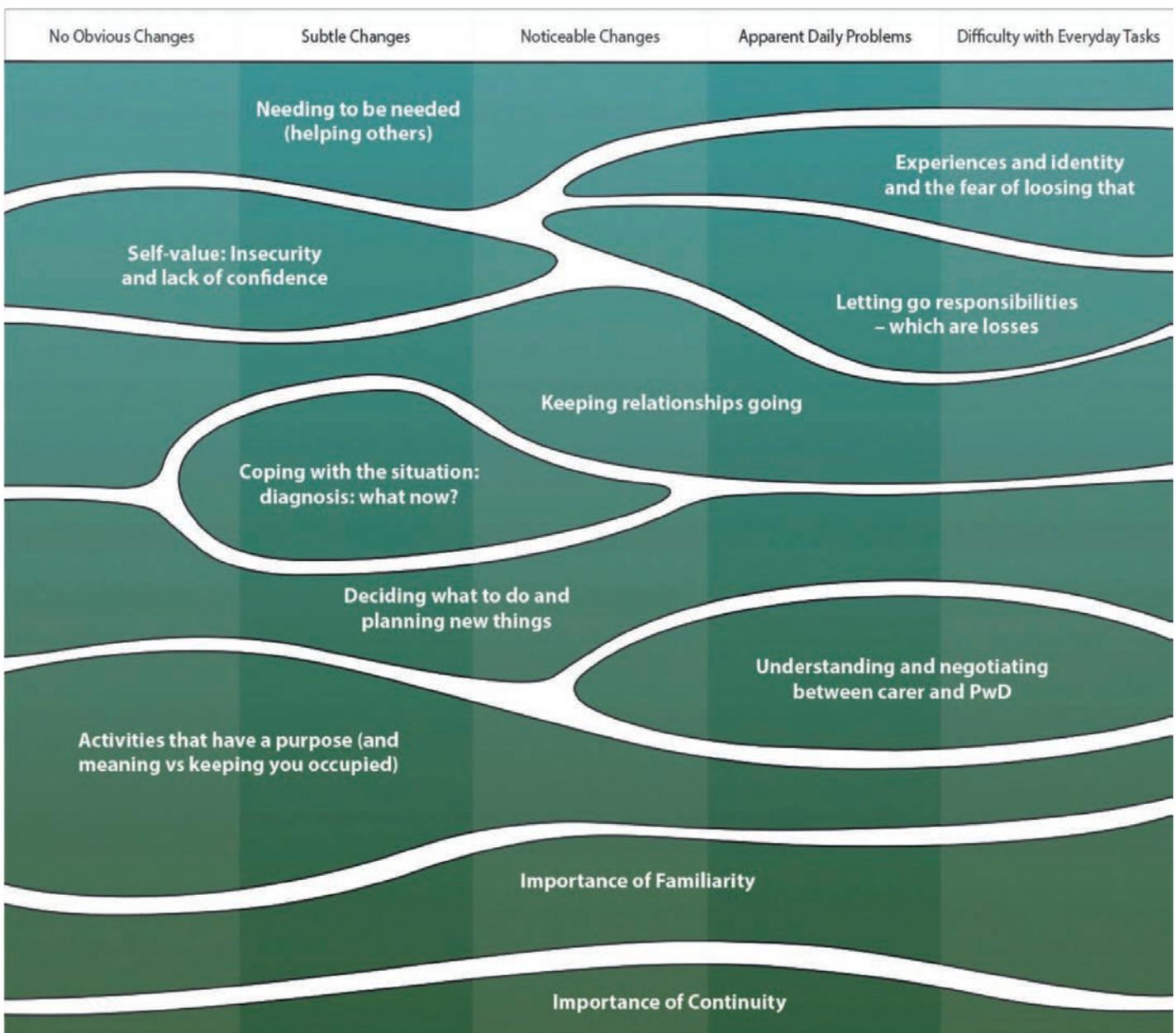


Figure 4.4: MinD Themes

## 4.2 DEVELOPING METHODS FOR A MINDFUL DESIGN AND CO-DESIGN PROCESS

To create innovative designs, the converging phase of research and data collection was followed by a diverging phase, in which – based upon relevant insights of research and data collection – out-of-the box thinking and mindful imagining was stimulated. For this purpose, the design development phase adopted three design methods to enable the design process, which included ideation, persona development and scenario identification.

The design ideation process was developed through the broad brainstorming of possible solutions in response to the MinD themes. The process built upon the team’s mindfulness thinking in relation to identified personas and scenarios following a design brainstorming ideation model provided by partner Panton Design.

### 4.2.1 THE PANTON MODEL OF IDEATION

The Panton model of ideation utilises a multidisciplinary team of preferably 5-10 participants. It should ideally include participants with creative skills, with knowledge of target groups, their needs and context as well as participants with ‘lived experience’.

## Step 1

Step 1 explains the basic rules of the creative sessions:

- criticism isn't allowed as it blocks creativity
- every participant should try to come up with as many ideas as possible because usually it requires a large quantity of ideas to find that one innovative, outstanding idea, and
- copying from other participants is allowed because someone's ideas can inspire others to come up with even better solutions.

## Step 2

Step 2 defines the goals of the creative session and shares the relevant insights from research and data collection.

## Step 3

Step 3 seeks to describe what the situation would be in a semi-perfect world, in which dementia would still exist, but all imaginable technology and services would be at hand and free.

## Step 4

In Step 4, from these descriptions, many ideas are generated by all participants, both individually and after consulting others.

## Step 5

Step 5 invites each participant to detail their top 3 ideas.

## Step 6

Step 6 asks all participants to contribute to all top ideas.

For inexperienced teams, it is advisable to have a test run to familiarise participants with the model, its process and feel as well as its rationale, before applying the process in earnest.

### 4.2.2 THE PANTON MODEL OF PERSONA DEVELOPMENT

Personas are a thinking tool for designers to develop empathy in the design process with the persons with and for whom they design (Chang et al., 2008, Grudin & Pruitt, 2001). Personas allow exploring different scenarios to 'test' for a variability of imaginable situations to ensure that designs are fit for a broad range of people within a specific target group. The persona tool was introduced by partner Panton Design. Researchers developed personas drawing on the rich data describing real individuals, their experiences and lived-in worlds, from the first stage of the project. The persona tool was subsequently practiced and presented at a public design workshop. An example of a persona that was developed is given here.

## Persona (with dementia)

**Name:** Ursula

**Country:** Germany

**Place of living:** Leipzig

**Age:** 82

**Profession:** Shop assistant

**Living situation:** Lives alone in an apartment, with some other tenants (for the last 3 years)

**Family situation:** Widow

**Care situation:** Relies on social care and some family visits from her son and daughter.

**Diagnosis/Symptoms:** Alzheimer's disease

**Strategy:** Would like to see an occupational therapist

**Acceptance:** Accepts the diagnosis and tries to be happy. Hopes things will get better with taking medication. Would like to see an occupational therapist.

**Self-realisation:** It is important for her to help others, but it is dependent on her health. Is proud to have raised two children with good values e.g. openness, honesty, happiness/joyfulness, not using alcohol or tobacco (she is teetotal). Having a safe home gives her calmness and a positive outlook. She doesn't have to worry about the rent because the children help. She has a special room with everything in it: boxes with Easter and Christmas decorations, suitcase/travel/work bags, sewing machine, washer and dryer, vacuum cleaner, and shelf with cloths and cleaning materials. It also contains the heating control and fuse box.

**Emotions:** Joyfulness is important - not taking things too seriously so it is not a crisis when things don't go her way e.g. when she feels dizzy and finds it difficult to concentrate on what is going on around her. Sometimes she feels emotionally weak/vulnerable (especially when facing uncomfortable neighbours). Has disrupted sleep.

**Social engagement and interaction – Wants' and needs:** She knows other tenants in the apartment but some she likes and some she would like to see less often. She doesn't go out alone anymore, but if she did, she would take her key wallet (with all her keys), sun glasses and woolly hat (because of the cold). She has a cosy living room chair with a TV. One of the tenants has a small quiet dog which she likes.

**Planning and decision making:** She's glad not to have to take any responsibility at the moment (it would not be possible!). Would like to do less cleaning (doesn't feel that is necessary daily). When the children come to visit, she often goes out with them in the car.

**Communication:** Has difficulty with some tenants or neighbours if they are noisy. She likes tenants who are quiet. She is able to communicate well but sometimes it is more difficult if she has not been sleeping well.

### 4.2.3 MINDFUL SCENARIO TASK ANALYSIS (MSTA)

Following identification of relevant intervention points from the data collection, the MSTA had the purpose of interrogating potential design opportunities to understand the various opportunities, challenges, and potential mindful strategies and solutions. It is used to analyse real-world scenarios and user stories from persons with lived experience of dementia including individuals living with dementia and care-givers. MSTA, as used within MinD, draws on and synthesises scenario based design (Carroll, 1995) and hierarchical task-analysis (HTA) (Preece, Sharp, & Rogers, 2015) with a specific focus on mindfulness. Scenario-based analysis uses the elaboration of scenario cases to take a person-centred perspective on design problems:

‘Scenarios are at once concrete and flexible, helping developers manage the fluidity of design situations. Scenarios afford multiple views of an interaction, diverse kinds and amounts of detailing, helping developers manage the many consequences entailed by any given design move.’ (Carroll, 2000)

HTA helps to define individual aspects and steps within any one given scenarios, and which we have further defined for our MSTA through a focus on mindfulness values and characteristics. The mindfulness focus was developed through a test application with initial interview findings. In the initial stages of MinD, ‘lived experience’ interviews in the Netherlands and focus groups in Germany identified some exemplars in the context of understanding potentially challenging social situations such as going out to a party, family event, group leisure activity or a meeting. MSTA was used to break down the social going out task into its constituent components (before leaving, en route etc.) from discussion at one of the MinD exchange visits. Three aspects of the scenario were extracted and these were then further developed through UK GEE engagement:

- 1) Activities (mindful and non-mindful) such as planning or reflecting;
- 2) Mindful (and non-mindful) states such as experiencing of emotions, sensations, worries, thoughts, reactions and behavioural responses;
- 3) Mindful (and non-mindful) plans, tactics and strategies that are or could be employed in practice to mitigate the challenges or amplify opportunities (see Table 4.1).

**Table 4.1: Generic MSTA grid in MinD**

Define and complete for each persona in the certain scenario	Task step 1	Task step 2	Task step 3	Etc.
Activities				
States				
Strategies				

### 4.2.4 CAPACITY BUILDING FOR GEE INVOLVEMENT FOR THE CO-DESIGN PROCESS

In order to partner with people with dementia in the design process, it was important to prepare all participants – people with dementia, carers, researchers and designers – for the co-design process through information and preliminary and introductory joint events.



situations highlighting the various positive achievements of which people were capable, when fully involved in creative partnerships.

The MinD scenario framework was then tested within a co-designed and co-facilitated session, that presented to small groups the various stages of preparing for, partaking in and looking back on a social situation which each group agreed on from within their personal life experience. The MSTA grid was adapted by breaking down the tasks into mindful and non-mindful activities and mind-states (Table 4.2). An accessible guide to scenario completion was developed by a researcher with lived experience. The grid itself was enhanced through GEE innovation of a further dimension to capture things that help or hinder in personal environments or within relationships with others. Consideration of non-mindful states alongside the mindful ones was another lived experience add-on.

**Table 4.2: Adapted MSTA grid used for GEE activities in MinD**

Define and complete for each persona in the certain scenario	Before: Preparation	On the way	There	Going home	After
Activities (mindful and non-mindful)					
Mood states (mindful or not-mindful)					
Mindful strategies (planning, reflecting, imagining)					
Things that may help / Make it easier					
Things that may hinder / Make it more difficult					

The real-world scenarios drawn from personal lived experience were collaboratively developed and reflected on in the session, which demonstrated the value of the approach for all participants. A worked example is shown in Table 4.3. The method was found to be useful in generating on many levels, anticipation, identification and understanding of need, creative coping strategies and innovations and, furthermore, in demonstrating and validating lived experience potential for involvement and collaboration in the meeting of any such need, through a manner sufficiently deep and informed to feed into the design process where mutual solutions could then be pursued.

Significantly enhanced understandings were gained moreover about improved co-production working partnerships between practitioners with learned experience and people with lived experience. The process of reflecting and feeding back on activity was used to good effect and produced useful insight into 'what works' within processes designed around 'working together'.

**Table 4.3: Mind scenario building example**

WHOSE PARTY IS IT ANYWAY? GROUP 1 – GREAT GRANDCHILD’S CHRISTENING

	Before: Preparation	On the way	There	Going home	After
Activities (mindful and non-mindful)	<p>Worrying / Clock watching</p> <p>Who will be there and how will I feel about them?</p> <p>Checking on transport arrangements</p>	<p>Reflecting that walking around would be tiring</p> <p>Where are the petrol stations</p>	<p>'Being there' with family and friends</p> <p>Sense of being aware and involved</p> <p>Knowing where the toilet is</p>	<p>Thinking 'we will get home'?</p>	<p>Planning for my next days</p> <p>Sharing the event memory with friends</p> <p>Nudging my grandson Adam for the photos of me holding the baby</p>
Mood states (mindful or not-mindful)	<p>"Will he be on time? (thinking and then worrying)</p>	<p>Apprehensive about getting there</p>	<p>Appreciating what is happening</p> <p>Peaceful in the church</p>		
Mindful strategies (planning, reflecting, imagining)	<p>Plan what to wear (to boost confidence)</p> <p>What to bring (to remind them of my visit)</p> <p>Plan to be early</p>		<p>Knowing my own sense of confidence (I see myself as an outgoing person and able to go up and chat to people)</p> <p>Reflecting back on memories of baptism of my own son in this same church</p>	<p>Reflecting on the event and the people I meet there</p>	<p>Imagining the pictures and hoping for an album for Christmas!</p>
Things that help / Make it easier	<p>Information, explanations, reassurance</p> <p>A phone call or number to ring</p>	<p>Knowing who is driving</p>	<p>Aspects of faith and family life honoured</p> <p>People speaking to me</p>	<p>Having had a good experience</p> <p>Knowing who is driving</p>	<p>Photographs to remember the event</p>
Things that may hinder / Make it more difficult	<p>Not knowing, no reassurance</p> <p>No way to contact for this</p>		<p>Ritual, standing, kneeling sitting during service</p> <p>My daughter unable to be there because of work</p>	<p>Time of day or night important (late finish so I was worrying)</p>	<p>No way to capture or recall the experience</p> <p>I don't know how to use my smart-phone</p>

## 4.3 APPLYING MINDFUL DESIGN METHODS

### 4.3.1 AN OVERVIEW OF BRAINSTORMING AND IDEATION SESSIONS AND RESULTS

The brainstorming and ideation process in response to the MinD themes was started by a small team of designers and design researchers, broadly following the Panton process, and initial results were then critically reviewed by a larger team including GEE representation. The aim of the design team was to generate a large number of ideas in response to the themes (up to ten ideas per theme), and they produced a total of over 60 ideas. As is the case with design, often one idea can have different applications as a solution for different issues or can incorporate different solutions. The design team therefore re-organised the ideas according to application areas/solutions. Figure 4.6 illustrates the matrix that was produced. For example, for social inclusion, ideas included fear reduction therapy, motivation raising, a travel map, dementia friendly events, and environmental design for connectedness.

### 4.3.2 TRANSITION AREAS

Subsequently, in the next secondment, the design ideas and application areas were critically reviewed by the larger design team, alongside the collected data, and related back to the original MinD themes in order to highlight areas of promising design activity as well as need, which we called 'Transition Areas'. Figure 4.7 illustrates this schematically and Figure 4.8 shows how MinD themes and possible design applications started to be aligned with each other. There were obvious areas where there were much activity, or where there was nothing. There were also clear areas where there were wants and needs indicated by the quotes, but no designs yet. These were the areas that were highlighted as Transition Areas.

MIND - DESIGNCONCEPTS MATRIX - OVERVIEW

4	ACCEPTANCE	POSITION SERVICE	PERSONALISED SUPPORT INFO BOOKLET	LETTERS TO YOUR FUTURE SELF	TOOL TO IDENTIFY WISHES AND REQUIREMENTS / CHANGE OVER TIME	TOOL FOR REFRAMING YOUR LIFE	TOKEN OBJECT PAST SELF	CHECKPOINT FOR REMEMBERING THINGS DONE	ALLOW ME TO FORGET		
4	SELF REALISATION	PWD AS AN AMBASSADOR	BUDDY SYSTEM	PWD AS A CO-DESIGNER / RESEARCHER	TOOL TO IDENTIFY SKILLS	SELLS MARKETPLACE	CARING ABOUT	DEALS FOR DEMENTIA	SENSORY STIMULATION		
4	EMPATHY	EXTERNALISE AND SHARE FEELINGS FOR EMPATHY	TOOL GAME FOR RELUCTANT	TALKING STICK LISTENING TOOL	PLAYFUL COMMUNICATION BETWEEN PWD AND CAREGIVERS	VR PRACTICE FOR PERSPECTIVE SHIFTING	EMERGENCY CARTRACK				
4	EMOTIONS	TOOL TO EXPRESS POSITIVE FEELINGS	WEARABLE TO MANAGE MY OWN EMOTIONS	WEARABLE TO SHARE EMOTIONS	TOOL TO REDUCE STRESS AND ANXIETY	TOOL TO EXPLORE EMOTIONS	POSITIVE BODY EXERCISE				
4	SOCIAL (RE-) COGNITION	PAUSE-SENSORY TOOL FOR PERSON RECOGNITION	DIARY TRACKER / DIARY ORGANISER	AREA TO ALLOW REMEMBERING WITHOUT GETTING LOST	UNIFORM VISUAL LANGUAGE TO USE IN THE ENVIRONMENT	PRODUCT/DEVICE/SERVICE FOR OVERCOMING SENSORY PHYSICAL CONSTRAINTS	OUTDOORING BRAIN DEVICE	FACTCHECKING COGNITIVE CONTINUITY			
4	SOCIAL INCLUSION	DEMENTIA FRIENDLY MESSAGES FOR EVENTS	WEEKLY MEETINGS	VR TRAINING FOR SOCIAL INTERACTIONS	FEAR REDUCTION THERAPY	MOTIVATION BOOSTING	PREPARATION FOR VISITING EVENTS	TRAVEL MAP	DEMENTIA FRIENDLY EVENT	PARTICIPATION IN EVERYDAY LIFE	ENVIRONMENTAL DESIGN FOR CONNECTEDNESS
4	PLANNING & SDM	EMPOWERMENT THROUGH SELF-MANAGEMENT	FUTURE SCENARIO PLANNING	TOOLS TO SUPPORT DECISION MAKING	TOOLS TO ACTIVATE SHARED DECISION MAKING	A TOOL FOR DECIDING IN HEALTHCARE SETTINGS	TOOLS TO HELP NEGOTIATING	KNOWLEDGE MANAGEMENT MODELS	POSITIVE INFORMATION		
4	COMMUNICATION	(INTELLIGENT) TALKING STICK	PERSONAL AND VISUAL TOKEN AS CONVERSATION STARTER	(VISUAL) CONVERSATION RECORD	SENDING AND VISUALISE MOOD	STORYTELLING PIECES					
4	SOCIAL VULNERABILITY	INFORMATION OVERLOAD PROTECTION SHIELD	LITTLE SPACE FOR WITHDRAWING	8-TEXTILES OBJECT	POSITIVE SERVICE FOR DIAGNOSIS MEETING						

Figure 4.6: Initial design ideas organised by design themes

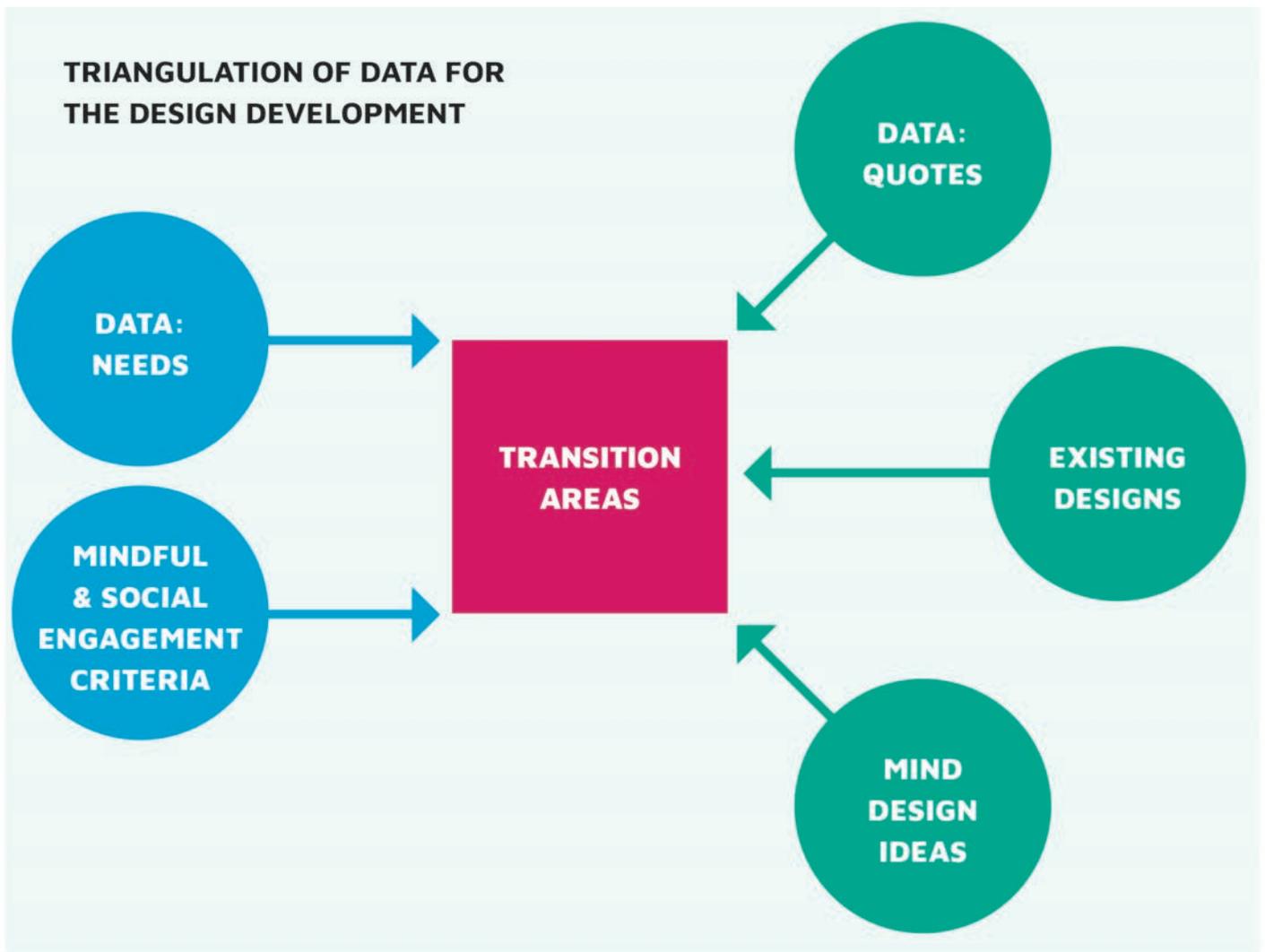


Figure 4.7: Triangulation of data leading to the transition areas

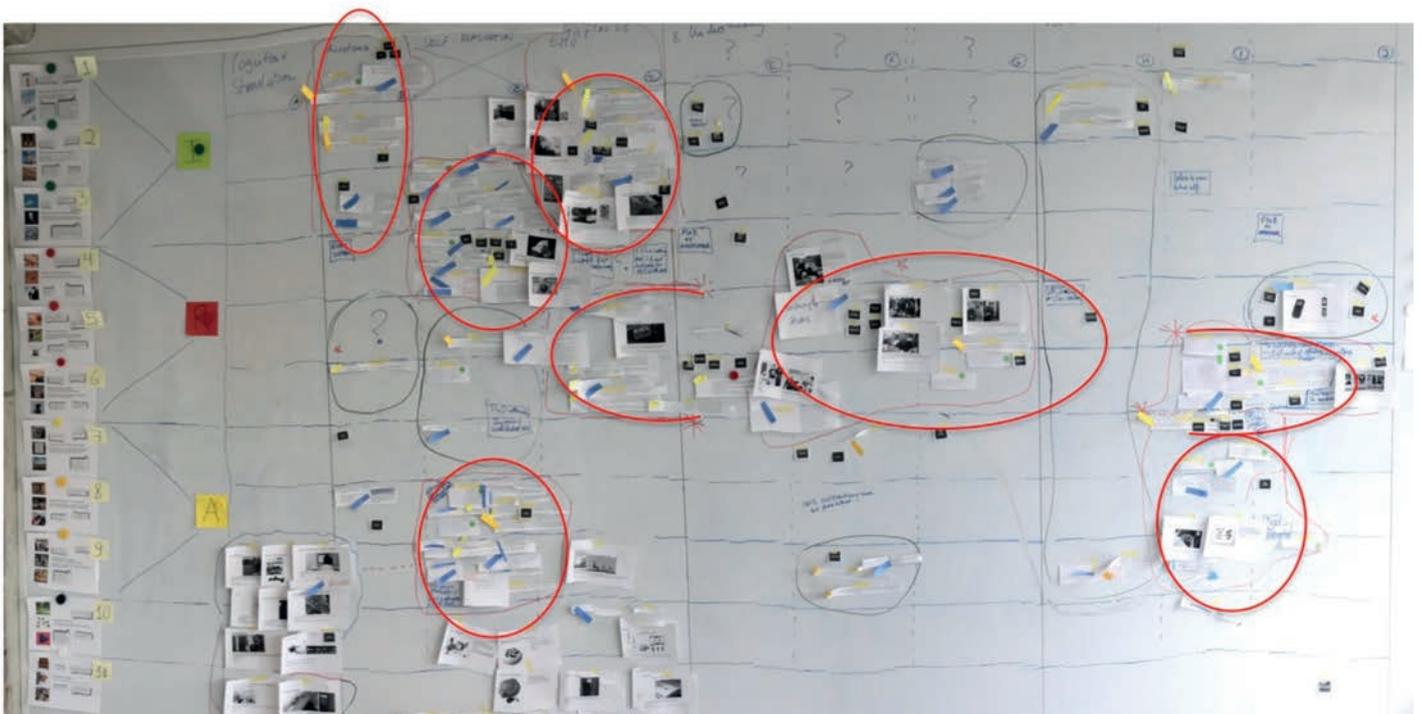


Figure 4.8: Triangulation map with transition areas. X-co-ordinate: MinD design themes; Y-coordinate: design application areas; Content: existing designs, quotes from data collection, MinD design ideas.

Transition areas can be described along a linear scale, as being connected to:

- no obvious change
- subtle change
- noticeable change
- apparent daily problems
- difficulty with everyday tasks

These changes relate to various stages in the dementia journey from initial awareness and identification of difficulties to later issues such as self-management and requiring care. Along the way, people experience a whole range of problems, needs, experiences, dilemmas and wishes. Originating within the data obtained from people with dementia and their care-givers during the interviews, focus groups and home tasks, and then clustered into themes, we identified certain transitions as being important points at which to offer specific design areas for potential solution or opportunity creation as follows:

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

#### **4.3.3 PARTICIPATORY DEVELOPMENT WITHIN MIND DESIGN IDEA DEVELOPMENT**

Making sense of and responding to the collected data was typically a co-design activity that was conducted by the researchers and designers. This activity was based on the data collection results and hence based on the direct expression of lived experience. In this sense, people with dementia, their lives, aspirations, needs, relationships with caregivers and with the world were ever central to these processes. In order to maintain the authenticity of voices of lived experience within the design process, a GEE representative contributed to the discussion through Skype. This helped shape the language of analysis, design and sense-making to avoid a needs-deficit based approach related to the dominance and authority of the clinical model and to move towards a strengths- and opportunity-based approach that includes the development of a shared language, collective journeys and mutual horizons. In parallel GEE capacity building activities took place, which were led together for the design decision making and co-design processes (concept and prototype developments).

#### **4.4 DESIGN CONCEPT DEVELOPMENT AND DECISION-MAKING PROCESS WITH GEE INVOLVEMENT**

After the idea generation stage, MinD needed to develop the initial design ideas into more detailed design concepts before deciding which design concepts to take forward to realisation. For this process, ideas were developed in relation to personae, scenarios and transition themes. The process integrated concept development and decision making in an iterative cycle to enable narrowing

down the choices to a shortlist and for the final decision making. This involved different stages of consultation with carers and health care professionals, and with people with dementia and carers to guide the iterative idea development and the decision-making (Figure 4.9), which was accomplished through co-working with GEE groups in Germany, Spain and the UK.

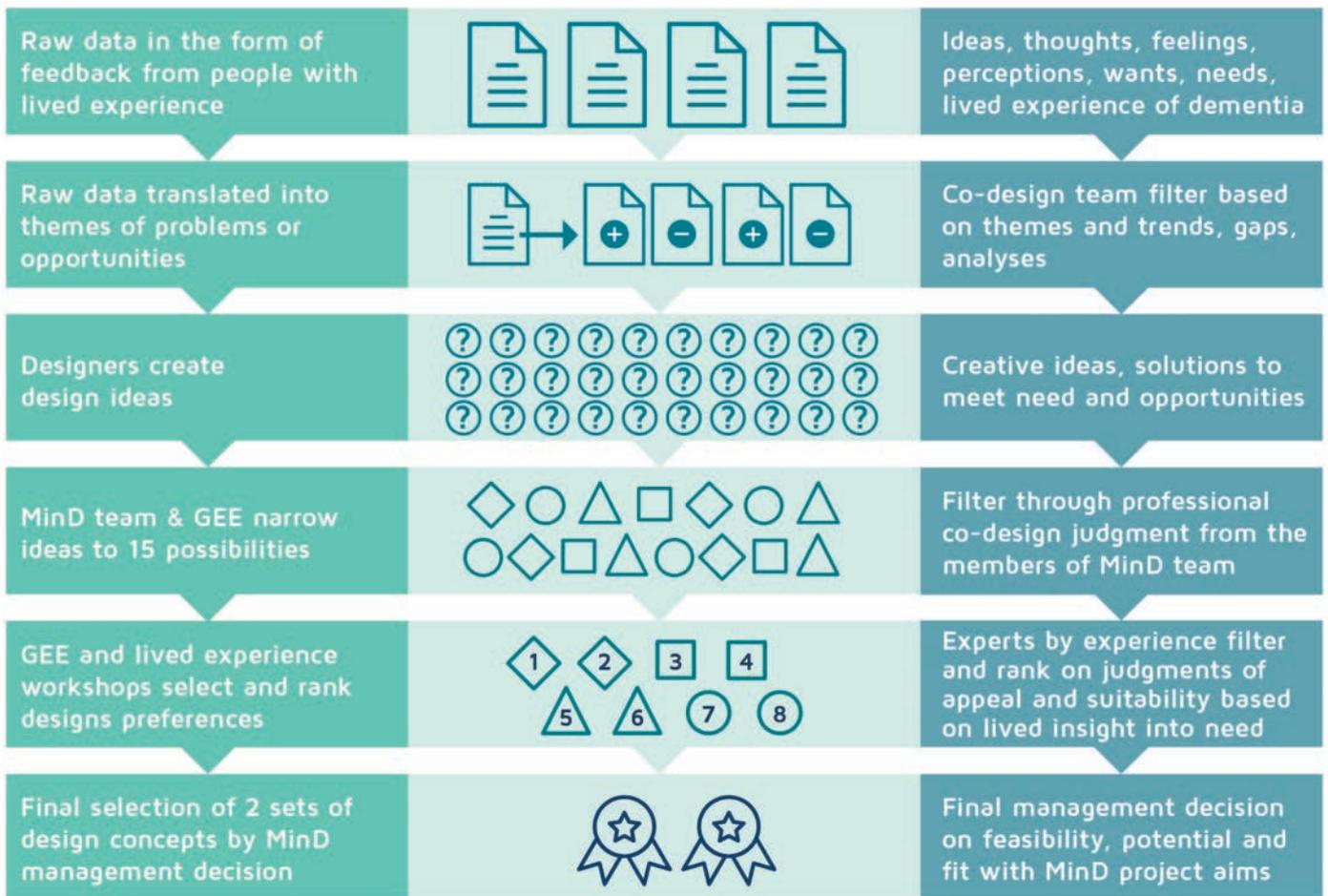


Figure 4.9: Ideas filtering from raw data to product selection.

#### 4.4.1 PARTICIPATORY CONCEPT DEVELOPMENT AND DECISION MAKING WITH GEE

In the first instance, the design ideas for each transition area were developed in more detail, and they were then presented to carers and healthcare professionals in Germany and Spain in a standardised short form, see examples below (Figures 4.10 and 4.11). The complete set of plates is included in the MinD project prototype report . GEE participants (care professionals, carers) were asked to comment on the different designs. Although a template for scoring was developed, this did not work well within the consultation process and was abandoned. Instead, verbal feedback was elicited regarding whether the designs were judged to be useful, relevant and appropriate, and whether it might be worth taking them forward, and this was entered by the researchers into an overview table (Table 4.4).

In a second stage, a shortlist of the 13 most promising designs was presented to a group of people with dementia and their caregivers in the UK as well as to one lived experience representative from the EWGPWD who joined via skype. The workshop based in Nottingham was facilitated by a researcher with lived experience. GEE input assisted in preparing the 13 design ideas to for the event, enabling a presentation with a large clear image and a non-technical description of how each potential product could enhance experience for people living with dementia. Besides the

group of people with dementia and caregivers, designers and MinD healthcare partners also scored the designs. Overall, design ideas were presented to a total of 26 MinD design and healthcare colleagues, external healthcare experts and carers as well as people with lived experience of dementia and memory problems to indicate and discuss their preferences and reasons for them. Based on the collated feedback (Table 4.4), which indicated some clear preferences by the majority of participants, the MinD management group was able to make the decision on which design ideas to take forward. The decisions for two groups of designs were made.

**Idea Set 1: Good Life Kit, including the ‘Savouring the Good Times’, ‘You & Me’ and ‘Over to You’ features**

The Good Life Kit (Figure 4.10) aims to support people after they have received a dementia diagnosis through mindful-reflective prompts and exercises to help reflect on and manage the condition, focus on what people can and want to do (rather than what they can’t) as well as support social interactions, including emotions and making decisions. The designs respond to feelings of uncertainty, powerlessness and depression that people have reported following the diagnosis as well as the need to be respected and stay in control of their life.

**Idea Set 2: Social Engagement Map, including the ‘What I can do service’ feature**

The Social Engagement Map ‘Let’s meet up!’ (Figure 4.11) is an interactive electronic system that seeks to help people with dementia to stay connected through enabling them to initiate contact with family and friends and arrange joint social, leisure and physical activities. The design responds to the need for people to stay active and socially engaged to lead a fulfilling life. Rather than changing the environment, the design seeks to empower people with dementia by helping them to stay socially connected, and to plan and prepare for going out with confidence. This solution appeared to be most suitable for people with early to mid-stage dementia, most of whom still live in their own homes.

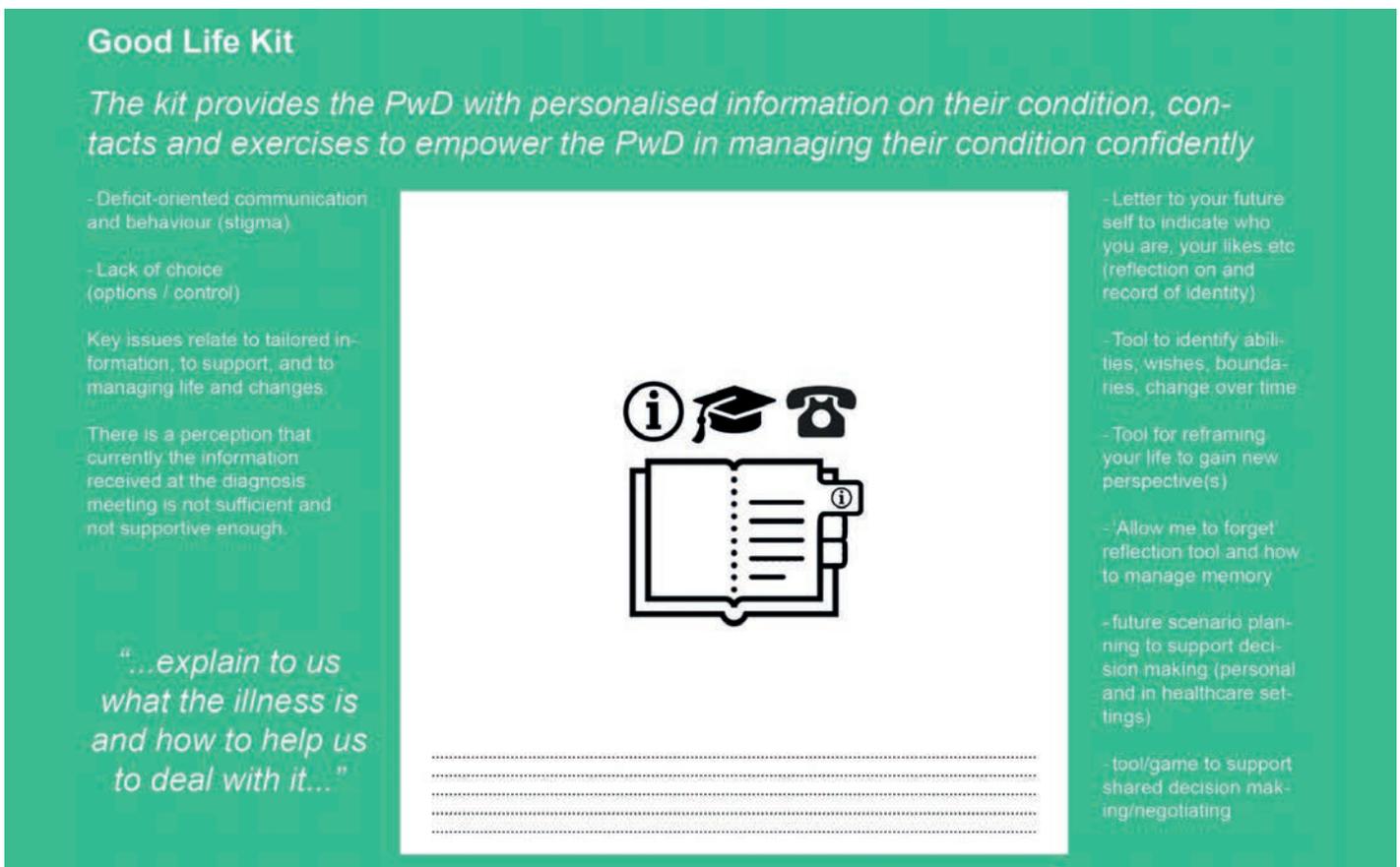


Figure 4.10: Presentation sheet of the initial idea of the Good Life Kit

## Social engagement map

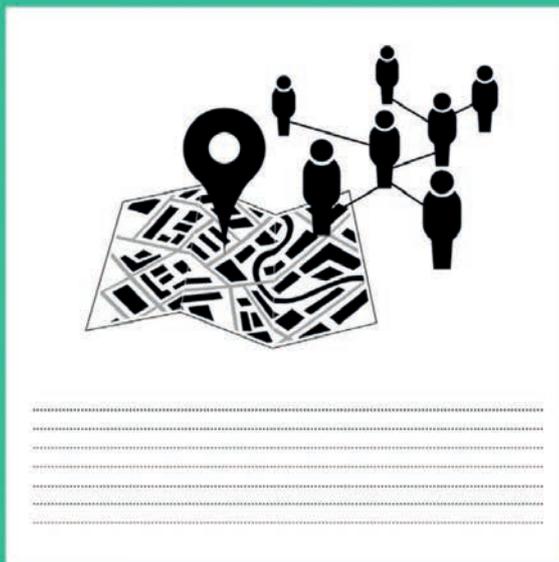
*interactive map to connect, plan, support and visualize social participation*

### DIFFICULTIES:

- lack of people to connect with
- problems recognising people or forgetting names
- problems with orientation or remembering purpose
- forgetting where you have been, what you have done and with whom

*"Going out with my friends. Meeting new people [is important]"*

*"Yesterday I found him desperate when we met...because all the time he had been trying to remember my name without success"*



### DESIGN ASPECTS:

See people's availability

Indicate that you are looking for somebody to connect with

Plan for the journey, activities and meeting people

Support orientation and memory through a wearable-portable device when going out

Visual/sensory record of what you have done or where you have been

Figure 4.11: Presentation sheet of the initial idea of the Social Engagement Map

**Table 4.4: Design Decision Matrix, October 2017**

Design ideas	Germany		Spain		UK			Luxembourg		MinD	Total
	Designers based on experts*	AKB*	Experts BA**	INTRAS	NHT GEE 1	NHT GEE 2	NHT GEE 3	AE	EWG PWD	Designers (BA group)	
Good Life Kit	x	x	x		[x]	x	x		x	x	8 [7]
Me & You			x	x		x	x	[x]		x	6 [5]
Over to You			x				x	x	x	x	5
Savouring the Good Times				x			x			x	3
Social Engagement Map			x	x	x			x	x	x	6
What I can do service		x	x			x		x	x	[x]	6 [5]
Positive Service	x				x	x	x		x		5
ID Bracelet	x										1
Dry Run						x	[x]				2 [1]
Just in Case					x						1
Now you're talking											
Tell it as it is							x				1
Filter out	x										1

### Legend to Table 4.4

AE, Alzheimer Europe; AKB, Alexianer Klinik Berlin; BA, Barcelona; EWGPWD, European Working Group of People with Dementia; GEE, Group of Experts by Experience; NHT, Nottinghamshire Healthcare NHS Foundation Trust.

\* These groups made their selection from ideas from the first three Transition areas only

\*\* This group made its selection from ideas from the last four Transition areas only

x = expressed their preference for this design idea

[x] = tentative support



abilities and to encourage team building and joint decision making within a relaxed and positive partnership. The workshop generated a lot of creative energy and synergy between people as well as laughter which put everyone at ease, providing a good starting point for the following decision-making process. There were genuine moments of shared inspiration during the design selection activities; those flashes of shared understanding that reassured participants within the micro-moments of shared action that as a group, partners had all 'got it'.

#### **4.5 CONCEPT AND PROTOTYPE DEVELOPMENT OF SELECTED DESIGN IDEAS WITH GEE INVOLVEMENT**

Following the design decision making process, two concepts – the GLK and the Social Engagement Map (later renamed 'Let's Meet Up!') – were selected for further development. First the concepts had to be refined, then the concepts had to be translated into specifications for tangible prototypes, and ultimately prototypes had to be produced. This required an iterative process of developing the concepts by designers, presenting work to people with dementia for their feedback as well as input and suggestions for further development, and so on. The design development itself has been reported in the MinD prototype report . For the purpose of formulating the design guidelines, this section focuses once more on the co-design methodology that underpinned the full concept and prototype development.

##### **4.5.1 FINDING A SHARED LANGUAGE FOR MIND**

The importance of finding a common language is highlighted amongst the Hendriks principles (Hendriks et al., 2015) and, in MinD, this became itself to be essential for a number of reasons:

- multiplicity of languages
- variety of disciplines
- 'special needs' perspectives

In terms of finding a balance, it has not just been the traditionally 'needy people with lived experience' being wheeled into the professional arenas of academic research and creative design who have required support with terminology. Project partners who struggle with English or are not conversant with disciplines outside of their own domain have been equally vulnerable and power has shifted rapidly during interfaces on account of this multiplicity of languages compounding with one another. Similarly, the vernacular of public involvement and its array of competing near-synonyms (e.g. PPI, GEE, 'lived experience') are often unfamiliar, even unknown, outside of UK public service provision.

The pervasive influence of the medical model within dementia conversations has permeated MinD with invisible linguistic bullets, burying need, suffering, conditions and therapeutic intervention deep into project talk and textualities. Though well challenged from many sides, ongoing vigilance from advocates of non-pathologised discourse remains necessary. Our language needs to focus on capabilities and activities, not deficits and disabilities.

To best represent the collaborative nature of MinD, its shared language seeks to describe activities in a mutual sense; partners, researchers with or without dementia, 'we', co-designers. The project title itself has shifted power dramatically through a change from designing for to designing with and for. To ensure this, we used a shared document on positive use of language.

#### **4.5.2 ESTABLISHING A CO-DESIGN WORKING ETHIC WITHIN TEAMS**

In order to establish a fertile atmosphere for getting started with the co-design work, we held a GEE event on 8 March 2018 in Nottingham with a rich programme (Figure 4.13), which was attended by 20 people of whom 14 had lived experience of dementia and memory loss.

The meeting began in a cafe where people with lived experience, designers, health care researchers and facilitators informally shared experiences, successes and difficulties and gave voice to hopes and suggestions around socialising, recognising that these are shared human issues (Figure 4.14). Tasks were shared, for example badge making, welcoming people, fetching drinks, so that everyone who chose to was able to contribute.

There was then a choice between attending a lecture on co-research with people with dementia, taking time out to walk near the lake or simply to sit quietly. Everyone chose the lecture and actively offered their views.

The afternoon session commenced with picture slides of the MinD project's journey and a brief introduction to the nature and purpose of design. Groups then worked with familiar objects brought from home in considering how useful these were as memory aids and guides; what we liked about them, what was difficult, and what improvements were wished for (Figure 4.15). People with lived experience began to think like designers; designers began to see more clearly the lived-in world of memory loss.

The afternoon finished with an introduction to the proposed Social Engagement Map design developed from the stated needs and wishes of people with dementia. Participants were able to conceptualise what improvements or variations might be useful. A large amount of material was gathered from all participants, which helped to inform the next iteration of the design process. Energy levels remained high throughout the day, with participants eager to attend the follow-up workshop in May.

While in part mirroring information that had been gathered before during the data collection phase, this exercise differed significantly in that all participants were required to share personal information about themselves, rather than just people who had been previous subjects of the research; designers, researchers, 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 the experiences that separated them. Recognising that everyone can find socialising difficult, along with the fact that we all have problems of memory and thought processing, helped to reduce the distancing of 'special needs' that can segregate and stigmatise some people as less capable than others in society.

This format of working was continued in a series of further workshops with the GEE group in Nottingham to further help with the design development of the Social Engagement Map and the Good Life Kit. This practice was also introduced by visiting researchers with lived experience to develop GEE group sessions at MinD partner INTRAS in Spain.

# MinD DESIGNS FOR LIFE

## Something About Me and Something About You

*Researchers, Design Specialists and 'Expert Insiders' come together  
to Socialise with Coffee and Cake and Get To Know One Another 😊😊*



### MEETING IN STARBUCKS CAFE FOR 10:00am

We will be researchers, designers and people with lived inside experience of the problems of memory loss (often declared 'experts by experience!') But we will all have things in common with one another and things that are unique to each one of us - this is what makes connecting interesting!

We will talk together about our experience of socialising; what feels good and what may be difficult or get in the way of us reaching out to others.

We will share and compare experience. We will talk, listen and understand

We will also reflect on being here - now - together. Thoughts? Feelings? - what has helped? - what got in the way? - what would make it better?

*we will make a record of our discussions to share with others and to help people understand what is needed for our good socialising*

### A CHOICE OF ACTIVITIES AT 11:30

*A talk about involving people with memory problems as researcher partners in the IMH Room A07*

or

*Break-Out - to walk around the lake or to sit quietly*

### LUNCH TIME 12:30

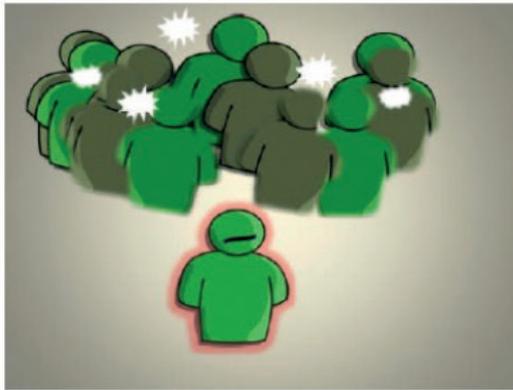
more opportunities to get to know one another and enjoy mixing.

**\* PLEASE WILL YOU BRING ALONG WITH YOU SOME OF THESE OBJECTS WHICH WE CAN TALK ABOUT IN THE AFTERNOON**

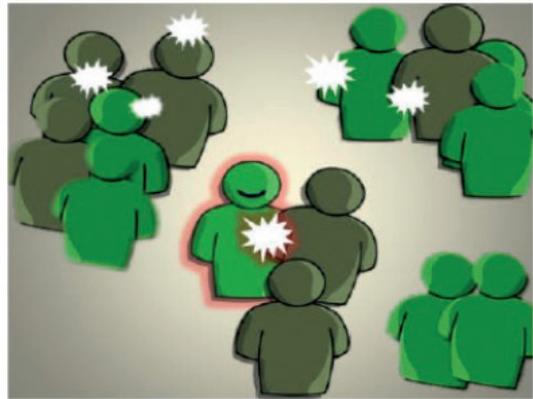
phone / diary / calendar / watch / alarm clock /  
Filofax / map / tablet / i Watch / sat-nav / laptop



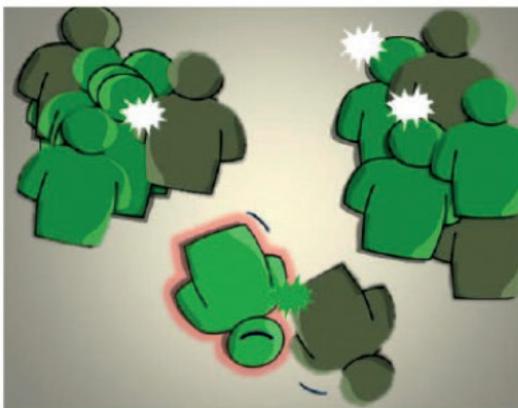
Figure 4.13: Programme for the GEE co-design workshop, March 2018



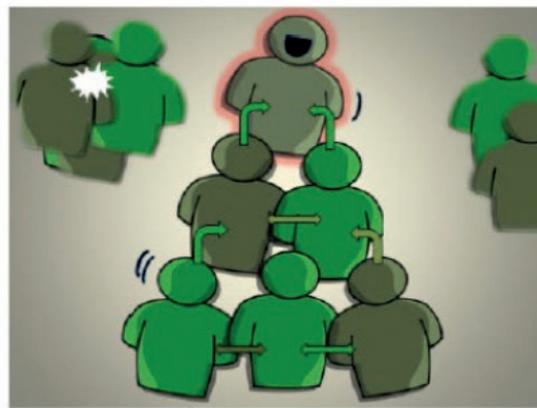
**something about mixing with other people that worries me . . . . .**



**a social experience, activity or event that I am looking forward to . . . . .**



**something I would like to be different or new when I'm with other people . . . . .**



**a social situation that I have handled well and I'm pleased or proud about . . . . .**

Figure 4.14: Task for the morning workshop to begin partnership working

# MinD DESIGNS FOR LIFE

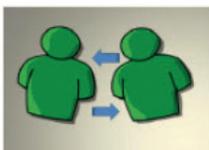
## Let Us In - We're Co-Designers!

*Researchers, Design Specialists and Expert 'Insiders' work together  
Lived Experience + Learned Experience in PARTNERSHIP = SUCCESS*



We all have memory gaps and for many reasons - too busy - distressed - under pressure - confused - overloaded - distracted - getting older - tired - born with or acquired impairments - general fast pace of modern life.

Everyone's memory needs a nudge occasionally - but some of us may need more help than others at various times in our lives.

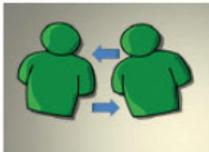


Making contact with other people and socialising is a real problem if we don't remember names, faces, places, times, travel routes . . . .

We can use lots of familiar things to help or guide us. Such every-day objects didn't just 'happen' - they were '*designed*' to solve problems!

*diary / calendar / watch / alarm clock / Filofax /  
compass / map / tablet / i Watch / sat-nav / computer*

**what time?  
where? how  
when? who?**



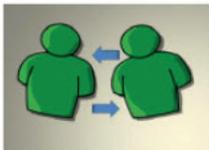
Developing aids to assist our memory is helpful for all of us; good solutions can enable us to connect, socialise and fully enjoy being with other people

### **IN OUR AFTERNOON WORKSHOP - 1:30pm IMH Room A07**



we will talk about our everyday memory and connection aids and explore:

*what is good about them?  
what is problematic with them?  
how would you like them to be different?*



We will handle and test and use our different objects - to question:

*how usable are they?  
how useful are they?  
how do they impact on our wellbeing?*



The designers will use the questions, thoughts and feelings, suggestions, opinions from the 'experts by experience' to work on and improve some new ideas and products that will assist the effects and impact of memory loss. *Our experience will help design the features of the new technology*

**We are co-designing better connections with one another!**

Something  
NEW !!!!  
co-designed  
with YOU in  
partnership  
- to help us  
all CONNECT

Figure 4.14: Task for the morning workshop to begin partnership working

### 4.5.3 UNDERSTANDINGS OF MINDFULNESS FROM MIND GEE WORKSHOPS

The concept of mindfulness was a key driver for the development of the project, both in terms of the design outcomes as well as in the co-design process. In the GEE sessions, researchers and facilitators aimed to incorporate mindfulness values to create a safe non-judgmental space and enable participant empowerment. Insights from MinD GEE lived experience and workshop notes (2018-2019) include an understanding that mindfulness is our relationship to our own experience. Mindfulness in those terms can be variously described as:

- an internal mirror that helps us reflect in compassionate and non-judgmental ways on the moment-by-moment reality of our inner and outer worlds;
- encouraging the active capture of, insight into and learning from our experiences in both these worlds;
- being in the here and now; not dismissing, over-reacting to, or being overwhelmed by our outer and inner worlds, but feeling anchored to stability and peace through acceptance of uncertainties of flux and disorder, and ensuing fear;
- holding ourselves with tenderness, humility and compassion through the opening up to experience in its entirety within protected spaces of reflection and insight;
- enabling mental, spiritual, emotional and physical well-being, contributing to and enhancing feelings of wholeness, appreciation and purpose;
- fluidity from moment to moment in a conscious journey, letting go and moving on, seeing a clearer way ahead;
- enabling us to ask and answer questions about ourselves and our inner and outer worlds, and make choices about how we are within them, enabling the possibility of change;
- a way of understanding who and how we are, and who we could become and how.

MinD as an organic learning framework encouraged all its actors, with or without dementia and regardless of expertise, roles or professions, to be together in mindful learning spaces (Figure 4.16) in order to explore and develop mindful designs and processes that promote mindful behaviour and further, enhance social engagements, meaningful activity and self-empowerment. The GEE workshops illustrated that a mindful attitude had the potential to enhance participants' awareness, attentiveness, acceptance, adaptation, positive action and autonomy in relation to the lives we are living or are wishing to live.



Figure 4.16: Mindful reflection during MinD GEE workshop, March 2018

## 5. Key Insights and Outcomes: MinD Design Guidelines

The design guidelines are addressed to designers as well as researchers and GEE teams who wish to engage in joint co-design activities. Their purpose is to offer guidance on co-production and co-design processes as well as direction for the content of co-design activities relating to the focus area of this project, including subjective wellbeing, self-empowerment and social engagement. A summary of findings and insights is provided in the following sections.

### 5.1. PARTNERING WITH PEOPLE WITH DEMENTIA FOR CO-DESIGNING

This section reflects on our experiences from the MinD project about combining a mindfulness approach and co-designing with people living with dementia. We consider how mindful co-design and co-production have been applied, before summarising key insights.

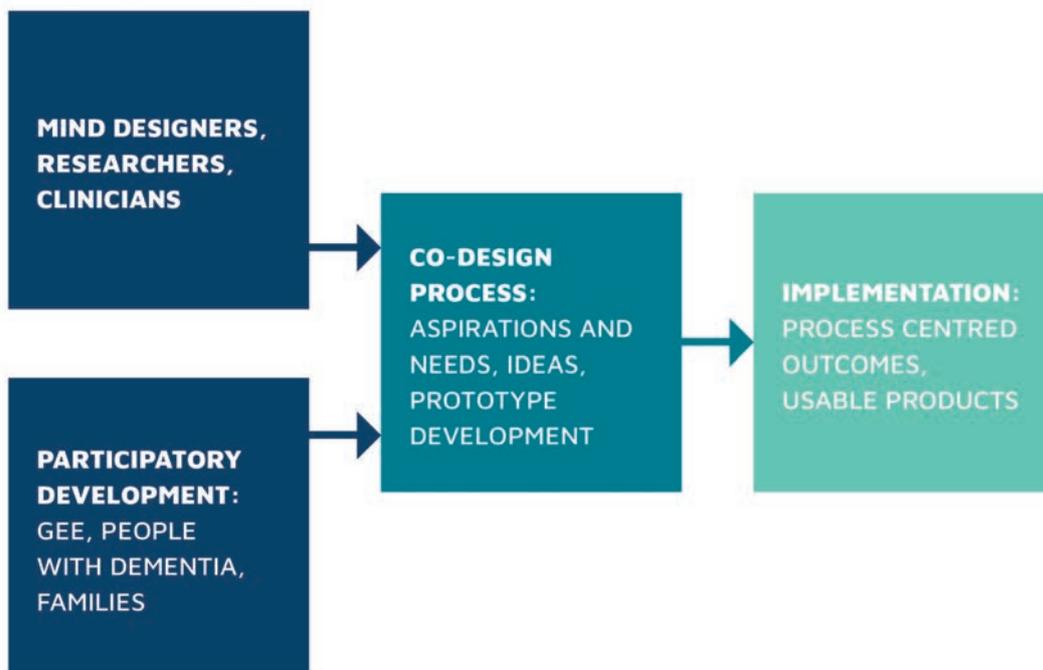


Figure 5.1: Interaction of MinD designers, researchers and GEE leading to co-design and co-production

Figure 5.1 represents the interaction of the different groups within the MinD project and how this interaction has contributed to co-design and co-production. Mindful co-design takes place from the initial stages when the aspirations, wishes and needs of people living with dementia are explored. Co-design then leads through to the final designs, prototypes and products, interspersed (hopefully) by moments of shared inspiration where the group as a whole takes a major shift forward.

In discussing outcomes from the co-production and co-design story, it is helpful to consider the following:

- design methodologies and outputs from co-design
- mindful values and practices that guided participation and co-design
- participative and co-production processes and outcomes

Much of the relevant material has been described in detail in Sections 3 and 4 of this report, so here we merely summarise key insights.

As regards design methodologies and outputs from co-design, this is the narrative of what happened. We have described how initial data collection led to the identification of needs, and proposals for design ideas. The design ideas were then reviewed before selecting two ideas for further development. Sections 3.1.3, 4.2.4 and 4.2.5 have described how people with lived experience of dementia participated in all the phases of research, design and development.

The notion of participative and co-production processes and outcomes concerns how co-design takes place. Our description of this in Section 4.4.2 covers how partners were introduced to one another, what steps were taken to create an atmosphere of mutual trust and respect and a level playing field for everyone to make genuine contributions that were listened and responded to. At various stages, the contribution of lived experience participants was vital and strongly influenced the design process. Generally, the impact all partners appears to have been favourable. From feedback gathered throughout partnership activities, it is clear that people with lived experience have enjoyed being involved, particularly when they are in a position of being hands-on and able to contribute actively.

A large part of this was related to the introduction of mindful values and practices into the partnership and co-design process to guide the qualitative aspect of the interactions within these processes. They have aided to create an open and equitable atmosphere where participants could trust each other and become creative.

The effects of partnering with people with dementia in the co-design process and, within this, of creating novel outcomes have been profound. There have been undoubted instances of collaborative creativity, for example sessions where outcomes have been different from what was envisaged and novel ideas emerged, or where people with dementia were able to have tangible input into the design development. The effect of this has been to heighten the commitment and enthusiasm of those involved, including both the lived experience participants as well as other members of the research and design team.

## **5.2. CO-DESIGNING WITH PEOPLE WITH DEMENTIA: INSIGHTS ON CONTENT AND DIRECTION**

Insights regarding design content are always linked to the immediate aim and context. In this case, they relate to the aim of the project to support subjective wellbeing, self-empowerment and social engagement in everyday (social) living situations for people with dementia. These are the basis for the MinD design themes (described in Section 4.1.4, Figure 4.4), which we extracted from the data collection with people with dementia, and which provide a rich basis for the development of supportive designs in various contexts. The themes are underpinned by qualitative data (interviews with participants) which provide insights into the feelings and experiences, wants and wishes of people with dementia about the respective themes. These can offer the basis and further inspiration for the development of future design solutions.

Beyond the nine themes that related to specific aspects of the dementia journey, two additional overarching themes emerged that can provide generic design guidance. These are familiarity and continuity. Familiarity can be interpreted in a number of ways dependent on the context, and might include familiarity with an image, a functionality, a situation, or similar. For example, the 'This is Me' component of the Good Life Kit offers a combination of reminiscence and life story telling

in the familiar from of a convivial board game, which meant that people knew what to do, and this helped to make the design successful. Continuity relates to the continuity of experiences and processes in people's lives, including maintaining routines.

What our work on the content and directions of designing with and for people with dementia shows us is that, first and foremost, it is necessary to derive the basis (underpinning data) for any design directly from participants. Therefore, we need to plan for including people with dementia and other stakeholders into the decision-making process from the beginning, or as early as possible. We need to recognise that the interpretation and development of initial design themes derived requires the involvement of the people who the design is for (in this case, people with dementia) in order to develop relevant and appropriate design solutions.

We need to understand how the project will flow from the initial identification of needs to the development and evaluation of design prototypes. This includes being aware of the large number of possibilities that even a small amount of data will provide for designing. It is also important to consider how families and caregivers may interact with the prototypes. And there are likely to be potential applications to other groups, e.g. with other long-term conditions, that should be borne in mind.

### **5.3. MINDFUL PARTNERSHIP: INSIGHTS FOR MINDFUL CO-PRODUCTION AND CO-DESIGN**

In this report, we have brought together, and discussed the contribution of mindfulness to partnership, co-production, design and co-design and co-production process. At various points throughout the process, valuable insights have emerged in relation to the aims and conditions inspired by mindfulness values, and for implementing mindfulness in co-design and co-production.

At each stage of the design process, it was important to consider aspects of mindfulness, and to embed mindful principles within the design through 'living mindfulness', for it to become an intrinsic component and not to remain a tokenistic add-on to the project. 'Living mindfulness' meant considering own individual mindfulness at each stage and in each meeting with other members of the MinD group, including promoting awareness of self and own experiences and feelings as well as promoting awareness of and consideration for others' experiences and feelings. This enabled a mindful co-design process through extending mindful awareness to the process through considering the mindful opportunities in the co-production and co-design processes, as well as the mindful (or mindless) potential of design on its users during the design development process.

#### **Mindfulness values can be further extended to create the conditions for a successful mindful co-design partnerships by:**

- Creating a shared commitment to openness and collaborative creativity; creating a shared journey and horizons; and enabling mutual capacity building.
- Using space mindfully, through providing calm spaces for mindful awareness and self-empowerment; shared spaces for equality and inclusion; open spaces to pool ideas and different forms of knowledge; and safe spaces to hold and explore positive experiences as well as difficult ones, e.g. shared successes, gratitude, amazement as well as tensions, dissent, or negative experiences.
- Jointly creating lived experience designed tools for workshops including suitable means to express and record outcomes of the process, their value and (extent of) shared aims.

Facilitated in this way, a mindful approach to co-design will allow for 'motivational' factors to influence directions and enhance creativity among partners, with scope for the design process to move in novel directions.

#### **5.4. MINDFUL CO-DESIGN AND CO-PRODUCTION WITH PEOPLE WITH DEMENTIA: SUMMARY INSIGHTS**

In the following, we draw together the above insights on mindfulness values, partnership, co-production and co-design into concise guidance notes for a holistic process that incorporates mindful values and practices.

First, it is important to share in a **spirit of openness and fairness**. This includes breaking down tasks, responsibilities, and roles between all participants, in ways that help us to contribute, to give our best, and allow mutual recognition and rewards. There needs to be an open dialogue to include and respect everyone, and people need to give and take experience, wisdom, compassion and kindness. Use of a common language recognises and respects the varied ways in which people express themselves. Participatory design work must celebrate diversity and uniqueness and recognise the common humanity of everyone involved.

Second, attention needs to be given to meeting the **needs of participants**, as far as is possible. People should be clear about what they need and try to name it, ask if they don't understand, or say if they disagree or feel uncomfortable. It is important to recognise that any member of a group may feel nervous, excluded or shy. Participants should look out for each other's needs and be ready to assist if they are able to. There should however be openness about what needs can and can't be met by GEE events or meetings.

Third, there are important **rights and obligations to participation** (including legal and ethical frameworks). These include such things as the right to join in, not to join in, or to drop out (unless work role precludes this); the right to give or to refuse to give information and to say who can have it; the right to understand confidentiality when sharing private information; the right to be heard, to agree or disagree, without blame or reprisal; and the right for our differences to be respected and our personhood valued. Obligations include being respectful and to challenge disrespect, and an obligation to protect one another.

Fourth, **collaborating as partners** is different from the usual practitioner-client relationship. To promote this requires that participants think and talk using the shared language of 'we' rather than 'us and them'. It is important to think about people's strengths and potential, not deficits, and to recognise that feelings and thoughts are both important and expressed through many ways. Working successfully in partnership requires that participants should actively mix with people and not simply huddle with those of similar backgrounds.

Fifth, **working together is not always comfortable**. Everyone in the room may feel anxious or uneasy especially at the start of a meeting. Respecting people is more important than liking them and personal prejudices should not compromise partnership. Nonetheless, working together should always allow people to feel safe. Challenging of ideas is important but has to be approached in the right kind of ways. It is important to bear in mind that challenging is about ideas and behaviours, not people. As well as this, not challenging (through kindness) can come across as patronising; not challenging (through dismissiveness) can come across as discriminatory; and not challenging (through fear) allows poor ideas and behaviours to prosper.

Sixth, **Honesty and consideration** in collaboration are essential. Participants should be honest and transparent, and not promise things that they cannot commit to. Working together is about

everyone's well-being and collective growth; everyone can learn and all should reflect upon how the partnership is progressing. The exchange of experience needs to be mutual, and participants should support and protect each other without compromising the partnership. This may include moving from personal comfort zones into mutual territory. There should also be some openness about power within the project, in that some members of the group may have more subsequent opportunities to influence its course and outcomes.

Seventh, **A joint commitment to shared spaces and journeys** is key to enable mutual capacity building and to allow collaborative creativity to develop. This includes providing and creating space(s) where people can feel safe, comfortable and inspired – both physically and mentally – to enable mutual trust and openness to allow creative exchange, exploration and experimentation to flourish.

Finally, **jointly creating lived experience designed tools** for workshops can create a feeling of joint ownership within the process, aid mutual understanding and idea exchange, and provide suitable means to express and record outcomes of the process and their (shared) aims and values. Different physical and visual means also provide participants with different means and hence choice for expressing themselves, in a situation where words are not always the preferred or best medium, thus creating a more level playing field.

Many aspects of involvement centre on practical factors such as venue, timing, accommodating special needs, or GEE training. But if the above values are embedded in the organisation and delivery of co-production events, then the fluid mutual adjustments necessary for collaborative and respectful participation will become natural for all involved.

## **5.5. MINDFUL CO-DESIGN AND CO-PRODUCTION WITH PEOPLE WITH DEMENTIA: RECOMMENDATIONS**

Taking into account the principles offered by Scie (2019) and by Hendricks (2015), we have developed a set of guidelines relating to research partnership, co-production processes, language and communication, and co-design from our insights which integrates our mindfulness perspective.

### **Multi-disciplinarity and inclusion in participatory (design) research projects**

- Participatory co-design projects require a mixed team of designers, lived experience partners, health/social professionals and other stakeholders involved at each stage.
- Involvement of GEE is invaluable for successful design development to create design results that are relevant and appropriate for its users.
- The collaboration with GEE should start as early as possible and continue throughout, including funding applications, data collection, design idea generation and design decision making, concept development and prototyping, data collection and design evaluations.
- Attention should be paid to who will be involved as GEE partners (people with dementia, carers, ethnic minorities and/or other under-represented groups) to ensure as much diversity as possible.
- People with lived experience should be seen and treated as experts with valuable experiences, skills and abilities.
- Where possible People with lived experience should have roles as co-researchers.
- Dealing, where possible, jointly with ethics to manage practical and legal challenges in the spirit of the collaboration.

## **Mindful partnership and co-production processes and values**

- Creating fertile conditions for mutual, mindful collaboration includes considering personal, psychological, environmental, and relational aspects for all partners and tools for facilitation.
- Co-production can work well, offer valuable and meaningful experiences and a sense of reciprocity, if facilitated creatively, sensitively and supportively among committed partners.
- Collaboration needs to be based on mutual respect for individuals and their diverse understandings, viewpoints and ways of working to appreciate and balance them.
- GEE co-production workshops/consultations need to be planned collaboratively through partnerships who offer the necessary values, knowledge, skills and lived experience.
- Collaborative planning needs to consider what should be addressed in sessions, how to do this, as well as when, where and how partnership experience can be maximised.
- Continuity and familiarity of personnel and settings can be important for some participants with dementia.
- Collaborations should share responsibilities, tasks and acknowledgments to create mutuality – people working together to achieve their shared interests.
- Collaboration should be based on an equitable distribution of power where applicable to create participatory spaces, a collective voice and genuine inclusion of less powerful voices.
- One-to-one interaction and group work both have strengths and can yield positive results.
- Where small groups of people living with dementia work together, it can enhance their contributions, validate shared worlds, strengthen identity as lived experience partners and share mutual enthusiasm.
- Space for mindful reflection at the completion of an activity is valuable.

## **Mindful partnership, co-production and co-design: language and communication**

- Studies need to give clear definitions of processes, including issues such as engagement, equality and diversity.
- People with lived experience should receive enough and clear information about the project, their involvement and what it will entail, and their expectations should be considered and accommodated where possible.
- All other project partners should receive enough and clear information about the involvement of partners with lived experience, what it will entail and expectations placed on them to facilitate meaningful interaction.
- It is important to ensure mutual clarity about how the project will flow from the initial identification of needs to the development and evaluation of design.
- What is meant by 'design' needs to be clearly specified, and it is useful to create a shared understanding in the use of terms like co-design and co-production.
- It is important to consider the power of language within interactions: Respectful, appropriate and accessible language should be used when working with people with dementia. All terms used must be acceptable to the user group and fit for purpose.
- It is important also to consider the power of non-verbal communication within these interactions.
- Each activity needs to be accompanied by clear instructions, discussions and examples, in order to prepare participants for the different types of activities that they will carry out.

- Alternative materials for enhancing communication (e.g. pictures, physical models or samples) can be useful.
- Design proposals that are presented have to be quite concrete – having something tangible in the room works better than an abstract notion or just a picture.
- It should be considered and well communicated how the input provided by partners living with dementia will be integrated and acknowledged in the project.
- Clear feedback and continual reinforcement are essential in order that participants living with dementia (along with all project partners, stakeholders and other wider audiences) are left in no doubt as to how their input has influenced the project.

### **Mindful co-/design processes with and for people with dementia**

- Design development should be evidence-based: Qualitative research tends to be most appropriate and data should be derived directly from people with lived experience (people with dementia).
- Flexibility of approach is important to suit the study aims and research participants. Adjustment of co-design techniques may be required. Focusing on experiences, attitudes and behaviours in co-design activities, is likely to be most productive.
- A mindful co-design process can be enabled through promoting mindful awareness, mirroring mindfulness in all partnership interactions, and embedding mindful principles within the design through 'living mindfulness'.
- The interpretation and development of design themes requires the involvement of end users (people with dementia, families and people closest to them) to develop relevant and appropriate design solutions.
- Supporting partners with dementia to try out and play around with models of design proposals can assist their understanding and releases potential creativity.
- When evaluating designs, it is important to be clear about/plan for what is being evaluated: functionality of and user experience with design or formally measured effectiveness in longitudinal assessments of impact, and how this is done.
- In our experience from MinD, design should be positive, non-stigmatising, and focused on aspirations, not on limitations such as illness, deficit or disability.
- Designs developed for use by people with early-mid-stage dementia in social contexts should be suitable for use at home with family as well as other settings, e.g. day activity groups, social and community organisations.
- It is useful to consider the wider potential applications of designs, e.g. for people living with other conditions such as cancer, or in other situations, e.g. after trauma.

A final note of caution: No guidelines are prescriptive. Any (design) partnership needs to be aware of its own context and interpret experiences from previous studies or guidelines accordingly.

## 6. Conclusion

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This report has detailed the design process used throughout the MinD project, with particular reference to mindfulness, participatory involvement and co-design. We have set out the background to the project and discussed some of the theoretical concepts that are relevant for design for and with people who live with dementia and for their families, including issues around personal design, public involvement and co-design in relation to dementia. The mindfulness framework and AIR (Activities-Internal world-Relationships) model used during the course of the MinD project are then presented. The report traces how we have combined principles of co-design with the concept of mindfulness, and how we have used these to enhance our commitment to working in mindful partnership with people with dementia.

This report traces the different steps and phases of the MinD journey, data collection, persona and scenario development, identifying needs and transition points, generating ideas for designs, selecting the best design ideas for further development, and then taking those ideas through to prototype and into implementation stages. At each point, we have described the contributions made by people with lived experience of dementia, indicating how they have profoundly affected the outcomes of MinD.

We have concluded by describing some of what has been learned and setting out guidance for good practice in designing with people who live with dementia. It is difficult to be perfect with collaborative working, especially in a long and complex project like MinD, but we think our experience has much to offer to others who wish to embark on co-design projects, and we hope that our readers will find the guidance which this document provides useful. We thus offer the following insights and recommendations, divided into guidance for research projects, designing, and involving people with dementia.

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