

# **Empowering People Living with Dementia Through Designing**

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## Abstract

The 'wicked problem' (Rittel and Webber, 1973) of dementia is a leading global healthcare concern. The prevalence of diagnosis is increasing significantly and correlates with longer life expectancy (Spijker and Macinnes, 2013). In the UK has an estimated 850,000 people living with dementia (PLWD). For whom the greatest burden of care is placed on loved ones and privately funded approaches (Alzheimer Society, 2015). The result can be hugely challenging for the person diagnosed with dementia and their loved ones, leading to further issues of ill-health (Marriot, 2009). The Prime Minister's challenge on dementia (2012) has encouraged development of multi-faceted responses and interventions to deliver improvements in care and research. As a result, designers have been encouraged to become skilled specialists engaged in thinking differently around dementia and the associated problems.

This research explores co-design (Scrivener, 2005) with people living with dementia in order to understand their complex problems, and to propose and to shape interventions or solutions that can alleviate pressures which include, social isolation, stress, infantilisation and a sense of hopelessness (Kitwood, 1990).

Through fifteen projects achieved within series of co-design workshops, the research explores empowerment of PLWD through their own advocacy. The research shares how co-design can be an enduring process that stimulates new behaviours and memories whilst building resilience and keeping people active in society. Which, ultimately asks questions as to how common practices of co-design can change hierarchy and ownership in order to transform practices of design done 'to' or 'for' PLWD to integrated projects 'with' and 'by' them.

The results propose that people living with dementia can maintain highly significant efficacy in shaping lived experiences, making decisions, building relationships, and producing impactful designs. The resultant projects and processes supports their right to make decisions and to develop their own prowess through meaningful, deeply involved, and astutely delivered designs.

## **Declaration**

The work presented in this PhD thesis is my own original research and material. This thesis has not been submitted for the awards of a higher degree or other qualifications to any other university. The work is the result of my own research, independent study and investigations. This work is in the field of design for dementia with significant onus on co-design where collaboration forms part of the investigative method. Therefore, in generation of the research collaboration has occurred, however, the investigation is an original investigation set within this framework. This has occurred under the supervision of Professor Paul A. Rodgers and Dr Emmanuel Tseklevs.

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## With Thanks

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To my children Mylo and Skye you have been my inspiration, I hope I can inspire you to achieve valuable and wonderful things in your lives. Dream big and achieve your hearts desires.

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## List of Publications

The following is a list of peer reviewed publications generated during the production of this research:

WINTON, E. and RODGERS, P.A., (2020) "Realising the Potential of People Living with Dementia Through Co-designing and Making Interventions", In A. Woodcock, L. Moody, D. McDonagh, A. Jain & L.C. Jain (Editors), *Design of Assistive Technology for Ageing Populations*, Springer Nature, Switzerland, 2020, pp. 363 – 376.

WINTON, E. and RODGERS, P.A., (2020) "Towards Design and Making Hubs for People Living with Dementia", In P. Langdon, J. Lazar, A. Heylighen, H. Dong (Editors), *Designing for Inclusion - Inclusive Design: Looking Towards the Future*, Springer Nature, Switzerland, 2020, pp. 3 – 12, ISBN: 978-3-030-43864-7.

RODGERS, P.A., INNELLA, G., BREMNER, C., COXON, I., CADAMURO, A., CARLEKLEV, S., CHAN, K., DILNOT, C., FATHERS, J., FENNELL, J., FREMANTLE, C., FRENCH, T., HENRIQUES, D., LLOYD JONES, P., KETTLEY, R., KETTLEY, S., KHAN, M., LOGGE, K., ARCHER-MARTIN, J., PULLEY, R., SHAHAR, D., TEWARI, S., TREADAWAY, C., TSEKLEVES, E., MORADI VALADKESHYAEI, H., VENTURA, J., WILTSE, H. & WINTON, E., (2019) "The Lancaster Care Charter", *Design Issues*, Vol. 35, Number 1, Winter 2019, pp. 73 - 77, ISSN 0747-9360, DOI: 10.1162/desi\_a\_00522.

WINTON, E. and RODGERS, P.A., (2019) "Designed with Me: Empowering People Living with Dementia", Proceedings of the 13th European Academy of Design (EAD13) International Conference, 10-12 April 2019, University of Dundee, Scotland.

WINTON, E. and RODGERS, P.A., (2018) "Designed with Dementia: Developing Creative Communities", Design4Health2018, Sheffield Hallam University, 4 – 6 September 2018, Sheffield, UK.

Winton, E. (2017) Designs Need to Care for Carers in Rodgers, P. Bremner, C. Innella, G. and Coxon, I. (ed.) *Does Design Care...? : An International Workshop of Design Thought and Action. Imagination* Lancaster, Lancaster

## List of Invited Presentations

'Designed With DeMentia' at RESEC (Research into Specialist and Elderly Care) House of Lords, 26th November 2018

'75BC' Lancaster University Centre for Ageing Research Town and Gown Event, 7th September 2017

## Researcher's Personal Project Background

As a teenager I experienced how destructive and helpless dementia can be through its effect on two grandparents. For each of them their experiences were different but their cognitive degeneration resulted in them residing in care homes as their conditions worsened. From undertaking this study and understanding dementia in a fuller sense; I have noted that my grandmother probably had dementia for the better part of 25 years. Meaning that she experienced early on-set dementia. My Nana showed significantly less signs of dementia and lived independently for longer but when the deterioration set in it was far more obvious and rapid. Both of them have since passed away. Reflecting on undertaking this study, I realised that, at that time, we knew and understood considerably less than society is aware of now. Commonly, grandparents going through dementia was seen as somebody 'losing their marbles', little consideration was given to how to retain the best standard of life possible. The experiences of dementia in our family disrupted relationships and caused for substantial challenges for my parents. Through undertaking this study, I now understand significantly more about how people can be supported but also how we can continue to do better.

Having worked in design for over 25 years my experience of change has been significant. In particular how design has become increasingly central and valued in diverse global, social and health concerns. Therefore, when I had the opportunity (through this AHRC funded PhD) to explore design's ability to change or at the very least bring additional value to the provision of care I was inspired. I have previously been involved in richly rewarding co-design projects such as 'Our Environment, Our Future' (2009), 'Scotland's Housing Expo' (2010), 'We Are All Designers' (2012) and '12 Closes' (2015-present) and believed the approach could provide value to people in the early stages of their dementia journey. This meant I believed that design and co-design in particular had the potential to improve people living with dementia's lived experiences and to empower them to shape their own future.

My motivations therefore, have been to remember the challenges my family have faced and to do something valuable through my own abilities and specialisation in design. What follows is a series of investigations and projects that, I believe do this.

The experience of relatives living with dementia is focussed upon how it has affected them and what it has been like to witness their decline. With the knowledge that no two experiences of dementia are the same this personal understanding proved to be positive and negative. Positive in regards to informing an underlying empathy and negative as much as that personal experiences had the potential to influence expectations during the conception of plans and projects. On reflection this was also likely to influence a view or expectancy of incapability. As such, it became important to resist these personal frames of reference; particularly to refrain from limiting expectations and demands of capability in regards to tasks. This included a need to eschew a sense of over-helping the co-design participants.

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## Glossary of Terms

Terms Used in the Explanation of People

PLWD

People Living With Dementia

PnLWD

Person Living With Dementia

Carer/Primary Carer

Refers to the primary care giver i.e. a loved one, spouse, family member or friend who provides the first instances of care on a daily basis.

These carers are not paid for the service they provide.

Co-designer

A person living with dementia who is participating in co-design projects.

Day-ops

Bridgeton Resource Centre's Day Opportunities Group

Professional organisation of care

Service Provider

Charitable organisations or representatives including networks who provide paid for services and care for people living with dementia

BRG

Bridgeton Resource Centre

EMELDAN

Edinburgh Mid and East Lothian Dementia Action Network

SDWG

Scottish Dementia Working Group

PD

Participatory Design

Environment, Environmental or any other variation on these terms

Refer to the place, surrounding structures and influences in which activities have occurred.

They are not used within the landscape of the green imperative.

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BDes (Hons) MDes PGCert FHEA FRSA

Word count 79,306

## Chapter 1: Introduction

This thesis explains the work undertaken in projects titled *designed with me* and *designed with deMEntia* which were vehicles for exploring ways in which design might improve the lived experiences of people living with dementia (PLWD). Within this thesis, collaborative design or co-design (Scrivener, Bell and Woodcock, 2000) has been examined as a means for rethinking what PLWD are capable of. Challenging common preconceptions towards their ability to remain active and valued participants within society and communities in which they live. This approach has allowed for the creation of products, systems and interventions designed by PLWD in order to reconsider what they are capable of and how their actions can make positive changes. Co-design as a process has been chosen due to its potential to put creative and directive power into the hands of the people most central to a situation or set of circumstances. To achieve these co-design outcomes a method of 'workshopping' (Ørnsgreen and Levinsen, 2017) has been used, which has allowed for prolonged creative relationships to develop but within relatively short regular bursts of activity.

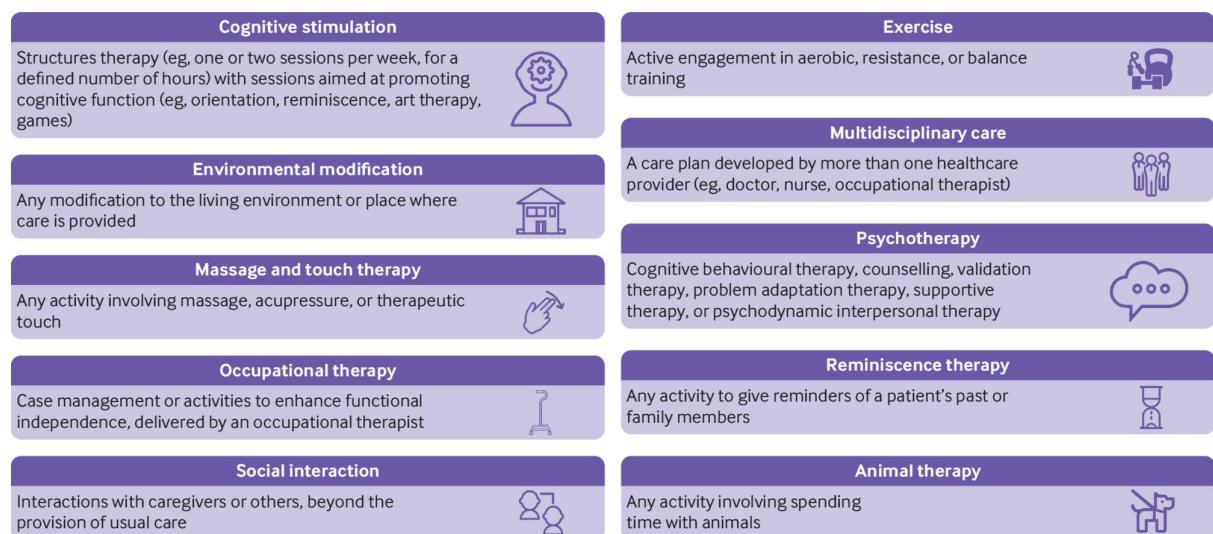


Figure 1.1 Areas of therapy provision for people living with dementia (Watt et al., 2021)

The research addresses the capabilities of PLWD who are in early to early-moderate stages of their early onset dementia journeys. There has been much work undertaken in the support and exploration of the needs of people who are in moderate and latter stages of dementia (some of which is discussed in Chapter 3 (the Literature Review), however limited accounts address the needs, opportunities and capabilities of people in early stages of dementia. The research also undertakes an approach fixed within personal presence and mental presence along with co-design

projects based in present or near-futures. Aspects outlined by Watt *et al.* (2021) as being the key approaches to addressing depression in people living with dementia (Figure 1.1) have been brought together through co-design practices. In particular, these relate to 'Cognitive Stimulation' and 'Social interaction' although aspects of 'Exercise' and occasionally, 'Reminiscence' add to the investigation. In regards to 'reminiscence', personal pasts are used to explore individual knowledge and framing in, and during, projects. However, an over-reliance of linking to the past is also eschewed. The various excursions, walks and activities in workshops support an element of exercise and require the employment of fine motor skills.

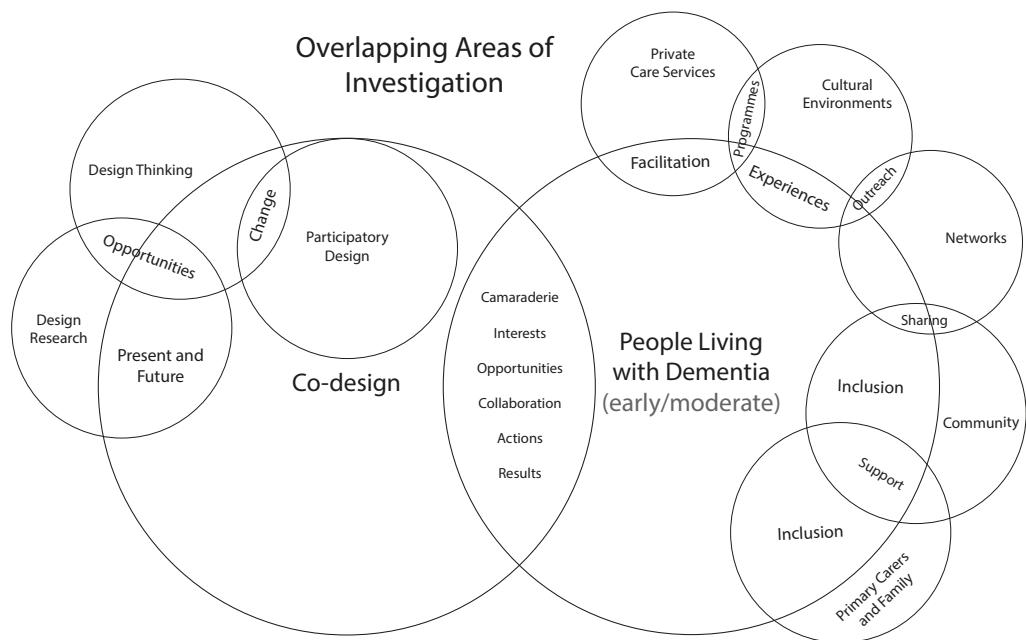


Figure 1.2 This research explores interlinking themes through exploration of co-design and cognitive stimulation care for PLWD (early to moderate stages of dementia).

The work contained within this thesis is focussed upon design and design-led activities including co-design and does not build a relationship with art-therapy. Instead, the work represents design as being capable of developing enduring, meaningful activities that take time to develop, involve iterative processes and that deliver results to be enjoyed, engaged with and even purchased by a variety of audiences. The work develops design as being ongoing systems for community inclusion and projects that gain momentum, where overlaps with new opportunities are likely be nurtured. Unlike most of the Art Therapy observed in this study, the projects are likely to develop forward-

looking propositions that evolve and develop through iterative collaborations. Not fixed within short and restricted expectations. These design-led projects aim to build on the capability of individuals to use their intellect, as it exists now. As such, the design method is comprehensive, progressive and proactive in affecting change or producing contributions of on-going value.

The work builds on widely acknowledged understanding that creativity and design in care and support of people living with dementia have been adopted and praised by governments and health authorities across the world (Camic, Zeilig and Crutch, 2018). Design as a creative endeavour, its processes and purpose, is most commonly recognised as a tool for business and commerce. However for many years, designers have been recognised and valued for engaging with work which tackles healthcare and social problems. Design can also be seen within this context as an engaging and enjoyable, creative tool for transformation and collaboration. As such, the word 'arts' in Camic, Zeilig and Crutch's assertion below can be replaced with the word design and the message would be on point for what this exploration aims to answer.

*"The arts have been shown to be effective for supporting the health, well-being and cognition of people living with a dementia, for aiding communication, for stimulating the residual creativity of those with a dementia, as a means of educating carers and also for challenging public perceptions and prejudice about the dementias"*

(Camic, Zeilig and Crutch, 2018: p. 641).

## 1.1 The Structure of this Thesis

### Chapter 2: The Nature of Dementia and Associated Challenges

Chapter 2, introduces the global issue of dementia along with the UK and Scottish situation outlining why this is such a significant concern. This leads into a discussion of what Dementias are and how differing kinds of dementia manifest in terms of cognitive impact and how these affect a person's identity, health and wellbeing. This is followed by discussion of informal care and care provision, finally introducing the nature of person focussed experiences and what these mean in terms of living with dementia.

### **Chapter 3: Literature Review**

The literature review defines what is meant by co-design and looks at historic models and precedents in collaborative practices with a particular focus on co-design with PLWD. It looks into the appropriate nature of design approaches and how these informed the study in practice. Within this chapter, considerations of co-design and trust, bespoke nature of design solutions, choice and individuality are set alongside discussions of the power of design in the form of intervention and change. Participation in the process looks to unveil the necessity for fun in disruptive engagement. Further consideration is given to dementia and wellbeing, unexpected revelations and latent talents. This chapter also positions how design differs from traditional forms of art therapy.

### **Chapter 4: Workshop as Research Method - A Methodological Explanation**

The chapter outlines why co-design workshops provide a suitable and valuable approach for researching the capabilities and potentials of people living with dementia and how they allow for tailored and responsive series of creative adventures to occur. The outcome of this chapter is the introduction of the approaches taken explaining the case studies in the following chapter.

### **Chapter 5: Co-design Workshops Part1: Failing to work *with* People Living with Dementia**

This chapter introduces the initial ways in which collaboration and workshop participation was proposed and how these failed to gain traction. The discussion of which explains how setting up independent workshops approach can be a challenge due to unexpected, restrictive or unresponsive behaviours of both people living with dementia and of their primary carers. In the discussion, the first set of failed attempts are used as to explain how new approaches were required and outlines challenges in working as a design researcher in dementia. This chapter explains that stand-alone workshops proved unfruitful in attempts to stimulate participation and reflects on failure within the investigation and the path taken

to develop positive appropriate responses. Furthermore, explanation is given to how learning from failure led to the development of initial collaborations.

## **Chapter 6: Co-design Projects**

Chapter 6 introduces new working collaborations and amendments to the approaches highlighted in Chapter 5. These provided improved access and greater participation. This chapter presents the development of the rewarding 'designed with me' and 'designed with deMENTia' workshops which shaped and informed many outcomes. The chapter also presents a range of co-design projects undertaken during the research, which includes:

- Re-design Sunday
- 75BC Fabrics
- A Stained-glass Window for Glasgow
- The Dementia Scanning Lab

Alongside these larger projects, smaller linking projects help to explain the long-term evolving design relationship that developed. These interlinking projects also help to make sense of the ever-changing collaborations and opportunities, particularly outlining the responsive nature of the bespoke co-design workshop approaches.

## **Chapter 7: Results, Analysis and Discussion**

Chapter 7 discusses how the alignment of the standard product design process as explained by Milton and Rodgers (2012), and the co-design method employed in this series of projects, occurs. A review of commentaries, actions and points of learning within each project brings together the discussion of participation, actions, results and PLWD-led insights to develop a representative value of the investigation. In so doing, this chapter presents feedback from the co-design workshop participants, their carers (family and friends), care support staff and reactions from the general public. The chapter highlights the processes of how these testimonies and analyses were undertaken.

Resulting from this chapter is a distillation of the understanding that has been developed and the effective socio-emotional value that the projects have delivered. This information looks at the production of designs and what those designs have achieved for the people who were involved in designing and making them.

## **Chapter 8: Conclusions, Future Work and Guidelines**

This chapter presents the contributions to knowledge that this work makes, developing conclusions of what co-design can afford people living with dementia and how future projects might be undertaken. The chapter presents the potential for further research and provides a set of guidelines for anybody intending to work in the area of co-design and dementia to consider.

### **1.2 Impact of Covid-19 on this Research**

It should be noted that this research started prior to the Covid-19 pandemic and the subsequent lockdown restrictions in the UK from March 2020 onwards, but it has been affected significantly by this situation. During the production of this research and thesis, the impact of health and wellbeing services for people living with dementia has been massive. Centres of support for people living with dementia and their families have closed down and social interactions have been effectively outlawed. Charities and the professional service providers they employ and work with have been forced to find completely new ways of providing services and support. The Scottish Government has since identified a need to make social interaction for people living with dementia a priority in 2021 and beyond (Haughey, 2020).

*"The impact of the pandemic has reminded us just how social contact and involvement in community life means to people with dementia and that it can be as important as medical support in keeping people well for longer and living an independent life at home for as long as possible."*

(Haughey, 2020: p.12))

Discussed within this research is the importance of social interaction for wellbeing and that the onset of dementia, for both PLWD and their primary carer(s), can create social withdrawal leading to

isolation which increases stress, anxiety, reduced sense of value and purpose. Through this situation people lose their sense of belonging and become removed from friends and naturally developed support. Therefore, much of what is discussed in this research project will likely be required in the reboot of services which are more focussed in how well people live rather than the resolution of health-based issues alone. To evolve with new problems and to resolve known shortcomings of care, new methods will be required to quickly manifest. The COVID-19 pandemic has shown that adaptation and quick roll out of interventions or solutions is necessary to ensure that people can live as well as they can for as long as possible. The pandemic has robbed people of the all-important social connections and interactions that we as humans require. The reality is that technological innovations are good short-term interventions although not ideal longer-term. For people living with dementia and their primary care givers, it will be essential to regain opportunities for social engagement through centre-based support although this is likely to be very complicated and limited by severe legacy restrictions. A Scottish task force of specialists working in the field to plan ahead and to get care services (including third sector organisations) working with PLWD as quickly as possible. Central to this aim is one-to-one and group activities within social settings in the safest but quickest manner possible.

In regards to the continuation of work developed within this research and in response to the COVID-19 situation, engagement with new networks of collaborators has already begun. For example, a proposal for a project with a new partner centre in Kirriemuir, Scotland, has been made. The proposition will look to develop the co-design practices undertaken in this research through face-to-face interaction and creative collaboration. The approach from Kirrie Connections suggests that the work discussed within this thesis appears to be well suited to augmenting the services, resources and methods for engaging people living with dementia to make a telling contribution in the future and to rebuild opportunities to socially connect.

This research outlines a pre-Covid situation which was very different from the one currently faced but which appears to have a valuable contribution to make to real world settings in developing resilience within communities' purpose and connectivity, supporting the actions of people living with dementia as they, and service providers, recover from the COVID-19 pandemic.

### 1.3 Institution, Partners and Funding

This research is funded through the Arts and Humanities Research Council's (AHRC) Collaborative Doctoral Award scheme (Grant Ref: 1655706) and has been undertaken at **ImaginationLancaster**, Lancaster University in collaboration with Alzheimer Scotland.

**ImaginationLancaster** based at Lancaster University, is an open and exploratory research lab that investigates emerging issues, technologies and practices to advance knowledge and develop solutions that contribute to the common good. **ImaginationLancaster** conducts applied and theoretical research into products, places and systems; using innovative strategies including disruptive design techniques that combine traditional and social science methods with practice-based methods arising from the arts. **ImaginationLancaster** emphasises productive collaborations to create desirable and sustainable design interventions that break the cycle of well-formed opinions, strategies, mindsets, and ways-of-doing, that tend to remain unchallenged (ImaginationLancaster, 2020).

**Alzheimer Scotland** is Scotland's national dementia charity. Its aim is to make sure nobody faces dementia alone by providing support and information to people with dementia, their carers and families. It campaigns for the rights of people with dementia and funds vital dementia research.

**Alzheimer Scotland** has Dementia Resource Centres in twenty-one different locations across Scotland, which provide a safe and friendly environment for people with dementia and their carers to visit and take part in a wide variety of activity groups. **Alzheimer Scotland** has over 9,000 members, over 90,000 Dementia Friends and is supported by over 1,000 volunteers. It employs around 550 full and part-time staff in its service-provision projects across Scotland. (Alzheimer Scotland, 2020)

**The Arts and Humanities Research Council (AHRC)** invests in a diverse range of funding initiatives for wide ranging and often disparate research focussed engagements across the UK. Its contribution to UK initiated and globally impactful research is significant and its funding of this PhD project has supported the central investigation along with providing other opportunities. The AHRC

has supported design and dementia research, where in doing so it has expressed a belief in the impact that design research can make to society, health and wellbeing.

## **1.4 Participants and Collaborators**

The work in this study has directly engaged many hundreds of people living with, or with personal experience, of dementia. Through attendance at and participation in existing workshops and events, a rich experience of the situation, care provision and challenges has been shaped by people living with dementia. Through this informed position, more focussed and intimate co-design relationships have been nurtured. These long-term collaborations have engaged twenty-six people living with dementia, seventeen carers and nine professional care staff in formation, production and undertaking of collaborative workshop settings. The workshops developed over a five-year period in which there were eighteen workshops, underpinned by thirty-two cultural excursions and many more creative meetings. These resulted in a variety of products, propositions, exhibitions, pop-up shops and a scanning lab. Through this approach, the work has reached thousands of people who have visited our pop-up shops, taken-part in creative pop-up events, attended open public presentations, read the Alzheimer Scotland Magazine and attended professional and academic conferences. Aspects of this work have also been presented at the House of Lords to RESEC (Research in Specialist and Elderly Care) - a charity/ think tank that lobbies government for support in health and social care contexts.

## **1.5 Overview of How this Work Occurred**

This work has been undertaken by diving into groups and networks of people living with dementia, attending meetings and events, participating in conferences and delivering formal presentations. It has engaged groups across Scotland and has allowed for collaboration with other researchers from other disciplines across the UK. Within this approach, participation in existing workshops to gain understanding and experience has occurred and observational approaches have helped to shape what is believed to be possible with people living with dementia. The result of which has been design research through actions, interventions and most importantly collaboration. During field

excursions and co-design practices, notes and thoughts have been recorded and have helped to situate what was explored. To underpin the practical aspects of the study, interviews and site visits have supported and broadened understanding in how care providers shape and supply their services. Working with Alzheimer Scotland has been fundamental to gaining access to specialists, carers and people living with dementia and their insights have been developed within the resultant co-design activities, methods and tools.

## 1.6 Research Aims

The key aim of this work is to:

*empower people living with dementia through designing*

The research is situated within a series of co-design activities where collaborative models of design are used to explore mutually beneficial design investigations and to result in perception changing processes.

The outcomes of this research are a series of designs, guidance documents and exhibitions achieved through co-design by people living with dementia. The projects and these resultant designs promote design with PLWD as a process of planning, exploring, making and testing, stimulating social interaction, that develops personal and shared skills, influences communities and society and empowers people living with dementia.

## 1.7 Research Questions

The research questions of this PhD align closely to Hendricks and Wilkinson's question of "how design research can be an enabler within the context of care and dementia" (Hendricks and Wilkinson, 2017: p.2). In an attempt to address this question, this exploration aims to answer questions in regards to:

- How can acts of co-design develop or reinforce the creative capabilities of people living with dementia?

- What are the benefits for people living with dementia, their primary carers and private caregivers of working in a design-led manner?
- What can design skills and design processes afford people living with dementia in terms of self-actualisation, ownership, creative prowess and empowerment?
- In what way can co-design be shaped to provide the most holistic ways for designers and people living with dementia to work together?
- How has the approach challenged popular preconceptions surrounding capabilities of people living with dementia and appropriate methods of developing care practices which include them to the fullest possible mental and physical extent?

The work engages with two means of supporting people with dementia; one is the supply of professional care services and the second is how designers engage in design for dementia (with a particular focus on co-design). These design-led approaches are discussed in the following two chapters and relate to actions that commonly engage people within care and co-design approaches. The work challenges to what extent any collaboration becomes more than introductory offerings at the beginning of a project. As will be seen in the literature review (Chapter 3), the engagement of designers in most of the examples discussed is in the form of an expert ready to do designs for or on behalf of people living with dementia. This work therefore, provides a breakdown of how the designers working within dementia tend to operate and an assessment of how collaborative the approaches appear to be. In this review, the approaches undertaken by design researchers differ greatly in response to the stage of the dementia journey on which the people they are working with are. As the disease develops and mental functions diminish, more acting on behalf of (for) people living with dementia is likely to occur. This research concerns itself with people in early to moderate stages of the dementia journey and commonly those who have early onset (under the age of 65) and is particularly focussed on working *with* them not *for* them.

Encompassing the following expectations, the later design-led perspective sits within deeply explored territory where, as Niedderer *et al.* (2017) explain, the five common interventions in non-pharmacological approaches to dementia care extol the need to:

1. *Stimulate cognitive engagement most commonly associated with memory, lifetime events and experiences known as 'Reminiscence Therapy'*
2. *Act within the spaces used and lived within to minimise confusion and maximise ease of use to increase independence and to reduce stress, these are termed 'Environmental Interventions'*
3. *Affect the senses and evidently influence mood or behaviour including, but not limited, to light, smell, tactility or aural (e.g. music) known as 'Sensory Stimulation'.*
4. *Utilise technology to support independence, track individuals or that stimulate behaviours through reminders or prompts termed as 'Behaviour Management Techniques'.*
5. *Introduce 'psychosocial' stimulus in the form of buddies or pets who provide support through companionship be that in the form of trained pets or people.*

What appears to be missing from these overviews is progressive participation, action and empowerment through design, the development of creative camaraderie is also missing. What might be worth introducing is an idea that designing is both focussed in a process with tangible outcomes and a method which requires social interactions which shape futures. A note that Neiderer *et al.* make, when they state a *"need for attention on the quality and meaningfulness of interaction and the role that people with dementia play within it"* (2020; p.10).

What is therefore being suggested here is that co-design can perform as a valuable and valued actor in socially focussed, collaborative participative methods for stimulation, enactment, empowerment and wellbeing of people living with dementia. The following work will investigate how the design process can work in producing full and engaging collaborative practices. Making it

accessible, meaningful and useful to people living with dementia. This is deemed possible by means of sharing with, and adopting, a '*learning by doing*' approach (Dewey, 1916; Brockbank and McGill, 1998). The intent of which is to reveal latent skills and knowledge and to understand how (when given the chance) people living with dementia might make use of them. The research places significant expectations upon the design process, along with the capabilities of people living with dementia to result in improvements in personally lived experiences. Therefore, the co-design approach developed for this research is situated within the context of recognised stages within the design process. This supports the review of how collaborative ('co') the workshops and engagements are and to what extent they achieve a full process engagement. The research uses co-design as a participatory form to engage themes of personal being, notions of agency and capability, and to demonstrate prowess and achievement. Finally, the research hopes to provide insights as to how designers and design researchers should work with PLWD so that they may enable and enact enriching propositions and in so doing, address the challenges laid out by Niederer *et al.* (2017).

This thesis discusses many interlinked projects undertaken through a co-design approach and explains how the participants engaged in and through the processes, created valued outcomes, developed public facing content and engagements. In this guise, co-design is utilised to augment the lived experience of people living with dementia through fun, collaborative activities that are purposeful. The research is framed within the opinion that design is a social activity that involves interplays and exchanges of human relationships and which should value everybody involved in the process, including PLWD. Ultimately, the projects undertaken during this research should afford the public and the participants the opportunity to think again about what they know about dementia and about the capabilities of people living with early-to-moderate stages of early onset dementia.

The next chapter '**The Nature of Dementia and Associated Challenges**' sets the background to the project. It outlines dementias and introduces combinations of the issues along with the kinds of support observed by private dementia care providers in Scotland. It also introduces issues providing care generates for carers, professional support providers and people living with dementia.

## Chapter 2: The Nature of Dementia and Associated Challenges

This chapter looks to inform the reader about dementias, the prominent forms and the problems associated with a diagnosis, including the pressures of care. The discussion puts in context the issues of dementia in a local, national and global context where new modes of engagement are being sought in order to support, challenge and change existing modes of care. The work looks at governmental, social and healthcare objectives outlining the requirements to consider where, when and how to engage alternative approaches to working with PLWD and identifying potential avenues for new interventions in care support.

This chapter provides an overview of the most prominent classifications of dementias and the impacts these have upon people living with degenerative conditions. It considers modes of non-governmentally supplied care and the individual networks required to support each person living with dementia. It considers the impacts that such care provision has on friends or family who supply the vast majority of care in the UK. Alongside this scenario are a number of organisations and charities who fight for the interests of PLWD and their primary care givers (carers). These charities also provide significant respite through the provision of services shaped to alleviate stress and provide care along with friendship, community and guidance. The strategies and services they provide are discussed further in this chapter.

The central tenet of this chapter is to grasp the methods which attempt to assuage the burden of personal care, to understand the requirement of resources and methods for supporting individuals and their loved ones. This includes a discussion of the burden of care which is experienced by friends, families and loved ones. The insights have been garnered through interviews, visits, observation of and participation in workshops, web and literature investigations, and attendance at public talks.

*"Today in Britain there are more pensioners than young people under the age of 16"*

(Cottam, 2015; p.3)

## 2.1 Positioning this Work

In the UK, we have an aging population. According to the Office of National Statistics in 2017, 18% of the population were over the historical pensionable age of 65 and since the 2011 census, for the first time in the history of the UK, those over the age of 65 outnumber people under the age of 16 (Spijker and MacInnes, 2013). The aging population trend carries a multitude of complexities which place significant stress on healthcare, the welfare state and families alike (Knapp, 2014). In recent years, the government has invested in and directed its focus in challenging how the population ages, with particular emphasis on 'healthier for longer'. With an aging population, there has come an increase in life expectancy and the pressures to promote how to live both productively and well for longer (Kuh, 2007) - the emphasis being to maintain good health, independence and wellbeing for as long as possible. Craig (2017) states that within this situation design through the products, environments and services has been charged with supporting the alleviation of dementia related stresses that exist within society. In alignment, the emerging trends in design intervention and concerns for an aging population are "*long term healthcare*" and "*ageing population | Non-communicable diseases*" and "*wellbeing & mental health | social interaction & support | active living*" all of which concern interventions within the care and support of PLWD (Tsekleves and Cooper, 2011; p.260-261).

Spijker and MacInnes (2013) provide evidence that people are successfully living better for longer and despite national concerns, do not necessarily impact the health and welfare systems to the extent that may have occurred in the past. Their suggestion is, that despite age, 'older generations' are healthier and wealthier than they have ever been and are living healthier for longer. However, with greater numbers of people living for longer, the evidence indicates that a higher risk and incidence of some health conditions continues to develop, in particular, the prevalence of Dementia. The series of conditions termed as Dementia have become a significant local, national and global concern. In 2013, an estimated 86,000 people were living with Dementia in Scotland (Alzheimer Scotland) and in 2015, the estimate was that 850,000 people in the UK were affected by

the condition (Alzheimer's Society). It has been suggested that this will grow to nearly 2 million by 2050 (Thackara, 2007). Globally, the number of PLWD is thought to be in the region of 47 million with an expectancy for that number to reach 75 million by 2030 (World Health Organisation). These kinds of statistics indicate both societal and health service pressures which Prime Minister David Cameron set the challenge to address in the shape of failings in diagnosis, care, support, awareness and how communities should work together to make for better care provision (Department of Health, 2012). The 'Prime Minister's Challenge on Dementia' identifies a number of problems which are unaddressed by current conditions which includes an understanding that as much as 40% of PLWD are undiagnosed, and that the burden of care falls heavily within society rather than on governmental solutions. NHS support and care are supplemented to a massive level by people who are providing care as a result of their relationship to the person with a diagnosis. It is suggested that these family caregivers, aligned with the tendency of personal or family payment for private care, accounts for two-thirds of the £26billion cost of Dementia care in the UK (Alzheimer Society, 2015).

The intention to develop integrated and interdisciplinary responses for supporting care in the area of dementia are discussed further in Chapter 3 (Literature Review) but include the need for government agencies to work with disparate, interested and engaged parties across society, charity, academia, creative industries, businesses, high street retailers, banks, and care providers; both formal and informal. This list is not exhaustive. Instead, it starts to unpick the huge number of people responsible for providing suitable solutions that care and provide support to, for and with PLWD. In addition, there are trends in the knock-on effect of caring on the ill-health for carers which must also be considered in the provision of support systems and interventions. What is clear, is that the challenge requires substantial focus on people existing at the centre of the maelstrom.

To engage with the problem of dementia, many factors should be considered. This chapter introduces some of those elements including, a description of dementia and what the term covers along with the personal effects of living with dementia. Consideration of the effects on family and unpaid carers is also informed to elucidate the need for intervention by all manner of agents of change which includes design research and the design profession.

## 2.2 Explanation of Dementias

As Kenning (2017) indicates, and in regards to the core research in this work, it should be notable that Dementia should not be expressed as being a condition that is solely an age-related concern. According to the Alzheimer's Society (2018), there are 40,000 people living in the UK who are under the age of 65 and have a diagnosis of Dementia.

*"Dementia are higher level cognitive degeneration"*

(Crutch, 2018)

The term Dementia, covers a plethora of conditions that progressively reduce a person's mental capacity and with that comes faltering memory, altered reasoning, declining fine motor skills, more rapid deterioration of sight and increased levels of immobility leading to the need for support and care. The conditions termed as Dementia, strip people of personal thought structures and cognitive function, and as such, degrade and eventually, destroy a sense of self. The recognised prognosis is one where in the *"Long-term improvement is an unrealistic outcome for people living with [such] a degenerative condition"* Kenning (2017). The prevalence of the problem in the UK suggests that most of the population will have had some knowledge or relationship to somebody living with Dementia. Historically, there has been much awareness raised about Alzheimer's Disease which, though the most common, is only one form of dementia (Alzheimer's Society, 2021). The title 'Alzheimer's' has become synonymous with activist groups, fund raising initiatives, charities and populist recognition. However, greater research and understanding has developed a view in which dementias consist of a variety of diseases and degenerative conditions:

*"Dementia is an umbrella term for a range of illnesses and disease symptoms, which primarily or secondarily affect the brain."*

(Alzheimer Scotland, 2013)

Dementia is most widely recognised of consisting of five overarching conditions that have their own particular symptoms and resultant patterns of brain function degeneration. In extension of these

core categorisations, there are a further 200 subsets that have been identified (Dementia UK 2018).

The five core forms of Dementia are defined as:

- Alzheimer's Disease
- Vascular Dementia
- Dementia with Lewy Bodies
- Frontotemporal Dementia
- Mixed Dementia

As research, understanding and insight is developed, differing forms of Dementias are being recognised as are the impacts of historical conditions or effects. This has led to significant breakthroughs and awareness occurring in some conditions. For example, that of historic brain trauma leading to Chronic Traumatic Encephalopathy (CTE). This condition has recently been identified through cases, such as the former professional football players Jeff Astle and Frank Kopel, as a condition resulting from repetitive heading of the ball. As such, it has been recognised as a dementia directly attributed as an industrial disease. However, for most people diagnosed with dementia, there is no clear explanation as to why they have developed Dementia. The Jeff Astle Foundation (2020) identifies the most widely accepted interpretation of causes as follows:

- *Age is the strongest risk factor for Dementia. While an unusual diagnosis in younger people, around 1 in 50 of those aged 65 to 70 have some form of dementia, with that number rising to 1 in 5 in people aged over 80*
- *Gender can influence risk of dementia, with women slightly more likely to develop such conditions than men*
- *Genetic studies have identified a small number of genes that can alter a person's risk of developing dementia. One example is the apolipoprotein E (APOE) gene, which can alter a person's risk of developing Alzheimer's Disease and Vascular Dementia*
- *Medical problems such as heart disease and high blood pressure can increase risk of developing dementia, in particular, Vascular Dementia.*
- *Dementia risk is also increased in some other conditions, including Down's syndrome, chronic kidney disease and multiple sclerosis*

- *Traumatic Brain Injury (TBI; head injury) is recognised as the strongest environmental risk factor for Dementia. In particular, a form of Dementia called Chronic Traumatic Encephalopathy (CTE) is increasingly recognised in people exposed to repetitive TBI, including retired boxers, footballers and rugby players*
- *Lifestyle factors including diet, exercise, smoking and alcohol are all recognised to influence risk of dementia, particularly through their effects to increase risk of heart and vascular disease. A healthy diet, regular exercise, not-smoking and alcohol in moderation are accepted as ways to limit dementia risk*

Alzheimer Scotland (2013) suggests that though the journey of every person who has a Dementia is unique to them and their condition, there are fundamentally three recognised stages of Dementia:

- *Mild Dementia - affecting tasks and remembering problems with complexity, however, to a large extent the person is capable of living independently and dealing with a variety of day-to-day tasks.*
- *Moderate Dementia - where recognition of people and places can become problematic, support is required with day-to-day tasks and to facilitate in home living. Behavioural changes may also occur.*
- *Later Stage Dementia - The brain functions start to fail more significantly inhibiting memory, reasoning, communication, fine motor control and physical capabilities.*

It is also relatively common for people to experience Dementia alongside other conditions such as Parkinson's Disease. This amplifies the complexity of Dementias and related issues of self-sustained independence and mobility, along with increasing the pressure on support and care givers.

## 2.3 The Nature of Dementia

*"Imagine a carefully crafted, individual brain with connections that are responding to, activated by, strengthened and shaped by sequences of specific experiences that no one else has ever had, or ever will have; now imagine that those highly individualised connections are slowly dismantled as the branches shrivel back"*

(Greenfield, 2011; p.57)

As noted above, there are many different types of dementia and each person will experience their dementia in their own unique way. Common symptoms of dementia can include problems with short term memory where new information is difficult to retain. PLWD can get lost in seemingly familiar places, may experience confusion with names, and may also experience confusion in environments which are unfamiliar to them. Even language can become troublesome and methods of communication restricted as words and intentions become confused.

As a result, people with dementia may lose interest in engaging with others socially. PLWD may become quieter and more introverted, and their self-confidence might become affected. Amongst older people, dementia is the most significant pressure on care provision, much more so than other types of impairment and chronic disease (Prince *et al.*, 2013). This demand for health and social care services will continue to increase as a result of demographic changes (Cottam, 2015).

Receiving a diagnosis of Dementia creates a "*biographical disruption*", with the chronically ill "*observing their former self-images crumbling away*" (Bury, 1982; p.169). Therefore, people need support from the point of diagnosis to come to terms with this life altering event. The effect of which is both psychological and physiological creating habitual, living and accommodation impacts. Dementia enforces the need for resources and people to act outwith personal historic modes of existence. It is recognised that to remain connected to their community and enable PLWD to live well, changes in public understanding, tolerance, training and social inclusion need to come into effect. However, people typically do not receive support until the illness is advanced and often at the point of crisis (Alzheimer Scotland, 2008) where all too often the effects have started to create social isolation and a sense of dislocation and where struggles in undertaking tasks are already creating distress. This pattern is becoming more acute as a result of pressures on health and social care budgets and the requirement for PLWD to privately support themselves.

Philosophical debates on dementia have largely focused around the fundamental nature of being and what constitutes personhood. The failure to recognise personhood and the negative impact of inappropriate care giving can result in 'malignant social psychology', which includes labelling, disempowerment, infantilisation, invalidation and objectification (Kitwood, 1990). One reason

behind this malignance is a failing to see the person and not showing them the respect that properly accords their being (Kitwood, 1990). Greenfield (2011) poses that, even when a person seems to have lost a significant part of what made them a unique individual, core elements of their identity will remain. These characteristic gestures and ways of doing things are what keep alive the sense of the individual, even if the more sophisticated levels of that individual have been eroded.

This has important implications for the approach to providing support and what people require in addition to the basics of daily living. A person's sense of self and self-respect can be fostered through "reinforcing any remaining elements of conscious self-identity"; less conscious elements in a person's identity can be preserved through physical surroundings to retain "physical links with their past, which help to support a sense of personhood" (Matthews, 2006; p.176). Whilst mood, behaviour and memory may be profoundly affected, personhood is not; the individual remains the same, equally valuable person throughout the course of the illness. Interventions to support the person with Dementia should honour their personhood and right to be treated as a unique individual; maximising, the valued representations of, selfhood that the individual still extends. This leads to an understanding that, when working with somebody who is living with dementia, "*Cognitive abilities are important parts of who we are, but it is important not to focus on loss but continuing abilities*" (Crutch, 2018).

This also poses a requirement to enforce personal capabilities and coping mechanisms and to identity as proactively for as long as possible. At the centre of the activities and systems that are designed for and around the care of an individual, there is also a requirement to let people be themselves and to ensure they are empowered to be so. Guidance and support of all kinds must, primarily, directly engage with the person and recognise their abilities and behaviours. Identities can even more quickly be eroded as can personal confidences if the approach is in anyway stigmatising or condescending. As one person met during this investigation explained "*I've always been a walker*" - a component of his being - "*now I have Dementia, I wander*"<sup>1</sup> - an explanation of

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<sup>1</sup> Scottish Dementia Working Group (SDWG) Male Board Member 1 - during a one-to-one conversation at Edinburgh, Mid and East Lothian Dementia Action Network Group (EMELDAN) in 2016. From Field notes. SDWG is an organisation run by PLWD who are championing the rights of PLWD in society and to the Scottish Government. <https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-Dementia-working-group>.

how he feels other people see him. He went on to explain that his diagnosis has caused people around him to become invasive, phoning to find out where he is and why he is not where they want him to be. He explained that having travelled much in his working career, investigative walking became habitual to him and that he would never have a destination in mind. Now, if he undertakes the same approach, it is a problem, not for him but for others. At another meeting for the Scottish Dementia Working Group, the same individual explained that often living successfully with Dementia is about habits and in place processes that are supportive, which, as he stated, *"you can appear to be getting better, but you're getting worse, you are just becoming more capable of dealing with it".*<sup>2</sup> By providing the requisite tools for better independent living, people can be supported, especially in the early to moderate stages of their Dementia Journey. Another person living with a diagnosis of Dementia shared her solution for successful navigation of the world at the same meeting. She removed a small business card and handed it over. On one side was her name, on the other an inscription that read *'I have Dementia. My brain sometimes misbehaves. I can have problems with numbers, money and telling the time. I may need a little help.'*<sup>3</sup> She reiterated that this simple designed intervention helped her to explain and overcome most obstacles in day-to-day living and could allow her to maintain her dignity or to reduce labelling.

These examples share the need to tailor solutions that best support individuals and that blanket care approaches may have stigmatising and demoralising effects. This does not negate that care, or in the very least, adequate support, is required from the start of an individual's Dementia journey.

For PLWD cognitive and physical degeneration are never the same and as such, the timeframe in which people successfully manage their condition can vary greatly. Intervention is required but when and to what depth is always unique, unscripted and responsive. No matter what degeneration occurs and the speed in which it occurs, the impact is massive for the individual, their families and the people involved in their care.

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<sup>2</sup> Male Board Member 1 - during a one-to-one conversation at the SDWG Meeting in Glasgow (2016) – From Field notes.

<sup>3</sup> Female Board Member 1 - during a one-to-one conversation at the SDWG Meeting in Glasgow (2016) – From Field notes.

## 2.4 Family and Friends: Care and the Social Challenge of Dementia

The frequency of PLWD and the expectations that people have, in regards to their familiar roles and responsibilities, means that families and friends have become essential in the caring roles required and undertaken. As a result, stresses placed upon primary support systems delivered by families and loved ones have become ever more common. Basically, state funded social and medical care cannot cope with the number of instances of dementia and economic burden, and so that burden has become privately resolved. As previously noted, it is estimated that £17.5billion of the annual £26billion cost of Dementia care in the UK is privately supplied, and that as much as £11.6billion worth of unpaid care is supplied by primary caregivers. Unpaid and untrained people are working from a position of duty, societal pressure and love whilst 'cobbling together' suitable solutions.<sup>4</sup>

In the UK, the predominant, accepted expectation and responsibility of care falls on loved ones, usually a spouse or relative. Glendinning (2014) suggests that as such, the ways in which care is managed and assessed from the carer's perspective are unsatisfactory at best. For example, questions as to whether or not people want to be in a caring role are not asked. Often, this results in a requirement for the carer to submit to a role never asked or wished for (Marriot 2011). It can have direct personal consequences including the need to give up on a career, pressure applied to family-based situations and relationships, a loss of self-identity and commonly reduced social interaction.

As a result, the evidence suggests that it is not only those directly affected by dementia that suffer ill-being or ill-health (Glendinning, 2014). The recognised impact on carers often leads to large groups of the population succumbing to the 'acceptance of their lot' (Marriott, 2011). Thackara (2007) suggests that the group affected *indirectly* by Dementia may be up to 4 times those *directly* affected. As of 2015 figures, this estimation equates to almost 3.5million people (Alzheimer Society, 2015). Here, stresses on primary support systems of families and loved ones become ever more common, and recognised patterns of behaviour exacerbate issues such as loneliness and isolation for both those living with Dementia and their primary support or caregivers. The impact includes

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<sup>4</sup> Interview with a former carer who took part in a 1hr interview after registering interest in the cancelled 4<sup>th</sup> *Re-design Sundays* event (2016). *Re-design Sundays* is a project from this PhD discussed in Chapter 5.

disjointed assessments of the parties involved, which, in many ways, suggest at least disinterest, and at worst neglect of the lived experiences of carers (Winton, 2017)<sup>5</sup>.

This body of work is not directly aimed at resolving solutions for carers. However, as a result of design thinking (Buchanan, 1992; Cross, 2011; Brown *et al.*, 2009) and design actions, there may be project outcomes that have the potential to impact on caregivers' experiences. In particular, the investigation is likely to highlight ways in which individuals living with Dementia can feel more empowered supporting different ways of thinking, moods and behaviours that arguably may lighten the load on carers. By all accounts of the discussions, interviews and observations undertaken in this investigation, lightening the load and burden of care by whatever means would be welcomed by care givers.

Within this view, there is a recognised emphasis on wellbeing for people directly affected by dementia, which must also include consideration of those people who are indirectly affected by the condition, such as carers and loved ones.

## 2.5 Caring and Engaged Communities

In theory, community support and the use of physio-social networks that deliver a sense of connection give people purpose, supply support, encourage individual identity and devise modes of empowerment. People therefore, become better equipped to make changes to the situation in which they exist. Government strategies have identified a need to embrace this position; In *Living Well with Dementia: A National Dementia Strategy* (Banerjee and Owen, 2009), there is a narrative of governmental services developing wellbeing and improving care through orchestrated top-down delivery. However, the recognition also exists of a requirement and encouraged objective to develop localised, locally provisioned and resourced structures in which communities can support themselves. Within this context, devised solutions must build accepting and encouraging scenarios for all of its citizens, including those who are marginalised. As Craig (2017, p.62) identifies, "people

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<sup>5</sup> Further discussion is available in Appendix 4.1)

with Dementia, and research about them, tells us that when people are supported to build community connectivity, individuals can maintain valued life roles and experience wellbeing."

With a knowledge that greater community involvement helps reduce the deficits of care (Buddery, 2015), there have been a number of approaches taken to develop social inclusion and interaction from a community-driven perspective, both locally and internationally, that have afforded valuable improvements in the experiences of those living with Dementia. Japan in particular has taken strong steps in changing opinions whilst increasing understanding and public acceptance of PLWD. Informed by the need to support the rapidly increasing aged population, its approaches have been driven by necessity for change. One such approach has been a training initiative known as the Dementia Support Caravan which has trained over 1 million people to be Dementia Supporters. It is a programme and network built to inform, innovate and educate and the supporters are trained to look out for issues ensuring appropriateness in dealing with somebody they recognise as having Dementia in public places. This network of trained citizens is encouraged to use their initiative in order to innovate interventions. Particularly important in this example is an openness to share ideas and the governmental reinforcement in support of the initiative. Mayumi Hayashi explains the significant difference from Europe is that the Japanese "Government doesn't focus on evaluation or evidence, so they encourage experimentation and let communities do whatever they think is good" (Tagawa, 2015). Here, there are likely lessons to be expanded upon as to how a co-design approach that disrupts the norm has become a complete approach in community-focussed-action. The Japanese example aligns well with Horst Rittel and Webber's '*wicked problems*' (1973) and the reasoning of why design is a viable method in which to intervene in such problems as Dementia. This is discussed more at the end of this chapter and sets the tone for the work that follows.

In Scotland, Alzheimer Scotland has been at the forefront of informing governmental strategies, helping to develop and promote the Scottish Parliament Cross-Party Group's '*Charter of Rights for People with Dementia and Their Carers in Scotland*' (alzscot.org, 2009) that reinforces PLWDs rights alongside models for standards and expectancies throughout care in the Dementia journey.

Alzheimer Scotland is an advocate of design within its working practices, developing resources and systems that support individuals and communities. Alzheimer Scotland and the Life Changes Trust are also driving the Scottish focus on wider understanding, acceptance and support through their

Dementia Friendly Community programme of which there are currently forty such communities (Life Changes Trust, 2020). Much like the Japanese Dementia Caravan, the programme is designed to create a society that is informed, knowledgeable and equipped to cope with emerging scenarios in daily experiences. The aim of the project is to provide *“everyone from shop assistants, public service workers, faith groups, businesses, police, fire and ambulance staff; to bus drivers, school pupils, local clubs and societies, and community leaders”* (Life Changes Trust, 2020) the tools to make areas more welcoming for PLWD. Resources and training are available to advance citizens and to build societal appreciation that supports individual resilience to living with Dementia. The Alzheimer Society in England and Wales is doing likewise and explains the importance of the approach by stating *“Dementia-friendly communities are vital in helping people live well with Dementia and remain a part of their community”* (Alzheimer Society, 2020). Of equal importance of society nourishing their knowledge and flexibility is the role that PLWD perform within such networks. As the Alzheimer Society explains:

*“People affected by Dementia have the most important role in any Dementia-friendly community. By sharing their experiences and connecting with others, they ensure that communities keep the needs of people affected by Dementia at the heart of everything they do.”*

(Alzheimer Society, 2020)

Scotland has been highly active in the development of support and care for PLWD and has been championing people's rights and responsibilities despite diagnosis. Within this approach, Alzheimer Scotland has been prominent. So too have been people who themselves have a diagnosis, through such organisations as The Scottish Dementia Working Group. The national campaigning group is a platform for living positively with Dementia and for giving an independent voice to PLWD. Run for PLWD by PLWD, it campaigns to improve services and challenge stigma. It is politically active and provides a voice in order to champion its collective rights. The group also produces valuable tools and services to its broader community. The organisation advocates how to live with meaning, purpose and value through events, films, a website, printed materials and active engagement with the range of support networks across Scotland. The organisation is an expanding entity with affiliate groups across the country and overall membership on the increase.

During one of the Scottish Dementia Working Group Meetings that was attended for this investigation, a presentation of a film made by the group about travelling locally and internationally with Dementia was presented. The professional quality production worked through a number of issues and concerns for those living with Dementia and suggested ways of reducing stress and fear in regards to the process. This kind of content provides insights that are helpful to all involved in the process and as such, shows the importance of having a network that is looking to inform and enrich the knowledge of communities. By doing so, the intention is to recognise where problems might develop, how issues might play out and how informed individuals might be able to alleviate complexity, strain and anxiety for all involved.

Visiting the working group and meeting with some of its members at other events gave insight into the wide-ranging scope of how Dementia can affect people. Some of the members of the group had been serving in excess of seven years, showing that diagnosis need not necessarily stymie the effective influence and valued input of an individual. What was also made exceptionally clear by the chair, Henry Rankin, was that *"one to one conversation is far better than anything else... you learn a lot from the person sitting next to him [sic] more than anything else".*<sup>6</sup> The group is using this knowledge in the hope of extending its influence.

## 2.6 Other Care Provision Through Charities and Organised Support Systems

This PhD investigation has been pursued in collaboration with Alzheimer Scotland, a charitable organisation which champions the cause of people affected by Dementia in Scotland. It provides a range of services in the form of support networks and hubs across Scotland and provides a voice for PLWD. Furthermore, it is active in canvassing and advising the Scottish Government in areas of Dementia policy and action. There are many charitable institutions providing Dementia care in Scotland and each city has many overlapping providers of day-care and respite. The aim of these organisations is to provide information and direct services, provide opportunities and to provide support to individuals and families. As third sector organisations, they are funded through multiple methods including Scottish Government, Local Authorities, private contributions and fees for

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<sup>6</sup> Noted at the National Dementia Working Group Meeting in Glasgow on

services. In this research, the central collaborator has been Alzheimer Scotland although many other third sector organisations have been worked with and these will be discussed throughout this work.

## 2.7 Research Network, Visits and Collaborations

In the development of the research, it was also important to develop backing and interest from a range of other Dementia support groups and services which expanded the offering of Alzheimer Scotland. This involved various visits and meetings with third sector organisations which included the Eric Liddell Centre, the Open Door Café, both in Edinburgh and discussions with Kirrie Connections in Kirriemuir, Scotland.

Initial investigations were also undertaken through attendance at meetings, discussions with specialists and relatives, attendance at networks, support groups, conferences, participation within Dementia care environments and various other associated groups. These investigations allowed for greater understanding of what PLWD do, how they are supported, how they direct their own interests, and how they might develop their capabilities through which further self-empowerment might be achieved.

A number of visits were undertaken to various Alzheimer Scotland Dementia Resource Centres where an understanding of the environments, activities and groups facilitated by these places was generated. The centres visited were in Bonnyrigg, Kilmarnock, Bridgeton in Glasgow and Helensburgh. Discussions were had regarding the design of these resource centres and the activities that occurred within. The environments at Kilmarnock, Helensburgh and Bridgeton are design-led reimaginings of Dementia Support environments and are changing historic expectations and aesthetics. The original Kilmarnock Resource Centre was a project driven by Joyce Gray of Alzheimer Scotland and designed by Graven, a Glasgow based design consultancy. The approach has since been rolled out to a number of centres. Designed in a modern and consistent manner, the Resource Centres could easily be mistaken as modern coffee houses or clubs, the intention of which is not to put forward well-formed societal ideas of situating people with Dementia in historical settings. These kinds of reimagined Dementia care spaces are also playing an active role in engaging with local communities and, in the case of Kilmarnock, is creating opportunities for intergenerational interaction between children and PLWD.

The events that occur in these reimagined resource centres are often progressive, incorporating multi-sensory stimulation. In discussion with Joyce Gray, it became apparent that design aesthetics were not the only changes that were being made in these care environments. She explained that every element of the service had been designed, including the incorporation of sensory design, for particular events. For example, cinema afternoons where the smell of freshly made popcorn was important as was the warmth of the cooked treat in their paper bag pokes. This multi-sensory design thinking is common in creative practice for the reasons as Jenny (2012; p.10-11) puts it “*While the eyes may be the antenna that leads to the other senses, every other sense is also able to take on the role of antenna... perception is made up of the interplay of our senses*”. In degenerative conditions such as Dementia and through the natural age-related degeneration that occurs, it appears to be valuable to be thinking of the design of environments and experiences in this holistic manor, allowing the more receptive senses to come to the fore. Within this thinking spatial strategy is also important and so, furniture is arranged to evoke thoughts of cinema rows with an aisle running up the middle. In the modern aesthetic of the environment, the arrangement of objects and tools is seen to be more important than the historic look and feel of the furniture. With this level of considered approach to the activities and spatial arrangements of the Resource Centres, the environments promote a positive attitude towards creative exploration. In addition to the structured traditional care that has a degree of reminiscence, such as the cinema days, football discussion groups or music-based activities, the centre continues to push the boundaries of expectation by offering other opportunities that include massage and grooming therapies. However, the core of the activities (witnessed) involved personal artistry and creative capability.

In addition, the Alzheimer Scotland Resource Centres are a valuable means of connecting their users with embedded experts. Here, they can meet with link workers<sup>7</sup> and discuss their needs and methods of support. In learning about the support systems on offer, a meeting was arranged with Jennifer Risk, a post-diagnostic support worker, based at the Resource in Kilmarnock, who was well positioned to explain the complexities and common stresses that are a feature of diagnosis. She articulated that the process requires substantial life adjustments in ways that are personally and socially impactful. As such, her work is about advising people on how to adapt and to live with

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<sup>7</sup> Jennifer Risk is an Alzheimer Scotland Link Worker or specialist community focussed occupational therapist.

change. This focus was on practical and immediate responses for dealing with highly stressful and deeply personal change “*For people living with dementia, everything needs to happen early to support things and their uptake*” and she stressed that “*Habit forming is possible, as long as people can accept it*” once these habits are formed then they can become part of the lived routine and tools to be utilised personally.

Jennifer also reaffirmed the importance of support systems, such as the Dementia Resource Centres, in identifying the stresses that are occurring for both carers and people with a diagnosis. She stated, “*Sometimes you can see how things are going on a family member’s face... It’s written on their face*”, and went on to say that by seeing people in places like the resource centres, when they are under stress, being able to connect can help significantly. As such, the importance of the centres as places of activity for PLWD is further enhanced by the support and care on offer for relatives or carers. In terms of activities and the potential for new approaches when working with PLWD, her advice was that it “*helps when there is positive behaviour*” which can lead to the “*formation of groups within groups of peer support*” and that it is a positive thing to encourage “*expert and non-expert collaboration for knowledge exchange*”. In the very least, this is suggestive of the power that interventions encapsulating such behaviours and thinking have the potential to gain traction and lead to positive effects.<sup>8</sup>

Through the various visits and meetings, many opportunities to observe and to discuss approaches occurred within this work. These included creative practice, discussion of current affairs, discussion of historic events and, personal and music-based reminiscence approaches. With Alzheimer Scotland (the central research partner to this work), a number of approaches were looked at to suggest methods for engagement and collaboration with their support networks and the PLWD that they help.

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<sup>8</sup> Field notes from visit to Alzheimer Scotland’s Kilmarnock Dementia Resource Centre and an interview there with Jennifer Risk, a specialist post diagnostic resource worker at the centre. Dementia Resource Centres are day care facilities offered as part of the private care offered by the charity across Scotland. The centres support PLWD and their primary carers through providing support and guidance services, day care activities and convivial places for socialising. The centres have been designed with a modern welcoming aesthetic to encourage a modern perspective in relation to Dementia care and support.

Within this thesis a discussion of the work of the Friday Opportunities Group at the Alzheimer Scotland Bridgeton Daycare and Resource Centre, Glasgow will occur. The resource centre is based upon the same range of new design led approaches applied by Alzheimer Scotland. The environment shares in Alzheimer Scotland's modern vision of daycare and support resources and in doing so, they facilitate and support a range of people who are living with Dementia. The groups who attend are at a variety of different points in their journeys and as such, particular groups are arranged throughout the week. Members of the Friday Opportunities Group are all under 65 and have a diagnosis of Dementia. In the Projects chapter, a large number of the successes achieved with this group will be shared. It should be noted that as Dementia is degenerative, the group involved in this study changed during the investigation and so working primarily within this setting allowed for much to occur.

During the background investigation and the initial workshops of this research, collaborations occurred with the Edinburgh, Mid and East Lothian Dementia Action Network Group (EMELDAN). Within the EMELDAN meeting structure, carers and people diagnosed with dementia come together to learn, participate, and get respite or social support. They gathered from a wide geographic area across the South East of Scotland every two months to discuss issues, raise concerns, participate in support, and to learn of advancements in Dementia research. The group tended to undertake both shared discussion and activities (or split activities and discussions, i.e. carers together and PLWD together) in a programmed 3-4hr session. Lunch forms an additional and important opportunity for conversation and interaction. The network always meets in Edinburgh but has been located in numerous environments over the duration of this work.

Here, the physical setting of the group plays less of a role and the structure of the day and events are more important. The group discusses everything from research in the field, opportunities for inputting into research and influencing local policy through to activities for collaboration and discussion. The group of carers and PLWD, (through the meeting), is supplied with a platform to influence and inform dementia support services and society. During the investigation into this body of work, permissions were granted to take part in the meetings and to be integrated in the same way as any other regular participant. After some time, invitations were then received to undertake some project work with the group. The EMELDAN allowed this PhD's early research workshops a

platform for progression, where the activities were largely adopted and then driven by PLWD and their carers (discussed in Chapter 5).

## 2.8 Other Collaborating Groups

In order to keep the opportunities for this research open and to engage with a wider understanding of the dementia care landscape, other partner groups and networks were engaged. This was particularly important in an Edinburgh context as at the time of this investigation, Alzheimer Scotland did not have a 'Resource Centre' in the city. Based in the Morningside area of Edinburgh, an affluent suburb that is aiming to gain recognition as being 'Dementia Friendly', The Open Door Café and The Eric Liddell Centre have supported initial investigations whilst facilitating participation in group activities of reminiscence, creativity, gameplay and social interaction (lunch clubs).

The Open Door is a care support system where friends and family are encouraged to work alongside carers in creative activities with PLWD. Based in a converted shop in Edinburgh's Morningside, the Open Door supports a variety of Dementia groups. Visits to this service involved observation of people who were predominantly in a moderate stage of their dementia journey. The visits to the group occurred on Saturday mornings over a couple of months and allowed for deeper understanding of how the group was entertained and engaged with. The experience allowed for integration and participation with the group where participation and support within the activities was encouraged if not somewhat expected<sup>9</sup>.

This kind of creative task gave insight as to what people who are a little later in their Dementia journey are capable of and reiterated the importance of peer-to-peer interaction and also of interaction with people who were facilitating. Through such visits and observations, personal inferences and preconceptions were challenged but also encouraged a rethinking of much of the written discussion that had appeared to err towards a discussion of incapability.

At the Eric Liddell Centre, people with a diagnosis of Dementia are collected by bus and brought into a caring environment for PLWD. Carers provide activities and pastimes inside the building that are embedded in reminiscence and the approaches observed included quizzes, music and singing,

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<sup>9</sup> Discussion of a sample 'Open Door Activities' can be read in Appendix 4.2

and film. The Eric Liddell Centre is a community hub and embodies a Dementia day care centre with its own existing network that spans generations. The environment is a modern conversion of a historic church that houses meeting spaces, care environments, activity halls, offices and a coffee shop. Though open to the public, the environment is particularly structured, controlled and secure with anybody using the facilities met at the open reception and asked to sign in.

In higher levels of the building, a Dementia Day Care service is provided that changes throughout the week. On a Friday, the group offers a lunch service for both attendees and their families or volunteers. On other days of the week, PLWD are largely picked up and bussed into the centre to undertake a few hours of activities that are broken up by a supplied lunch. In part of the research and development of this project, six visits were conducted to observe and to participate in activities. The group, most of whom were largely in the moderate stages of their Dementia journey, would play games and undertake activities that were deeply rooted in historical culture and shared reminiscence.

The Alzheimer Scotland Bridgeton Daycare and Resource Centre in Glasgow became key collaborators in the Co-design work that forms the basis of this research. The group members are all under 65 and have Early Onset Dementia. They are each in a place on their individual journeys that covers early to moderate dementia. They are more active people and are generally earlier in their journey than those who attend the Eric Liddell Centre and the Open Door's more traditional *in situ* care platform. The group actively engages with the wider environment of Glasgow undertaking regular excursions to places of interest and importance. Weekly, the group's participants are facilitated in gathering in an organised space for social interaction and to undertake arts and crafts, reminiscence and relaxed games or social activities. Importantly, the Bridgeton group, on the last Friday of each month, goes out to galleries, museums, public parks, local cafes and on some occasions, walking tours. These local cultural activities are often supported by site-specific Dementia friendly support teams, who help to explain parts of collections and who create activities relating to what the group might see during its visit.

## 2.9 Project Direction

Dementia is a multi-layered concern of our time. The prevalence of the range of conditions that are located under the umbrella term, Dementia, is ever increasing and living with the condition through diagnosis or as a family member, friend, carer, volunteer or professional care giver, requires greater knowledge and understanding of the impact of the condition. The situation is one experienced in many ways by a significant portion of the Scottish and UK populations creating the largest health concern at this moment. Wellbeing and the integrated empowered lived experiences of everybody connected through Dementia is of great significance and will be significant in combatting associated ill-health.

Governments require local input and direction on how to cope with the situation and responses, both national and international, are required to unite and support PLWD. Practices are changing and the importance of designed interventions, local communities and support networks is key in ensuring that lived experiences are fruitful, valued and safe.

This work will offer no route to a cure and cannot hope to change the biological situation. However, through design, it will look at how we all can live better with Dementia through connected and empowered positions. The following body of work explores the creative capabilities and challenges ingrained thinking within the generation of designs by PLWD. It challenges public perceptions through co-design actions where PLWD set agendas, drive project directions and reflect on design decisions. By highlighting capabilities, the work hopes to challenge stigma and social conventions that lead to negative treatment of PLWD. It will question how useful we see people after diagnosis and will pose routes for their creativity to bring practical, aesthetic and social value through design solutions. To interrogate this position, this work will build upon design research methods and design actions the outcomes of which will be explained to their fullest extent.

Co-Design and shared experiences will explore:

*How can design empower PLWD to transform local communities?*

Building upon a designers' diverse skillset to develop objects, tools, systems and services, that generate insightful and valued means of intervening, which move beyond normative approaches.

As the Heaths (2011; p.4) put it, government and service providers recognise that "*For anything to change, someone has to act differently.*" This work is focussed upon a belief that design is well organised and well placed to intervene in complex situations and to be challenged to devise appropriate solutions to Rittel and Webber's 'wicked problems' (1973) which they framed as consisting of the following attributes:

1. *There is no definitive formula for a wicked problem.*
2. *Wicked problems have no stopping rule, as in, there's no way to know your solution is final.*
3. *Solutions to wicked problems are not true-or-false; they can only be good-or-bad.*
4. *There is no immediate test of a solution to a wicked problem.*
5. *Every solution to a wicked problem is a "one-shot operation"; because there is no opportunity to learn by trial-and-error, every attempt counts significantly.*
6. *Wicked problems do not have a set number of potential solutions.*
7. *Every wicked problem is essentially unique.*
8. *Every wicked problem can be considered a symptom of another problem.*
9. *There is always more than one explanation for a wicked problem because the explanations vary greatly depending on the individual perspective.*
10. *Planners/designers have no right to be wrong and must be fully responsible for their actions.*

(Rittel and Webber, 1973; p.161-166)

The work that follows in this thesis builds upon the understanding of the 'wicked problem' and defines Dementia as such. The perspective of which is precisely articulated by Chamberlain and Craig:

*"An ageing population, a rise in the number of people with long-term conditions, reduced government funding and growing expectations from an increasingly informed population present huge global challenges for our future health care..."*

*A reductionist view of health that focuses on illness and treatment is being replaced by one where the emphasis is placed on ways of maintaining wellbeing and equipping individuals with the knowledge and tools to live well. Where individuals are diagnosed with long-term conditions, models of health increasingly focus on self-management. This shift in where and how services are delivered suddenly opens up new problems as well as*

*possibilities. We can draw on a tradition of creative and divergent thinking to address these fundamental and yet practical challenges to our societies' health. These challenges are by definition 'wicked problems', ones where there is no single true answer, where no one profession holds all the answers but where design's strength lies in creatively responding to these complex interdependencies."*

(Chamberlain and Craig, 2017; p.4)

With a recognition of greater expectation of society to solve its own problems, or to at least cater for complex requirements in a blended manner, the emphasis has developed to situate an individual and/or their loved ones towards becoming more active in problem solving. The approach has become focussed on empowering people to accept and respond to their own situations where they will develop their own personal values and to strengthen self-belief in what they can achieve.

This has been forced by the constraints placed upon them and as such, is not necessarily engaging with people in a way that they appreciate. With this in mind, the approaches required may also need for mindsets to be altered and optimism in face of adversity to become reinforcing and believable. Within this research, the work will not overcome the huge problems that converge with a diagnosis of Dementia.

Instead, the research agenda and outcomes of this work are developed through a proposition that, if achievements are considered as a measure for a valued life, then, giving people the resources to generate their own successes and to develop new forms of resilience in a given process might be key. As such, this indicates how design as a process can provide successful methods for intervention in the 'wicked problem' of Dementia care. Why and how design as a subject is well situated to act within the field of Dementia is discussed more thoroughly in the next chapter. However, within this entire thesis, Co-design methods and their application will be explored to impress the value in supplementing capabilities of PLWD. The processes will express how collaborative creative practices and the design process can develop camaraderie. Furthermore, the design agenda will express how projects that encourage working with PLWD can develop personal achievements and nurture resilience. These positions are strongly influenced by the assertions of Rodgers (2017) and Craig (2017) where design should be empowered to act differently within the field and to disconnect from historic design services provision, i.e., products, environments and

services shaped by the medical profession. This position instead develops an existing idea of enabling PLWD to act and shape what they require. The participants within this study are thus encouraged to 'think' about their own and collective prowess in shaping their environments, support systems, choice making and communities to live well with their Dementia. It is posed that design and in particular co-design is an important tool to achieve this goal as Milton Glaser explains:

*"The important thing that Art and Design does is help others and [to] build communities"*

(Milton Glaser, 2016)

This help might be best achieved through collaboration with the people at the centre of the problem. More than this, their involvement might help to change the communities in which they live.

## 2.10 Chapter Summary

In this chapter, a background to the context of this PhD thesis has been set. It included what Dementia is, what the experience of living with Dementia entails for the individual, friends and family, and sets out initiatives that are changing perspectives or providing support. The discussion covers society and the need for broad thinking and introduces the need for multifaceted care models to be considered. The following chapter provides '*Literature Review*' which expands on much of these themes and looks at how design methods are being applied to deal with the situation in an increasingly integrated and multi-faceted care provision. In consideration of these points, Co-design will be discussed in terms of its potential to engage and empower PLWD and a review of the extent to which it is doing so will be provided. This work targets considering design as a method for producing a different form of care activity and does so through the Co-design approach. The next chapter looks at existing Co-design approaches in the field and identifies opportunities that this work can further develop in order to tackle the wicked problem of Dementia.

## Chapter 3: Literature Review

The literature reviewed in preparation of this research covers a wide and varied set of influences. It charts the proposition of design as a subject for intervening in 'Wicked Problems' (outlined in the previous chapter) aligned with the increasing acceptance and indeed desirability for designers to get involved in complex societal and healthcare problems. The review explains the national expectation of design to intervene in dementia care, support and tools for living before investigating what design does differently in involving people within change-based scenarios. Considering, playful, disruptive and reframing approaches to complex problems and deriving suitable responses, the work puts together various themes of what design does before exploring the value of the mixed and inventive creatively-experimental methodology that constitutes a meaningful co-design approach. Focussing upon relevant contemporary design research in dementia co-design methods and techniques are further reviewed in order to develop an understanding of how the approach is used, the contexts in which studies are set and the depth to which collaborations occur. Finally, the discussion engages with the need for designers to understand interrelated aspects of personhood, capabilities and empowerment and in particular how these are being utilised to develop care concepts in design for dementia. Particular consideration is given to mental health and wellbeing and constitutes a framework that engages attention to individuals in creative research practice whilst reinforcing personal identities for people living with dementia.

### 3.1 Design and Dementia

The first ever National Dementia Strategy published in 2009 (Department of Health, date) set out an agenda to change the conversation about dementia and dementia support laying the foundations for David Cameron's, 'Prime Minister's Challenge on Dementia 2020' (Department of Health, 2012). The purpose of these works was to refocus the activities of all parties involved with dealing with dementia and to drive the understanding, discussion and research in new ways. The Prime Minister's challenge particularly acted as a call to action to find new ways of thinking about and reacting to the problem of Dementia and proposing the requirement for new routes for participation and collaboration in tackling the issue. Both devices helped to enforce the need for

change and were significantly funded or offering funding to do so. As a result of these "landmark" governmental initiatives; disparate parties, organisations and individuals arranged themselves in order to find collaborative opportunities to affect change. Starting new conversations that echo the idea that "Most advances in 20th century science came from creative conversations that blended ideas" (Leadbeater, 2008: p. 93). It was hoped that alternative solutions would emerge to many of the massive problems faced by society. The complex nature of dementia has, therefore, stimulated approaches which challenge convention and that support actions in terms of resources and systems, all the while, broadening the conversation about what is to be considered, understood, appreciated and responded to. In its evolution and wider appreciation, design has become a regular framework by which to undertake research and practices that "...routinely traverse, transcend and transfigure conventional disciplinary, conceptual, theoretical, methodological, and cultural boundaries" (Rodgers *et al.*, 2013: p. 455). In extension of this understanding, Cross' view (2011: p.136) that "Design intelligence involves an intense, reflective interaction, with representations of problems and solutions and an ability to shift easily and rapidly between doing and thinking" centrally locates design's potential and importance to shape responses and to pose new ways of doing things. Redstrom (2017: p. 2) expands this discussion of design's prowess to intervene when he states "...design's capacity to deal with complexity and conflicting concerns is perhaps its most fascinating feature". Muratovski (2016: p. 228) continues, that "Society today demands a new generation of designers who can... design systems for living" which requires, "becoming strategic planners and professional thinkers who can work across disciplines". Through changing initiatives in the design field, much broader interpretations of how and when designers get involved with such massive problems has occurred. Framed under many terms, one of which is 'social design', the desire to be in the middle of initiatives that engage with communities is high on the agenda (Shea, 2012; Shaughnessy, 2013; Fleischmann, 2013). The RSA (Royal Society of the Arts) and the Design Council have been working with communities, agencies, carers, charities, design researchers and those living with dementia to develop alternative ways of addressing their complex needs. Here, "...social innovation [that] demonstrates design's potential to confront a truly global problem and change real lives for the better." (Design Council, 2012: p. 2) is seen as a call to action. In 'Connected Communities', the RSA's Paul Buddery (2016, p.7) extols the intention for society to take greater responsibility for the delivery of tools and services which proposes that "a

sense of local identity, belonging and connectedness are crucial to subjective wellbeing, life chances, collective inventiveness and resilience".

The challenge for designers acting in this dementia environment is concerned with many overlapping and interlinking relationships and concerns diverse parties some of whom require significant specialist input or understanding. Herein lies the opportunity to change things and to uncover and nurture valuable collaborative approaches as Wenger, McDermott and Snyder (1998: p. 153) pose "...where the core of a practice is a locus of expertise, radically new insights and developments often arise at the boundaries between communities. There is increasing need to cross boundaries because today's complex problems frequently require solutions that are not confined to any one practice". For example, services and support structures, communities, societal infrastructure, the NHS and hospitals, clinical specialists, social workers and other governmental organisations, local councils, transport providers, retailers and financial industries, care centres, private and public care providers, families and friends along with people living with dementia represent a never-ending list of people and organisations with a direct involvement when somebody is diagnosed with dementia. Their interfacing and relationships along with particular specialist knowledge require recognition and evaluation for each individual and as such cross or inter-disciplinary research is likely to learn from a broad range of opinion, in order to devise solutions. As Chamberlain and Craig (2017: p. 4) state, the relationship "...across and within design and health is nuanced" and understanding of the complexities is required to shape solutions but also to allow parties to act democratically in finding resolutions. In this kind of working, parity of participants should place value on the diverse qualities that stakeholders can provide. For the UK, these diverse stakeholders who are converging to develop design focussed health-based solutions mark significant shifts in relationships between designers and governmental structures, such as the NHS. The shift in the last two-decades has resulted in design being recognised as providing frameworks which are responsive and that facilitate change which is fixed on human experience and need, and therefore has the potential to support specialists but also to transform thinking and approaches. Understanding people, the requirements of service providers, methods of communication, existing obstacles and by melding professional perspectives that will add value to new interventions can lead to coordinated responsive solutions (Figure 3.1).

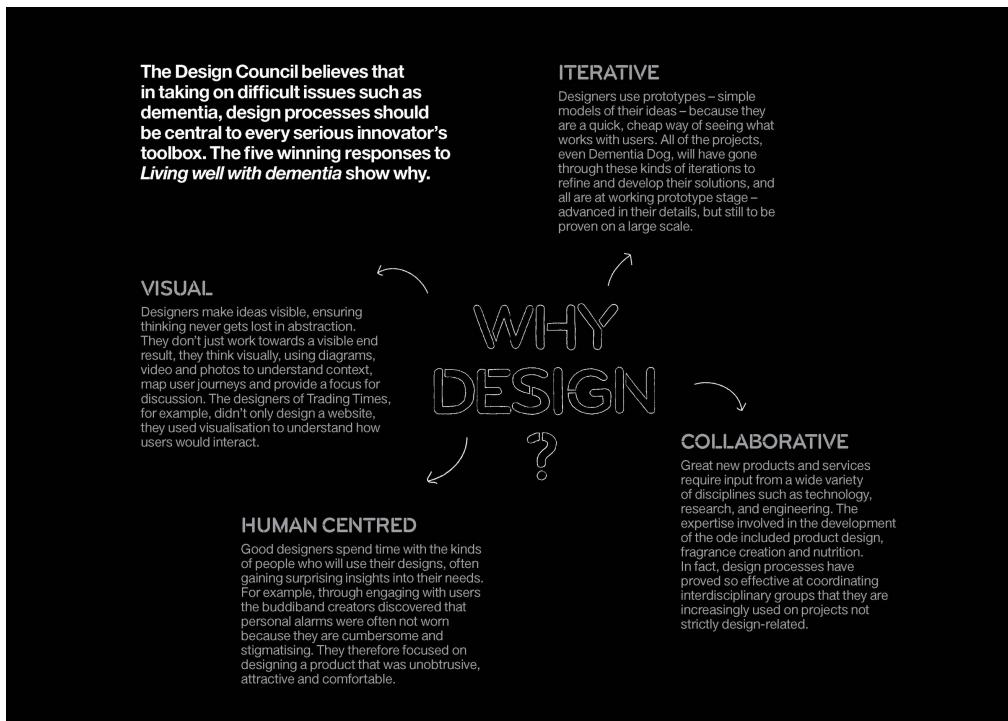


Figure 3.1. Design Council. (2012) Living Well with Dementia reasoning as to why design is suitable for working within the field.

Historically, at best, designers worked within healthcare in the UK in strict disciplinary led approaches to deliver tools and environments, communications and other products for the NHS (Tsekleves and Cooper, 2017; Chamberlain and Craig, 2017). However, the shifts continuing to occur through government policy and involving prised innovation in healthcare has resulted in the evolution of relationships, problem solving practices and interventions which have supported greater interdisciplinarity diversification. Designers are increasingly valued within complicated discussions and are seen to facilitate change. The apparently greater acceptance of design by other disciplines like health and social care means that objects and equipment, spaces of medical practice and tools for the support of patient recovery are no longer the crux of design engagement. Instead, wider considerations of health and wellbeing in alignment with a systemic healthcare switch, which now looks at the health of the population and the factors that shape health and wellbeing, have become central topics for collaboration. This, in part, is because design as a subject is so intrinsically linked with exploring the human lived experience. A situation Tsekleves and Cooper (2017) align to the evolution of design into areas of service design, systems thinking and greater engagement within design research around behavioural theories based within psychology, social and personal change through sociological understanding along with greater political

awareness. With this recognition of diversification in interests, new factors and pressures engaged through policy, along with more confluent influences and technologies there has been a shift in a sense of responsibilities and expectations. All of which has encouraged the generation of multi-faceted ventures for impact and change where design as a subject and designers as practitioners are equal to any other represented body. As such, new project ownership, in terms of taking up the challenges that are being revealed are inviting 'design intervention' as part of a blended, more holistic system of care and support.

In the best cases, the result of design intervening in the wicked problem of dementia supports the application of 'design thinking' (Rowe, 1987; Kelley and Littman, 2001; Brown, 2009) led propositions where new ways to affect personal, service and societal change are being formed. Recognised widely from business schools to emergent practices in re-shaping healthcare 'design thinking' is used to explain the designer's approach to questions and developing unexpected answers that are suitably adapted to make sense of the interlinking issues within a certain context. The process encourages many points of influence to merge and in most cases, leads to unexpected results which would not have been forecast. In order to generate leads and connections of knowledge, designer's like to work 'with' people being enlightened by them or through implanting themselves within alien situations, where they might locate the details that inform new methods, interventions, systems or products. However, as Craig identifies:

*"What we see commonly is an over emphasis on tracking, monitoring and brain training. On products that rather than de-stigmatizing dementia serve to reinforce some of the stereotypes that exist and that over-emphasise/ risk and risk culture."*

(Craig, 2017: p. 62)

What can be gauged from this perspective is that greater deployment of design approaches during different stages of a dementia journey which have a focus on people instead of how to apply technology is required (Chamberlain and Craig, 2017). A continuation of which is a need to recognise that the diverse nature of design, the tactical use of methods, merging of knowledge and convergent applied thinking provide the basis of tools for people to be empowered to make their own changes. Dementia provides a setting in which this 'design thinking' can produce highly

meaningful and impactful solutions. Design Thinking is meant to charge designers with using tools that support the input and buy-in of the people they aim to help and can lead to results which have been shaped by the people they are meant for. With this kind of recognised practice, the RSA's 'People Shaped Localism' proposes that society solve its own problems with the aid of designer-led innovation, where the onus is placed upon citizens to manifest new ways of looking at long term problems. As such, Taylor proposes "...local social movements as drivers of better health outcomes" (Buddery, 2016; p.6). Herein, supported individuals and collectives take upon themselves the opportunity to find solutions. This local focus suggests that local citizens know how best to engage with other local people or within communities of shared interests or needs. Therefore, citizens and communities need support that creates access to resource operators, system organisers and solution developers. By doing so, these citizens and communities can direct the services and tools they require, leading them to achieve personal empowerment and to make locally achievable improvements. This, however, requires the support of people who can connect with organisations, specialists and local amenities, support networks and government agencies who can understand the complicated environments and designers who can imagine reshaping them, who are used to navigating such environments and who can communicate with large audiences. A common consensus is that designers are likely to provide such complex skill sets and can develop tools to enable communities to engage and support all of its members. In dementia support and other major health concerns, the challenge is, therefore, locally empowering people to identify and fix the problems that cannot be overcome by an outdated, massive and cumbersome social care system. Nigel Cross who has widely championed the designer's ability to tackle massive complex problems states his reasoning for this belief is that:

*"Rather than solving merely 'the problem as given' they apply their intelligence to the wider context and suggest imaginative, apposite solutions that resolve conflicts and uncertainties"*

(Cross, 2011: p.136)

As Cross (2011) suggests, design is a human activity derived to respond to human behaviours and requirements and for making novel and informed solutions. As such designers are well-placed for working in challenging areas, such as supporting people living with dementia. It is here that the designer's ingenuity for producing integrated systems, for making things and for intervening in the

hope of improving the status quo is increasingly being incorporated into care planning and delivery (Muratovski, 2016). As has been stated, this may take the form of service or product designs, systems, environments, and technologies or through collaborating with those they mean to help. Nieusma (2004) suggests, this is founded in the belief that designers have skills, tools, knowledge and practical ways of working that are well suited to challenging the norms, confronting dominant practices and supporting the empowerment of marginalised social groups. Or as Dorst (2019:p 144) more precisely articulates, that when designers venture into new fields there is capacity to "...reframe the task of design as system transformation, rather than the creation of solution". Peter Lunenfeld (2003) originally pressed for more than this, with the view that designers have prowess to be made use of and to build new thinking around, when he states that designers can work within the "...interlocking systems that manifest, support, constrain and envelop products in order to move into the substance of a thing or situation and in doing so... lay claim to a much farther-reaching contribution" (Lunenfeld, 2003: p. 11). In 'What Designers Know' (Lawson, 2004), it is argued that designers find methods or solutions that may not be linear in their comprehension and analysis and therefore synthesis leads to unexpected and yet appropriate solutions. Part of this reasoning is the holistic nature of their creative activity and the constituent influences or frames of reference, but also through the view that as designers investigate and interrogate a situation, the real issues tend to emerge. Through the diversity of influences and the convergence of stimuli explained within a 'design thinking' model, that imbues the application of creative adaptive design research methods, it is common that the "...problem and solution emerge together" (Lawson, 2004: p 13). Meaning that which was originally ill-defined only comes into clarity through the design research occurring (Frayling, 2015). As Frayling reasons, such a view bolsters the need for change of common and historic views that design is for making things look good after the research has been done. Frayling instead postulates that the future of good research should incorporate design at its very inception and project definition. This in the long term, makes design as a research and transformational approach integral and inseparable from a project.

In social design, this process is rarely likely to find a definitive solution but a more unified proposition to resolve certain aspects of an ongoing and evolving situation. Lawson (2004: p. 13) argued "...each designer or design team is likely to end up solving a different range of problems" - this is not problematic, in itself, as it allows for iterative and evolutionary appropriate designed interventions to

develop. From the application of solutions or creation of artefacts and the ability to understand them in the field, design researchers are able to evidence and respond to designs in action and in doing so, communicate with and encourage other parties to be involved and to make their 'impact' on the situation at hand. In this understanding of design as a tool for boundary crossing exploration and action, it is therefore recognisable that "...design is expanding its disciplinary, conceptual, theoretical, and methodological frameworks to encompass ever-wider disciplines, activities and practice" (Rodgers, et al. 2013: p. 454) where it is impacting new territories and solving previously undefined problems. Furthermore, it is supporting people to rethink the problems they are confronted with and encouraging a wider adoption of creative and explorative design-led actions or 'design thinking' by all parties concerned; reinforcing their rights to think differently around the problems at hand.

*"Problem solving. It involves a number of things. First the solver (designer) recognizes a state of affairs that needs improving and a target state of affairs that would represent the improvement. Next for this to be a serious problem worthy of our study, we assume that it is not readily apparent how the solver (designer) can get from the unsatisfactory state to the improved state."*

(Lawson, 2004: p. 19)

In our current time, there are fewer more pressing social and health problems than those generated by the various forms of dementia, it is for this reason that wide ranging approaches to addressing and overcoming the challenges involved are being sought, proposed, tested and implemented. It is because of this societal problem, the massiveness of it, the cost of care and support, and the need for human focussed intervention that designers are increasingly involving themselves in different ways. Commonly, these may not result in huge problem-solving scenarios but possibly more importantly, take the form of social, immediate, experiential and intimate interventions. Here, the designer's skill to relate to people requires their intentions and actions to be compassionate, to be understanding and to behave empathically. Of utmost importance, becomes the designer's ability to work *with* the people they hope to help and to do so must be able to relate with their collaborators whilst unearthing their needs. Often framed within the context of 'empathy', it is argued that designers often act in two ways to achieve understanding 'with' and 'for' those they are trying to work with and for these, form 'emotional empathy' and 'cognitive empathy' where the idea is that we either mirror and feel the lived experiences of other people or that we can understand

their situation and make personal judgements and assumptions that care about those people (Gasparini, 2015). The softer social skills required to work in such a way form part of the designer's toolkit which is not focussed upon the traditional considerations of commerce driven industrial design. The empathic skillset is rooted in the idea of the designer's ever questioning mind-set. In this view, it is important for designers to understand the minutiae of a subject so that they may develop appropriate responses and actions which are framed by emotionally and cognitively informed empathic positions. Empathy has its issues, not least of all, that nobody can truly experience or feel another person's lived experience, their contexts and circumstances, what it is to live that person's life or what it is really like to have their condition (Coxon, 2015). However, to act with compassion and to make as best a job as possible of engaging in a positive manner. Here, empathic design at least centralises the socially and emotionally significant needs and desires that exist within lived experiences, providing greater scope towards conducting design 'for'. This requires designers to accept a position of weakness of not knowing and not being able to know, but be empowered by the desire to learn more, to think about what these things mean and do and to think with feeling around complex and difficult problems. As Svabo and Shanks (2015: p. 29) explain, the designing 'for' experience incorporates "*Sense, emotion and cognition [that] are intertwined*" and as such are complex "...*shifting entanglements and engagements*". Therefore, designers have to be able to navigate complex scenarios with feeling making sense of them in order to act effectively. Jorge Perales (2019) suggests that within this approach designers are equipped to "...*identify opportunities, reveal underlying needs, and understand user context*" to shape resources, products and solutions and to significantly help stakeholders make better decisions. This is because designers in training and practice utilise soft skills that incorporate 'conscientiousness', 'initiative', 'social skills', 'controllability' and 'commitment' (Ling et al., 2008) to the problem, cause and identification of solutions whilst working towards, intervening in, or changing the ongoing situation. Although Lauche (2007) argues that designers require greater understanding of the importance of, and training in, these skills, she suggests that they are inherent in the designer's makeup and are performed intuitively throughout projects. In part, this is a result in the variety of propositions, opportunities and problems that designers explore. When designers work within a social design context, practices 'for' and 'with' people, they will lean on these soft skills to unearth new insight, knowledge and understanding.

As a neurological condition, the problem of dementia requires investigation into mind, memory and identity and what that encompasses for an individual person. As part of the process, designers have to utilise their extant skills in working with people to understand and respond to needs, wants, wishes and desires to see opportunities and to identify places for action. In this approach, they bring to the fore, in any intended intervention or activity, personal values, empowerment and personal esteem and in doing so, support positive lived experiences. When people rather than the problem are placed at the centre of the design intention or investigation, then the methods in which designers act are very different; the business of design; economics, styling, materials, construction, packaging, distribution and application of supporting systems are put aside for the value of the lived experience (Benz, 2015). Being compassionate in their actions, designers can build upon "*micro-moments of positivity resonance*" within experience-based scenarios to "*knit you in a little tighter to your community, your network of relationships*" (Freidricksen, 2017 p.30). In relation to this PhD, mental health and wellbeing, personal identity and capabilities, individual and collective empowerment and social interaction are key to the process (Charter of Rights for People Living with Dementia and their Carers in Scotland, 2009). Within this 'wicked problem' (Resnick, 2016), the uncontrollable unpredictability of the effects of dementia and the equally unpredictable timeframe of each person's journey makes each individual act or intervention important in their lived experience. Designers working closely with people living with dementia need to use their skills to act in an appropriate and timely manner to make a positive difference.

*"...at its best, design can change, improve, renew, inspire, involve, disrupt and help solve the "wicked" problems of this world".*

(Resnick, 2016: p.12)

As designers look to act and move within the social design context, they are required to engage with people, groups and communities altering their understanding and becoming a valued part of something new to them. Within this approach to problems or situations that have never been owned by the design field, such as health or social care, invitations and permissions have to be received and granted in which, trusts must be developed and respect achieved. As Benson (2016: p.270-72) explains, "*building a relationship through listening to a community should help... Showing dedication to, empathy for, and genuine interest in their concerns lays the foundation of trust that eventually enables the designer to sew him- or herself into the fabric of the community*". Designers

have to be wary to what extent that they really can become emic in a particular field of investigation as they do not live within the conditions experienced by the subjects or participants. However, an empathic understanding and trusted position in which to nurture relationships is key.

Design is a specialism developed around investigation and research producing informed intervention where designers have developed specialist expertise and knowledge in the arrangement of responses which manifest in tools, objects, systems, events and entertainments. As a specialist subject that crosses boundaries, design employs complex systems of tools arranged differently for each investigation in order to gain insight and to interrupt the prescribed order of doing things (Rodgers and Tennant, 2014). As Jenny (2012: p.13) puts it "...breaking rules and trying unexpected things are part of the creative process. Allowing yourself to see things differently is essential for experiencing the greatest number of ways of perceiving". As such, design as a specialism is an interrogative and responsive approach that brings ways of seeing and doing that are not naturally revealed or responded to by those operating within different fields. In regards to this research, the different field is health and social care. Naylor and Ball (2005; p.26) explain that "...the work that emerges from this 'finding and responding' process is playful and serious, rhetorical and optimistic, valuing, embracing and reinterpreting the positive attributes". Play as highlighted by Naylor and Ball is a key learning process that strongly develops the mind of a child and adults alike. A rich resource, play is increasingly used to challenge the norms; creating platforms, which are accessible and thought-provoking (Norman, 2005). Bernie DeKovens (2013) extends this understanding by reminding us that play is a contemporary tool often used to fuel collaborative practices which he terms "CoLiberation" where playful practices influence creative practices and vice versa through the sense that they also both shape participants and practice. Sedghipour (2016, p38) elaborates this view by stating "without play, it is very difficult to sustain a collaborative relationship, even if all parties involved do have that intention". As the mind diminishes, it is considered that play, or at least a playful spirit, continues to be of value, disrupting patterns of normality and changing our relationship with the world around us (van Leeuwen and Westwood, 2008). Play stimulates the brain and "...encourages childlike engagement" (Bullivant, 2007: p.73) but play is not merely about the idea of games. Rather, it is a spirit of exploration, risk-taking, disruption and inventiveness in a manner that is freed from normal constraints or expectations. Indeed, van Leeuwen and Westwood (2008: p. 156) extol the virtues of play as

concerning "...motor and cognitive action including processes of attention, activation, emotional responses, intrinsic motivation and control" and that play can have an important role for "maintenance of identity and self". Play in a design context is sensory allowing for stimulation beyond the visual field that so often fills our relationship with the world. As such, it can stimulate memory, offer new connections that build in to personal virtual places and experiences, encourage pattern making and personal disruption of thought in order to achieve tasks, or goals and to generate new outcomes. In community practice, play builds relationships and affords creativity to exist. Play in design also allows us to think about spaces and places of interaction or playful acts and as such, creates opportunities for intervention and action (Treadaway, Kenning and Coleman, 2014). Play in this sense may be about the methods in which people engage with anything that they would not normally do, developing connections and understanding. Most importantly, this playful spirit holds no criticism, preconceptions or judgement; it is open, accepting and most of all enjoyable:

*"Joy for instance, creates the urge to play, interest creates the urge to explore... Play for instance, builds physical, socioemotional, and intellectual skills, and fuels brain development, Similarly, exploration increases knowledge and psychological complexity."*

(Norman, 2005: p.103-104)

Nigel Whiteley (1993) suggests in 'Design for Society', that the creative process of design and design research has a particular place in challenging the norms of environments in which designers do not naturally engage but more than just environments this intervention needs to engage the lived experiences; intervening and disrupting the accepted position of people living with complex conditions and as such, being inventive or playful in its application. The activity of collaboratively designing with people who are not designers themselves, seeks to challenge and alter preconceived ideas or restrictive thought processes. This playful and open spirit of design-led investigation incorporates methods for active research generation and gathering, leading to interpretation, all undertaken by ordinary people. These ordinary people, therefore act with a fundamental underpinning that they are central to the process and have agency, meaning they are empowered with the right to investigate, to ask questions, to draw conclusions, to make decisions

and to creatively direct responses to their own or collective postulations. Importantly, within a play narrative, these outcomes should be derived from an intrinsically fun and enjoyable experience.

### 3.2 Co-design a Means for Participative Collaboration

Co-design might well be described as originating in tasks of playful creation (Scrivener, 2005). Facilitated by a designer but in collaboration with somebody or some-group of people who are not a designer by training, new methods are regularly engaged. Co-design can break down barriers and open-up opportunities. Essentially the approach is involved in a process closely linked to or akin to '*participatory design methods*' (Ireland, 2003) where users help to inform the intended products, systems, tools, device, solution or services they are intended to use. However, in a co-design scenario the action of designing should be shared. Key to the approach is that outcomes are generated with a 'non-designer'; the general public, people with shared interests and/or commonalities local communities or individuals who are truly invested in the approach. In terms of the non-designers, access to latent skills and knowledge (Kelley and Kelley, 2015), understanding or capabilities is often revealed through task-oriented processes that are part of design practice. These allow for short bursts of considered creation where their concerns are not with the process but with responding to an opportunity. The methods involved in co-design have to be responsive and as such, inventive, which means that it is more often playfully experimental in its nature. Ideally in co-design, the actions of the designer and the people that they work with are inter-linked by collective responsibility and the desire to make an enjoyable difference. Therefore, co-design allows for personal investment generated by personal and collective empowerment where those involved enjoy the opportunity to intervene, to do things differently and to share in the collective momentum of change. Co-design is highly human centred, putting people at the core of thinking and practice through collaboration and as such, has an ethos of care. As Conradson (2011) identifies, care is central to change scenarios.

*"As an ideal, care invites us to recognize the lived experience of others as worthy of our attention. When these others are vulnerable, marginalized, or in need, care suggests that we respond in a way that is helpful and which perhaps facilitates positive change"*

(Conradson, 2011: p. 434)

Co-design has a long history and is rooted in the evolution of design; as a system of proposition, production and commercialism but also within the democratisation of ideas, products, systems and processes along with manifestos, theoretical positions and academic investigations that encompass the subject. As far back as 1946, the idea of "*qualitative focussed group-interviews*" (Merton, 1990: p. 22) were being used to generate market insights and directions for new explorations to emerge from, and "*taken as sources of new ideas and new hypotheses*". This collecting of insight through a qualitative means was seen as the predecessor of the more instantly understood and recognised design research methods of 'focus-groups' or 'user-groups' who are consulted to shape design research and to undertake prototype testing. The focussed approach was predicated on commonalities between participants in terms of specific experiences, particular situations or their having engaged with an artefact, of sorts, therefore framing the intent of the investigation. The outcome of which could include that an "*...array of reported responses to the situation helps test hypotheses and, to the extent that it includes unanticipated responses, gives rise to fresh hypotheses for more systematic and rigorous investigation*" (Merton, 1990: p. 3) - essentially asking people's opinions in order to generate informed hypothesis for new testing and study. These hypotheses, embedded in the act of the lived experiences of people, required real world intervention, response and action. Giving rise to the development of '*Participatory Design*' (Cruickshank, Coupe, and Hennessy, 2016; Sanders and Stappers, 2008), principles and practices in the 1960's and 70's where people were no longer observed, evaluated, categorised, analysed and understood in relation to a design investigation or scenario, but where they became central to, and imbedded in, the origination of proposals and solutions. Participatory Design was therefore the forerunner to any co-design proposition commonly used in design research today.

Building upon this position, co-design has been widely used in the commercial sector in order to differentiate products, capabilities, suitabilities and many other commodified enrichments of these products and services. However, more often, research-centric design discussions suggest an increasing uptake in and dependency on co-design or at the very least, the rhetoric of co-design is being used in the public sector and third sector actions, as a way of engaging citizens in design exploration (Lam et al, 2012). How 'co' these solutions or investigations may be, differs greatly and makes the subject difficult to grasp in terms of a common method of design exploration. The crux of co-design, in the current discussion, is that the approach provides opportunities for people-centred

activity that involves the people. The approach centres around to inform understanding, interpret information and propose solutions for their own betterment and for improvements in the scenarios or situations being explored. Arguably, historic co-design models of enquiry and participation have led to the formulation of a brief and to the largest extent, this is where the majority of the 'co' has existed, as seen in the two co-design process models below (Figure 3.2).

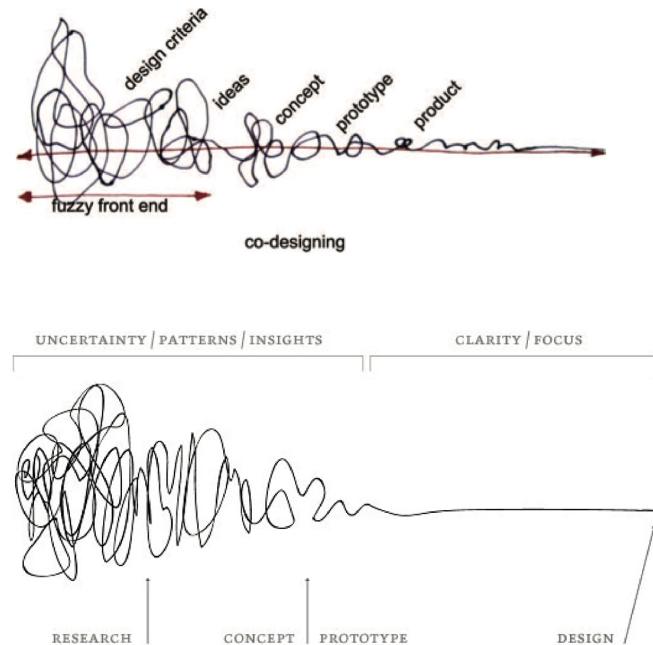


Figure 3.2 Front loaded models of Co-design

Evidence suggests that increasingly, co-design is involved with what is more akin to a 'change' model (Brown, 2009; Heath and Heath, 2011). Change scenarios develop the collective togetherness in approaching problems and situations through community-enabled and empowered outcomes. As Cruickshank et al (2016: p. 50) indicate, this kind of action generates a situation that empowers people through co-design to use their broad ranging "...experience and expertise to have a creative (not just informational) input into the design process". The work of Heath and Heath (2011) explores the nature of change scenarios and places collaboration as key to intention of invigorating people and communities to act in improving or altering a situation. However, this model is still predicated by the 'project driver' who more often than not is the expert or the most powerful individual. They are the force and the individual dedicated to ensuring action and are the force that brings people along with them cajoling them into action. The premise is that

there is a 'driver of change', a vehicle that has to be directed and a path to make that direction occur. In this model, the thinking is more commonly front-loaded by the instigator or driver resulting in community activity and actions that are loaded towards a point of completion.

Both the change and historic front-loaded co-design models reinforce a proposition that designers have special abilities in being attuned to seeing, understanding and engaging with subjects' lives. The two models make use of community or subject engagement but do not necessarily afford consistent, holistic and universal collaboration. Fixed within a historic model of the designer as expert doing stuff 'for' and 'to' subjects, only a modicum of 'with' is thrown in for good measure. Increasingly, the 'with' component of co-design is being championed and encouraged to be more complete and therefore compelling in results or outcomes.

Fleischmann (2013) argues, that a new form of this approach exists when co-creation and [co-] design thinking are utilised together, creating a co-design perspective that is inclusive and consistently engaging throughout the process. Such a method, indicates the prowess of collective endeavours where 'collective creativity' shapes complete solutions. Her argument is that these processes do not require deep knowledge of every aspect of a situation but a collected series of perspectives that, when using design approaches, can shape unexpected solutions.

*"Collaborations in co-creation and design thinking differ in the ways that they help create new solutions, not previously known, to respond to needs of the modern world. Co-creation and design thinking are an accessible way toward innovation, which unlocks the collective creativity of all involved in the process"*

(Fleischmann, 2013: p15)

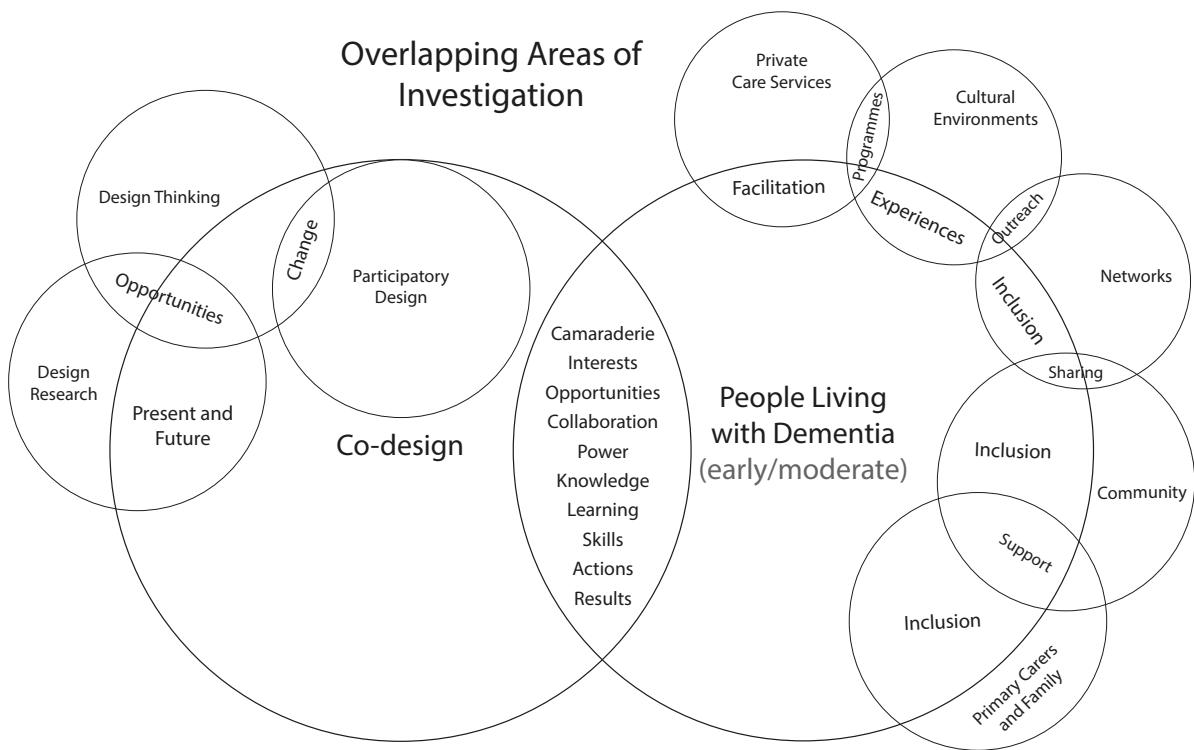


Figure 3.3 The overlapping areas of investigation concerned in this research representing pressures of influence converging through collaborations.

In this research, many overlapping factors will be explored and relationships between different contributing themes along with relationships between design research and practice approaches explored (Illustrated in Figure 3.3). Within this chapter, a review of Co-design, Co-creation, Design Thinking, Change and Participatory Design is undertaken. Built from the understanding it has developed, a new vision of co-design is being proposed to challenge how ownership of a project can be formed when working with PLWD. In this case, there is an attempt to change emphasis of the 'driver' (designer) in order to build upon Fleischmann's user-involved-creative-process. Therefore, this PhD understands that co-design has been an ever-evolving method which is increasingly engaging collaborators through continuous and creative practices, where origination of ideas and content is never clear. However, there is also substantial evidence that more historic models are still widely used and lauded.

This research aims to shape an approach to the problem of dementia where design-led relationships between invested parties develop continuing project interplays. This means that no one person is the owner of the process and the director of outcomes (Sanders and Stappers, 2014).

In this manner the project's collective of participants, through immersion, engagement and shared-responsibility, perform to develop outcomes where "...*insights may only be apparent or come about only during the creative process*" (Hansen, 2019: p. 175). In this model of co-design, the emphasis is calibrated by the term 'with' and is seen as a continuously interchanging relationship. As Hansen (2019: p.174) affirms "...*when explorative design processes are teamed with co-creation and user-involvement, we have an activity that is 'working with' rather than 'doing to*" which leads to shared ownership and value laden propositions.

For this PhD, the 'doing to' approach is eschewed in favour of a 'working with' approach in order to encourage collaborative, democratic co-design processes. The notion of 'doing to' or designing 'for' as an approach, is more conducive to separating the collaborators rather than bringing them together and is suggestive of a design expert-to-subject hierarchy. The 'working with' or 'with' approach adopted in this research suggests a greater need for the designer to have humility, to accept not knowing and that their expertise might not find the best outcome but that togetherness within the process, shared ownership and a sense of collective purpose can bear out more enriching solutions. Such an approach is necessary within an acceptance that some subjects are too complex and require many creative perspectives in order to orchestrate suitable solutions.

What follows is a review of the kinds of co-design driven projects and practices that populate the current design and dementia discourse. The analysis of this work has identified that there continues to be differing levels of co-design and that the use of the term is both confused and confusing. In an attempt to address this situation and to understand the different ways in which co-design occurs, a hierarchical pyramid has been produced (Figure 3.5) and will be discussed later in this chapter.

### **3.3 Design Research that is Synergistic with Emotional Health and Wellbeing**

This work situates personal wellbeing and empowerment as key concerns, and looks to understand the design process and the designer's position when they are engaged with health and social problems. In particular, it asks if co-designing as an experience and practice has validity in affecting change or impacting upon lived experiences, social interaction, identity, enjoyment and satisfaction for people engaged within co-design projects. Understanding that dementia is a degenerative cognitive problem, in order to underpin this investigation, considerable thought has been given to

how personal experiences, motivations, mindsets, moods, identities and cognition help to inform participation and engagement in collaborative practices. Within this context, the ideas of wellbeing and empowerment are central to creativity where emotional intelligence is likely to shape many of the decisions within the design process.

*“Emotions play a central role in the human ability to understand and learn about the world. Positive experiences kindle our curiosity, and negative ones protect us.”*

(www.interaction-design.org. 2018)

In health terms, we know that there has been a progressive political and social movement over the last decade that stresses the importance of individual and societal wellbeing and positive mental health (Parsfield et al., 2015). Personal happiness and emotional health are central to this focus of societal wellbeing, as is community activity and collective participation (Buddery, 2016). In regards to dementia, emotional wellbeing has been proposed as particularly important for both carers and people living with dementia (Marriot, 2011; Oliver, 2009) and is one of the aspects most impacted within everyday contexts (Thackara, 2007). Craig (2017) explains that without meaningful activities and engagements there is significant impact upon people living with dementia where “*they lose the skills to be able to continue to engage*” (Craig, 2017: p. 62). Craig continues to express that the result of this situation has “*psychological consequences*” which “*impact on mood, and the increasing social isolation*” where the “*symptoms of dementia are compounded*” (Craig, 2017: p. 62). Craig also explains that research with people living with dementia identifies that through “*community connectivity, individuals can maintain valued life roles and experience wellbeing*” (Craig, 2017: p. 62).

Within the lived experience of an individual’s dementia journey, “*emotional intelligence*” (Evans, 2001) appears to be of particular importance. The suggestion being that ‘*emotional intelligence*’, which is best described as the core way in which we relate to and respond to everybody, every situation and everything in the world around us, is one of the last parts of our identity to fade or falter (James, 2008). Why the human emotional facilities are so important lies in where and when they develop and in particular, how they form a person’s identity. Emotional responses represent the earliest set of cognitive tools that we develop for negotiating the world around us, likes and dislikes,

happiness and fear, comfort and discomfort processing occurs in this development and as such become central to the creation of individual identities (Greenfield, 2011). Emotional responses and frameworks are stored in those parts of the brain, the hippocampus and the amygdala, that tend to be last affected by dementia and as such, are where the essence of a person's identity exists for the longest possible time. The *emotional intelligence* that shapes identity reinforces what is important or what is powerful to an individual. The creation of memories is richly reinforced by this emotional conditioning and the memories created become a combination of people and events stored in the Hippocampus<sup>1</sup> but also, how we feel about those things, which is recorded elsewhere, in the Amygdala<sup>2</sup>. It is suggested that we store recollections of what is being remembered in a form of record which is imbued with an emotional tagging of how it made us feel (Evans, 2001, James, 2008). Kahneman (2012) poses that our emotional sophistication underpins much of our decision making and when doubt exists, the emotional response to a situation, opportunity or outcome will overcome (the prefrontal cortex) the analytical, rational brain gains agency. We are therefore individually programmed through our unique lived experiences and connections to make decisions that are influenced by, and responded to, through our emotional being. In Emotional Design (2005), Don Norman explains that designers need to understand that there is a deeply human trait that moves beyond rational appreciation of function or a designed intention and that how we respond to a design is also imbued with this *emotional intelligence*. In his examples, one object may work better than another but for a number of reasons people may gravitate to the other one because of qualities that are less tangible or for aesthetic or material appreciation. In this proposition, the most significant attribute that an object or design embodies is the emotional response a person has to it. In an educational framing, Barnett (2007) discusses relationships with, and too, things, which informs responses that are exclusively versed in a state of being; "*It is through her being that the student makes or declines to make her own interventions into those experiences, and so makes the experiences partly her own*" (Barnett, 2007: p. 38). Situated within the personal entanglement of emotional sensitivity through result of lived and learned experiential model is the

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<sup>1</sup> The hippocampus is a small, curved formation in the brain that plays an important role in the limbic system. The hippocampus is involved in the formation of new memories and is also associated with learning and emotions. (<https://www.verywellmind.com/what-is-the-hippocampus-2795231>)

<sup>2</sup> The amygdala is the part of the brain primarily involved in emotion, memory, and the fight-or-flight response. (<https://www.verywellhealth.com/amygdala-5112775>)

essence of cognitive existence, meaning that 'feeling' connects and empowers people to equip themselves to make decisions that come from the self. When designing with somebody who has "*higher level cognitive degeneration*" (Crutch, 2018), it becomes even more important to understand that decisions informed by how that person feels about the project and their choices within it, are valuable and personally justified, even if they might not be articulated with particular clarity.

Evans (2001) suggests that emotions are also capable of focussing attention in a manner that will intensify engagement and that moods resulting from positive or negative emotional engagements can be longer lasting than the moment in which they occur. The research of Anderiesen and Eggermont (2013) suggests that design activities enhance the mental and physical wellbeing of somebody living with dementia and that these kinds of stimulation prolong the active capacity of the brain. Between the two views, lies a sense that joyful and purposeful endeavours can have longer term value reflected in longer term positive mood. In a caring scenario, this can lead to less stress and distress for both people living with dementia and those involved in their care (Marriot, 2011; Oliver, 2009). Whereas, in a design exploration or research context, it is a desire that positive emotional conditioning is achieved, helping to contain and maintain focus in tasks and to leave a positive response to whatever endeavour has been undertaken. Furthermore, thought has to be given to how emotional intelligence and sensibilities of each individual will inform choices and reactions in regards to taste and personal decision making within design focussed scenarios. Jenny (2012) poses that "*We know that we see through our sense of vision, but we don't perceive only with our eyes, we also "see" with our ears, our fingers, our nose and our tongue*" (Jenny, 2012: p.10), but more than this we also sense through our emotional conditioning and personally constructed methods responding to what we like and what we don't like. As an underlying reality of our constructed identity, emotional intelligence plays a significant and very individualistic role in how we sense the world and respond to it. Within this design context, this will play a significant role in the construction of ideas, propositions and designs.

In *You and Me: The Neuroscience of Identity* (2011), Susan Greenfield writes that "*the more we stimulate and exercise our brain cells in different activities the more they grow*" (2011: p. 55). Though contradictory to our idea of what dementia does (i.e. reduce the brains capabilities and active neural

networks), there appears to be a degree of evidence that for some people, creative activity (or those tasks different from the norm) can stimulate new ways of thinking and learning for people who have a diagnosis of dementia. For example, in their booklet 'Don't Make the Journey Alone' for Alzheimer Scotland, Pat, James and Ian offer a provocative interpretation of their diagnoses. Alternative to commonly held misconceptions on capabilities, the trio discuss that post diagnosis they have developed new skills, learned the use of new technologies and have increased their own potential for creativity (Pat, James, and Ian, n.d.). When proposing new methods of working and developing social and practical interaction, Pat, James, and Ian's affirmative discussions support the idea of working with people living with dementia who are recognised as still having the capacity to undertake tasks, to build skills and to share knowledge. By enriching the esteem and lived experiences of people living with dementia, there is an opportunity to increase their mental and physical wellbeing. In this work, overcoming prejudices, both societal and personal, is important and how people feel about themselves needs positively reinforced. As Crutch (2018) described when talking about somebody who had recently been diagnosed with dementia, fundamentally, perceptions had to be overcome on all levels; the gentleman in question explained: "[we] went in as husband and wife and came out as patient and carer... the husband stated he had to relearn himself" (Crutch, 2018). Overcoming prejudices both societal and personal is important and how people feel about themselves needs positively reinforced. The challenge, therefore, is to develop meaningful, impactful methods of intervening in the situation that alleviates stresses, increase perceptions of personal capabilities, enhance positive new experiences and develop community engagement. Essentially, propositions that reframe relationships with dementia and most of all, facilitate a sense of wellbeing for all those involved. Or, as Conradson suggests design acting in a health and wellbeing scenario such as dementia can "*recognize the lived experience of others as worthy of our attention. When these others are vulnerable, marginalized, or in need, care suggests that we respond in a way that is helpful and which perhaps facilitates positive change*" (Conradson, 2011:p. 454 ).

Furthermore, design itself can be framed as a social activity and when working in the guise of socially focussed co-design which involves communities or groups or merely one other person, the interactions involved become a powerful tool in the process. With wellbeing as a tenet of this work the power of one to one interaction is key as previously noted in the *Chapter 2 Positioning this Work*, the

chair of the Scottish Dementia Working Group, and a person living with dementia himself, Henry Rankin stressed that “one to one conversation is far better than anything else”. (Field Notes, 2017)

Researchers such as Fredrickson (2013), Greenfield (2015) and Turkle (2015) indicate that the most effective and powerful wellbeing tool available for an aging population, and especially for those living with dementia, is social interaction. For example, Fredrickson posits that recent studies indicate the need for social, physical interaction is inherent to the human make up and is a fundamental requirement for improving wellbeing. The most recent evidence suggests that when we really connect with somebody it is not merely the externally signalled acts of mimicry and eye contact that are triggered but also physiological responses occur such as shared brainwave activity, increased oxytocin levels and even, shared breathing patterns.

*“When you especially resonate with someone else - even if you just met - the two of you are quite literally on the same wavelength, biologically. A synchrony also unfolds internally, as your physiological responses - in both body and brain - mirror each other as well.”*

(Fredrickson, 2013: p. 20)

In a time where much discussion is focussed on the use of new technologies and robots in healthcare that diminish the need for human social interaction (Broadbent, Stafford and McDonald, 2009), it is important to note that for such psychological and physiological interaction to occur, presence is a requirement. Reinforcing the need for shared personal experiences in the physical world. The importance of human-to-human bonds that lead to development of improved mood and the lasting effects of moods (Evans, 2001) accentuates the need for social activity in the development of care for those living with dementia. Of course, the social network of the real world also acts to support and nourish those who have the role of caring for their loved ones. John Thackara articulates the importance of social connectivity on health and wellbeing when he writes:

*“Study after study tells us that a sense of social support is a buffer against stress and illness. A strong support system lowers the likelihood of many illnesses, decreases the length of recovery time, and reduces the probability of mortality from serious diseases..., by far the most beneficial care for people of all ages, not just elders, is social contact and mutual support.”*

(Thackara, 2007: p.64)

Where value is placed upon the inclusive social actions of design activities, it is suggested that methods can be found in which greater personal and community connections can be made. As such, the proposal will be to develop ways and means to value the person living with dementia and to allow them to continue to make meaningful connections with, and contributions to, our broader society. As Leadbetter (2008) suggests, connectivity and collaboration is central to local and global activities occurring now and for the foreseeable future, which has led to evolved senses of what communities and individual contributions have become. Central to this is how people feel about their power to influence and inform.

*"In the century to come, well-being will come to depend less on what we own and consume and more on what we can share with others and create together".*

(Leadbeater, 2008: p. 25)

Within this project, that power to collaborate, influence and inform will be nurtured with people living with dementia in order to see what they are capable of through more genuinely collaborative design ventures. These ventures will engage with the acceptance that design through collaborative settings will be messy and will have to deviate from structured plans in order to respond to behaviours and practices of everybody involved including sense of empowerment and ownership (Thinyane et al. 2020).

This engages Westerland and Wetter-Edman (2017) view that solutions to wicked problems will be addressed within messy contexts and that designers need to learn and be open to the messy nature of processes. Their view here is that the more designers work within societal issues where they are not the expert and that need to learn about the complexity of ever evolving situations and propositions. As such it is proposed that iterative prototyping and reflective practices will help to build strength, depth and meaning within the designer's own behaviour and understanding.

*One designerly way of exploring and inquiring into these types of messy contexts is through various types of prototyping practices.*

(Westerland and Wetter-Edman, 2017: S890)

As Cook (2009) states the importance of messiness in research is that it leads to knowing and understanding that which is most focussed within the complexity of the real-world. It is here where trial and error are expected and accepted norms where practicalities and realities shape responsive and reflective practices.

*"The 'messy area' as a vital element for seeing, disrupting, analysing, learning, knowing and changing. It is the place where long-held views shaped by professional knowledge, practical judgement, experience and intuition are seen through other lenses. It is here that reframing takes place and new knowing, which has both theoretical and practical significance, arises."*

(Cook, 2009: p277)

By understanding that the processs of research within this project will engage such messiness; acceptance that deviations or propositions will evolve through working with people will living with dementia will occur. This should be recognised and valued for what they reveal and how they help to support the actions of collaboration.

### **3.4 A Review of Contemporary Co-design Dementia Research and Projects**

Co-design as a method for engaging disparate ideas and individuals, groups and communities is often used as a term which embodies a form of action research (Meyer, 2001). Within the field of design for dementia, both research method and a practical interdependent way of working with people co-design is undertaken within this research. It is done so, with a hope to include people living with dementia by motivating them and engaging them throughout the design process. Designed within a responsive, discursive and open process the intention is to develop through the sharing of ideas, perspectives, knowledge and insight, the design of systems tools and products. This approach allows for the testing of ideas and approaches that could lead to new ways of doing things. The degrees to which people are allowed to then actually design anything are open to interpretation and is open to critique. In some cases, the actions involved do not surpass the influence or generation of a brief. Whereas in other investigations, more is hoped for or expected. The focus generally is on the approach taken and the outcomes generated the success of which is considered in relation to what has been observed and undertaken. In many situations, the application of a co-design method appears to not fully engage with every collaborator partaking in

the fullest stages of the design process. For the most complete form of collaboration to exist within an entire design journey then, participation should be granted and facilitated to the largest extent possible. To understand what this means, it is helpful to look at what is meant by a design process or journey. Milton and Rodgers (2011) explain the process of design as requiring the completion of a series of steps on route to the production of an outcome. Below (Figure 3.4), illustrates the breakdown of the elements involved in the process of designing and producing a product.

Although focused within the design of products, it can be mapped to most design outcomes (e.g., services, environments, experiences, systems, etc.). The process supports reflection and review, which means that some stages may occur in a different sequence, or may even be omitted altogether, as each design has its own unique set of requirements, variables, influences and pressures. In noting that the process is not always linear, appreciation that reflection, review and testing might inform situations where some stages might occur many times or reveal new focus creating project deviations, alterations or indeed cessation.

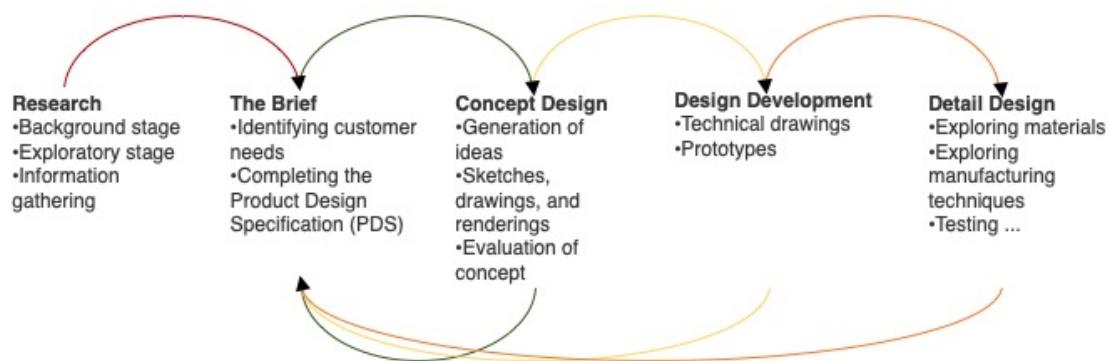


Figure 3.4 Milton and Rodgers Main Stages of Product Design Process

In its simplest form, the expectation would be that for something to be seen as fully collaborative, co-participants and partners in the design should be expected to take part in a significant number of the stages identified by Milton and Rodgers (2011). This will support shared outcomes and a sense of shared ownership. In many cases of co-design, this does not occur and as such, would appear to provide incomplete representations of collaborative ventures. Evidentially, more common forms of co-design with dementia appear to be in the frontloaded information gathering process (Figure 3.2) which results in a brief, occasional consultation and concludes with the potential for some user testing or review at the end. In these historic front-loaded approaches, objectives are

set or influences received from 'participants' so that the 'expert'-led design work can occur. Further, to this, what the term 'design' encompasses can be broad ranging and chaotic and therefore, projects engaging with the topic might present highly contrasting views of what it is to co-design.

For example, in the Design Driven Living Labs, Braenkhart and den Ouden (2017) frame their approach through a design context which is highly aligned to technological perspectives and human computer interaction. Therefore, the collaborative intent may be similar to projects explored through other forms of co-design but the focus is potentially different. Within their work, their proposition of Design Driven Living Labs is posed as being new thanks to being adaptive, responsive and new idea generating. In their view, these labs are environments of experimentations where people living with dementia have particularly central involvement and influence. They even pose that *"In a living lab, the validity of results is high because the methods are applied in a real-life context. Additionally, living labs involve various stakeholders... Indeed, living labs should involve end users in constructing meaningful innovation with and for them through co-creation"* (Brankaert and den Ouden, 2017; p. 46). The further discussion of this reveals what appears to be a highly scientific model for interrogating the technology that they have already developed with a view to collecting informed insights by the people that they aim to use their designs. The suggestion by them is that this living lab engagement supports collaboration though in this form, it comes at a point where a solution has already been identified and now requires shaping in order to fit the needs of its users.

In Denckworth's (2017) design of assistive wearable technologies, the co-design process engaged participants on overlapping levels where discussion and framing of objectives led to form giving and materials exploration. Within the collaborative processes, carers were engaged to support the shaping of and most significantly, the material qualities of, technological devices. These collaborations placed primary carers as informed experts, where their experience supporting people living with dementia on a daily basis was seen as important to the production of a set of wearable products. The devices themselves were informed through participatory means and hands-on form giving. This kind of co-design research is very reminiscent of the designer working for the benefit of a group in order to fulfil a perceived technical requirement or technological solutions and the reshaping of these to fit the situation. Presenting a view that the collected input from participants is beneficial for the buy-in of the tools being devised, the work situates a proposed

solution with a potential set of users. The collaboration therefore becomes more akin to action-based, participative consultancy supporting the expert product designers to imagine informed final products. Through this kind of collaborative activity, informative materials are produced and made available for the designers to turn into real world applications and solutions. However, the suggestion pattern reveals pre-set identification of where and how design-led intervention is required, i.e., that the design journey and collaboration is already fixed within a defined problem and prescribed solution. As such, this kind of co-design is engaged with user informed research generation which in turn informs a larger design process.

Jakob et.al. (2017) state in their 'Sensory Design for Dementia Care' paper that the "*Methodologies involved include co-design and participatory Compassionate Design approaches*" (Jakob, Treadaway and Manchester 2017: p. 20) utilised in the production of care interventions for people in the latter stages of dementia. The results of which were experiential objects and interventions which stimulated actions and reactions from their users. It is not clear in their discussion how the interactions occurred within a co-design process. However, evaluating the solutions and the situations in which their partners exist (later stages of dementia in a care home setting), it is conceivable that none of the solutions were shaped and formed by the design actions by their participatory partners or intended users. Instead, the discussion is of technological interventions of a specialist nature concerning complex teams. By this reading, the suggestion is that again, any co/participatory actions were likely to be of a discursive nature and again, highlights the massive differentiations that are accepted within a design for dementia co-design spectrum. This should not refute the apparent contribution that their work has made to lived experiences of people living with dementia. Their designs are evidenced as having positively influenced the experiences of those people. The project designs have proven to be enjoyed by more than the original recipients, meaning they are transferrable. The HUG (Figure 3.4) for example, has been part of a significant crowd-funding campaign to produce the product for the open market.

The outcomes of any of the projects in this discussion should be treated with the same hope, expectation and wilfulness to improve the lived experiences of people living with dementia. However, this work is hoping to understand and explore the potential of design and in particular co-design practices to empower people living with dementia to be significant contributors and shapers

of their lived experiences. Jakob, Manchester and Treadaway (2017) appear to be suggesting that a co-design contribution has shaped the result although much of the evidence suggests that this is still a significantly design 'for' approach rather than designed 'with' experience.



Figure 3.5 Cathy Treadaway sporting a HUG from the crowdfunding website (2021).

Within this context the products appear to have been refined through user testing and are centred upon those users, though the researcher's expression of the products collaboratively designed appears to be a challenging illusion.

In many of the academic discussions of design projects, this pre-ordained position of expert with agenda and participant invited to inform through action is a common theme. A further example includes the work of Bejan, Kienzlar, Wieland, Wolfel and Kunze's (2017) student-led investigation into the generation of experiential, interactive products for people living with dementia. Central to their discussion is a method of collaboration which follows the common design zeitgeist where discussion and observations appear to be central to the investigation, when they explain "...co-creative steps included observations of the environment of the individuals with dementia, formative and summative discussions with people with dementia leading to the creation of an *Empathy Map*". In their discussion, "...sketches, prototypes, music and Wizard-of-Oz-testing" are important to facilitating ongoing conversations (Bejan *et al.*, 2017: p. 12) – although this may be a valued and possibly the correct, approach for working with PLWD dependent upon their stage of their journey. The approach is suggestive of a situation where the acts of designing were restricted to the

designers (the experts) but 'user testing' helped to evolve their propositions. In relation to this investigation such a method is not indicative of the kind of holistic participation that co-design can and should fulfil. Instead, this framing continues the historic relationship to participative or collaborative methods where the process is still owned by the expert and flavoured by up-front discussion or observation. The observational positioning also delineates the participants as subjects to be studied rather than people to be interacted with. This creates an expert-to-subject barrier that does not encourage equality, participation or the potential for radical change.

There are arguments that this consideration of co-design is a common misconception of the term and that practices such as these might be more closely aligned to a kind of customer-service approach where needs are identified and met through some form of face-to-face engagement (Bloomkamp, 2018). Arguably, the methods of inclusion, duration and commitment of parties involved help to define the 'CO'-ness of such approaches as is the sense of hierarchy within the process. In these examples, a common proposition is an expert-to-subject Co-design process where the aim is to support the 'subject' individuals to have influence within a project. Effective achievement of such an approach is dependent on the direction of the design lead and their capabilities to bring people into the design process. Even in the expert-to-subject approach, the process can be valuable for affecting change and will underpin designers achieving better informed positions, personal-prowess in the field and empowerment to knowledgably affect change. When projects are run with suitable and expertly crafted opportunities for buy-in, participants will share lived experiences and aim to help the design researcher. This means that a degree of doing 'with' is achieved where unexpected influences, nuances or experiences are revealed. The approach will generate greater understanding for the people that the products or solutions are designed to support and will afford more meaningful results for the original-intent. However, these occur through an observational/consultative role, rather than one in which Co-design creates empowered active participants, with equal rights to act shape and deliver designs. This approach is suggestive that relinquishing control in design appears to be difficult. It is likely to require great skill on the part of a designer to accept personal positions imbued with misplaced-well-meaning or ill-judged preconceptions that have, through lived experience, developed in their own thinking (Craig, 2017).

Part of this problem is that many projects involving expert-to-subject collaboration are likely to have started well in advance of face-to-face interactions with the subjects. By the time the designers are dealing with the subjects, they are likely to have well developed ideas and intents. Equally, even if the engagement starts early in the project, without highly regular input and participation from the subjects, flaws of thinking in and around a solution have a high probability to occur. By the time the groups do come together again, these flaws might be so ingrained that they might not be easily negotiated or extracted. With significant personal investment on the part of the designers, it can be challenging to overcome self-set prejudice in favour of their solution. As Nikander, Liikkanen and Laakso (2014) explain, *“results show that designers tend to favour their own concepts in concept evaluation, which has some implications on design practice”* and that there is a tendency to hold on to early ideas for as long as possible. The position here is also dictated by the tools and approaches dictated by the designer/researcher which negate any option to shape or influence the process leading to the formation of a solution. Meaning again that the outcome is likely to be fixed and reducing the potential for collaboration. Whitham, Cruickshank, Coupe, Waring and Perez (2019) assert that for co-design to truly exist *“The co-design process must lead to tools and ways of thinking that suit the participants, not the designer”*.

Bearing in mind this proposition, it might be conceivable that it is difficult to admit failings and for the designer to refocus. What this might also propose is that without meaning to do so, the expert-to-subject design researcher(s) become more likely to construct feedback methods focussed on resolving their preordained propositions (Cross, 2001) or, at the very least, might be subject to paying greater attention to what is deemed positive. Therefore, there are always likely to be inconsistencies and differing positions in to what participation involves, how often it should occur and what form it should take. In Bejan, Kienzlar et. al's (2017) work, the position is taken that researchers engaging with subjects must at least attempt to address a sense of positionality and influence; *“it was important for me as a researcher to stand back after observations and compare my impressions with those of stakeholders, as I did not want to anticipate something or influence their impressions”*. Thanks to openness and sharing in this kind of design research method, insight and value judgements from the subject/participants become more meaningful and valued. However, it is what these insights mean and do in regards to the projects that isn't always clear.

Observational and discursively enriched instigation of projects is discussed in the work of Jakob, Manchester and Teadaway (2017). In their approach, a shared trust and understanding is developed and explored through collaborative probes which inform and shape an interactive outcome. Their approaches span both carers and people living with dementia looking for buy in and valued input in the creation of more technically proficient interventions. These sensory design objects appear to be enriched by the content generated through the collaboration though as is often the case, the translation of ideas becomes the job of the designer-technologist. This appears to be consistent with many Co-design approaches in that a positive 'with' component exists in the early stages but thereafter, does not exist in the form of togetherness throughout the processes of designing, refinement, aesthetics, prototyping and manufacturing.

Part of the issue lies in how designers and design researchers allow their work to be influenced, reviewed, poked and prodded, and this is always at the discretion of the designer. It follows that when and how to get this kind of input is a judgement of the design team and can be challenging in any fuller Co-design practice.

In their presentation of the MinD project, Niedderer, K., Coleston-Shields, Donna, M., Tournier, I., Craven, M. Gosling, J., Garde, J.A., Salter, B., Bosse, M. and Griffoen, I. (2017) outline what they term 'Traditional research participation' as consisting of "focus groups, individual interviews and diary probes" where "visual cards have been developed as prompts, memory aids and discussion points for use during the interviews" and where personal diaries acted as personally imbued probes. They suggest that these are participative research approaches though not part of a Co-design system. The framing of this contradicts Hendricks et al (2014) position where cards used within focus groups appear to be their central consideration in their co-design approach.

Neidderer *et al.* (2017) advocate a participative co-design that "invites mutual decisions and actions, and aspires to a meaningful and equitable co-creation within the design process" where shared responsibility and involvement activates power to "influence the values, process and content of the research". They espouse an approach where their design techniques are blended throughout the duration of the project, encapsulating and making use of 'traditional research participation' with bouts of ideation, wherein people with "lived experience of dementia" have shaped and informed

the research and the suggestion is of a Co-design technique. However, within this discussion, there still appears to be a lack of ownership by PLWD. As such, their work is a progressive 'with' approach thanks to PLWD involvement in different attributes throughout the duration of the project but certainly not 'by'. Their evidence would suggest that a certain amount of shaping of approaches and tools has occurred through a sense of shared interest (with) but any actual design embodiment is through the enactment of the specialists involved in the process.

Many positives of these kinds of co-design projects can be noted but one issue appears to exist in the form of participant-driven-action. The allowance of ownership beyond the thinking stage often appears limited. Commonly, ongoing creative relationships beyond specific periods or even single day workshops do not appear to exist. As such, the co-design process is limited to an intense period of activity with no extended design conversation or evolution. Another issue with this work was that it appeared to limit the discussion of design outcomes to the field of "for people with dementia by people with dementia" appearing to ring-fence the work and reducing the capacity for outcomes to be impactful elsewhere.

In their forward to the Dementia Lab Conference (2017), Hendricks and Wilkinson reinforce the co-design approach by mooted the involvement of those challenged by circumstances to become active players in informing and changing existing situations. Through Participatory Design, they extend the understanding that people should be engaged with processes that influence their situation and that are likely to include a myriad of influences not the least of which are likely to be political. This position and their framing of the designer is charged with being an empowered agent capable of eliciting ideas and developing opportunities. They reinforce this view by relaying Nieuwsma's idea that the "*designers' ability to work in ways that confront dominant design outcomes and empower marginalized social groups*", is the basis for good design-led collaborative practice that challenges and opens up situations. Hendricks and Wilkinson go on to situate this within an acknowledgement of the designer's ethical and moral will to act upon their agency which explains why designers can be considered to be equipped to work within complex wicked problems. Their position also suggests that the collaborative methods are positive ways in which to act upon this agency.

In the discussion of their work, Neidderer *et al.* (2017) explain that collaborative creative ventures are not merely concerned with resolving a problem but also deeply experiential and engaged with socially empowering scenarios. Enriching the purpose and value of co-design as both social and productive activities this kind of thinking is extending the way design can be effective as production technique and as stimulating endeavours which can enhance mood and wellbeing. As these more enriched models are explored, greater sense of the ability to create longer, more enduring collaborations are proposed. Tan and Szebeko (2009), for example, discuss their enriching co-design approaches that formed the Alzheimer 100 project by *thinkpublic* as being positive methods for pulling interested parties into the discussion of a situation. In doing so, *thinkpublic* used a set of design tools to ask questions and to provoke answers. But this preliminary set of actions were used in order to create opportunities for future collaboration and participation. The result of which was "*an approach that incorporated practical and creative design-led methods to involve stakeholders of dementia to generate ideas and make decisions based on their experiences*" (Tan and Szebeko, 2009, p.187).

Within their explanation of their work, many positive views are constructed highlighting the value of a process that facilitates people to "*share experiences and challenges around specific issues and devise ideas and actions to address these issues, tapping into the available skills and resources to do so*" (Tan & Szebeko, 2009, p.187). The discussion of involvement of the numbers of people committed to achieving something was impressive and the intentions to give empowerment to people affected by dementia laudable. Through its sharing in publications and online platforms, the work has given rise to ways about thinking and working with people living with dementia and as such, provided impactful insight as to what might be possible. Disappointingly, however, limited amounts of the ideas and projects proposed in their work were ever realised, indeed the admission is that "Time and budget limitations of the project meant that no idea got implemented in the run-time of the project" (Tan and Szebeko, 2009, p.189).

In the work Rodgers has undertaken with people living with dementia (2017), the core project elucidates the capabilities and powerful impact that Co-design can have. His work designing tartan with people who are living with dementia was a celebration of the serendipity of Disruptive Design approaches and the need to respond to what was grasped. Originating as an introductory project used to develop collaborative working relationships, it soon developed into a mode of working that

was responsive to what was wanted. Achieving positive outcomes that change public perceptions was central to this project and its development. By completion, what had occurred was that people living with dementia had shown that they were “capable of designing a new product that will be sold across the world”. Rodgers extols that a Co-design processes must be open in nature and that the designer’s intent and practice be equally ‘transparent’. Thus, introducing a project as having purpose that is equally beneficial for all parties involved:

*“The instigator of the Co-design project should be transparent about the project’s objectives and clearly articulate the reasons behind embarking on a Co-design project. In other words, the project rationale should always be known from both sides.”*

(Rodgers, 2017; p194)

Rodgers’ project is designed in a manner which encourages absolute collaboration from both parties and results in a position where for much of the doing positions, the design researcher is an obedient enabler to the creative desires of the other participant. The project is highly restricted in what is expected of the Co-design participant but the results they generate are very much of their own choosing and taste. The translation of the designs into achievable outcomes is generated by Rodgers but under the direction of the participant through translation of physical concept models into online digital design systems. The project represents a short exchange between the parties involved, however, the design outcomes are predominantly originated by people living with dementia. Ultimately, the system blended craft making skills which explored the construction of pattern undertaken by participants in response to Rodgers’ brief to design an Alzheimer Scotland Tartan. Through a controlled and consistent system of exploration, this work was replicated in a number of workshops across Scotland. The conversion of which through the online digital tartan design platform resulted in a series of outputs that were printed and exhibited, inviting the public to see what PLWD had designed. From these exhibited artefacts, a tartan was chosen as a winner to be produced as new product in the market. Requiring rules of engagement within the project and methods that could regularly be reproduced this simple approach raised guidance for other design researchers to consider when aiming to undertake such project:

As a key outcome of the research feedback solicited gave directional advice for anybody designing and undertaking similar kinds of investigation:

- [Tasks were] Not too demanding and a task that all abilities could engage in.
- It had a purpose and structure, but there was still a lot of scope for people to express their individuality.
- It was beneficial and people enjoyed taking part.
- Positive way of showing how people can design, show their ideas and be creative.
- People chatted and shared their results—lots of interaction.

(Rodgers, 2017)

Rodgers introduces, through this work, a simplistic, paired back collaboration which results in a very quick design project. The approach is simple but the collaboration is empowering in as much as the individual participants have a sample product designed by them and put forward to a position where, by the click of a button, it could go into manufacture. As such, the project exists with a large amount of 'by' somebody living with dementia. The reason it does not fully achieve such a position is that it requires a substantial amount of 'with' a designer/researcher to transform the final outcome and the original brief or project parameters existed prior to the collaborations starting. This is explained as being the case thanks to the project originally being posed as an icebreaker that took on a life of its own the more participants got involved.

Although much of the co-design projects above are developed with the perspective of introducing a tangible outcome as a result of hands-on making, the work of Craig and Fisher (2020) tells the tale of systems design resulting in new methods for working with PLWD to improve their dementia journey. The project described as 'a 14-year design-led enquiry' explains the need for broader design thinking in care approaches and shares insight of how, through collaborative means, impact has been of particular importance. The co-design enquiries have led to artefacts which enable overlapping processes and experiences and reminds the reader that co-design is not solely engaged with said hands-on practices. The results they share are most evident in the change to lived experiences which are articulated by statements of participants that include "*Rather than just talking, I've been able to learn new things. It's like gold*", "*You know you're telling me things that could alter my life*" and "*What you've done for us has got me to the top... it's put me back where I used to be*" (Craig and Fisher, 2020; p.3). These exclamations explain the importance of including people in the design process and open significantly important considerations of how people feel when design is done well be that 'to', 'for', 'with' or 'by' people living with dementia. As such, the

nature of how the co-design occurs is centralised on needs and requirements that change lived experiences of PLWD but which ask the right questions or engage the significant capabilities of people to inform and direct their own position. In this form, people are empowered to engage with their situation and individual actions for successful living are supported.

In the discussion, one particularly clear statement of reaffirmation of self and value in capabilities was presented as "You need to focus on the ability and the contribution that we can make rather than what we can no longer do" (Craig and Fisher, 2020). This presents a significant consideration of the co-design proposed in this thesis which aims to focus on the production of design works that occurs in the here and now. A position that eschews reminiscence in order to engage people with the world in which they currently live and in ways that supports continued flourishing.

Craig and Fisher share a position which at distance uses co-design in a different manner and with different intentions in regards to outputs or achievements. However, their intention for supporting people to feel empowered and relevant, now, is central to what the primary continued research of this work delivers.

The examples reviewed above help to define different methods of co-design and the way that designers have engaged with them. This includes positions which vary in regards to depth of engagement, relationship development, expectation, participation, and duration. The examples have been chosen from widely recognised projects and researchers working in the field and are a synopsis of the vast array of such projects consistently flourishing in the field at this time. This is by no means a comprehensive overview but the content discussed does help to frame the work that follows and explains where differences in approaches and applications might occur.

Lead Researcher	LR - Disciplinary Focus	Stage / Level of Dementia	Aims	Outputs
Treadaway (2017)	Textile Design	Latter/Severe	Compassion	Hug doll
Manchester (2015)	Education	Mild/Moderate	Socialising	Narratives through information curation
Carey (2017)	Service Design	N/A	Supporting carers	Service mapping tool
Jakob (2014)	Textile Design	Mild/Moderate	Relaxation/Stimulation	Sensory room
Hendricks (2014)	Design Interactions	Latter/Severe	Empowerment and Compassion	Care
Craig (2020)	Design and Health	Mild/Moderate/Latter	Supporting wellbeing	Self-care support
Robertson (2019)	E Textiles	Latter/Severe	Relaxation/Stimulation/Compassion	Sonic birds
Danckwerth (2019)	Wearable Technologies	Undisclosed	Improving daily situations	Wearable technological devices
Braenkhart (2017)	HCI	Mild/Moderate	Experiential intervention	Artificial Reality
Rodgers (2017)	Interdisciplinary Design	Mild/Moderate	Capability through design	Tartan designs
Tan (2009)	Health	Mild/Moderate	Capability through design	Dementia Diaries and Filimic Production
Bejan (2017)	Product Design	Mild/Moderate	Improving daily tasks	Products
Chamberlain (2017)	Design for health	N/A	Improving daily situations in healthcare	Service design
Kenning (2018)	Design for Aging	Latter/Severe	Inclusive design	Material exploration for future products

Table 3.1 Summary of Literature Review of Relevant Design (co-design) Research Projects

What is evident in this review is that co-design (in its many interpretations) is increasingly utilised in the field as a means for engaging people with dementia to be empowered in their own situation and is helping people to live as well as possible for as long as possible which includes notions of mental and physical, social and educational wellbeing. However, the approach does have critics who may not be convinced of what co-design can deliver.

The above collaborative designed 'with' approaches are challenged by Hendriks, Liesbeth, Huybrechts, Wilkinson, and Slegers (2014) in their paper 'Challenges in doing participatory design with people with dementia'. Within this work, the authors outline provocations for working with people in Participative Design (PD) projects. At the same time, they propose that participative processes are virtually pointless when dealing with people living with dementia (it should be noted that all of the authors appear to take diametrically opposed stances in later papers). Their view here, is shaped by experience of running two projects and identifying limitations in what has gone before. In order to frame their position, they make 7 assertions which are perceived as challenges to design researchers:

1. *"The cognitive limitations of a person with dementia may make PD too difficult"*
2. *"The results of PD sessions are difficult to be translated to the wide variety of forms of dementia "*
3. *"It is unclear whether the people with dementia, their caregivers and relatives are reliable"*
4. *"PD may be too stressful for the person with dementia"*

5. "The differences between the designer and the person to design for are too big to speak about equality in participation"
6. "The process of PD can be a burden for the designer"
7. "Minimal utterances are given too much importance"

(Hendricks et.al. 2014; p.34-35)

Based within the parameter of working with people living with mild to moderate forms of dementia, their discussion is suggestive of limited participation and substantial support is required by caregivers to achieve and undertake project tasks.

Within their discussion of the collaborative participatory method, an ardent statement is made that "*A central element in participatory design is the blurring of the borders of the designer and the end-user as the latter becomes an active user (from design recipient to design decision-maker)*" (Liesbeth et.al. 2014; p.35) which was extended to include a requirement of shared agency between collaborating parties. Suggestive of a desire to create a more equal, democratic and collaborative design system, the statement proposes intent. The practice of this proposition was to stimulate 'reciprocal' and 'transcendent' outcome or these aspects were, at least, aspirations of the project. The further discussion of the project indicates that this was unsuccessful. In their review, it appears as though the outcomes were flavoured by judgements of capability which identified failings in the process. Commonly, these were explained as failing to gain action from participants although it may also result from failing to provide stimulative enough means for participation. The outcome of their research defined an assertion that "no equality is gained, there is always a power relation which cannot be changed by using PD practices" (Liesbeth et.al. 2014; p.35). As has been stated, the paper indicates a provocative approach where the 'gauntlet is cast down' to designers and design researchers to prove them wrong. However, it is suggestive of a set paradigm which will be difficult to overcome. What was evident in their paper was that the participative approaches they undertook were to be supported by caregivers (family members, friends or professional) and those people's ability to instruct, guide and aid the person living with dementia. It is feasible, therefore, to question the efficacy of the individual, for example, when working with an intermediary (care giver) who will also inform and shape answers with a hope to supply some sort of response. It is conceivable that

over-helping and over-guiding can occur through such situations and as a result might be that the participation required of the PLWD becomes lessened.

Liesbeth *et.al.* continue to suggest that all designers should review this approach and potentially disregard an alignment to participative/collaborative approaches. Which provides a good foil to this work, where the intention is to explore Co-design and the results of collaboration for the advancement of design's foray into dementia. Throughout this overview, the authors appear to be setting down challenges for design researchers to prove them wrong but they have also provided a reasoned opinion of what collaborative participative practices should aim to achieve and the most significant of these is the ability to allow people to move from being subjects to active conspirators. With this proposition, people living with dementia would have to become advocates of the method and capable of profound engagement (in the Analysis Chapter of the work undertaken in this PhD this point will be addressed).

Recognising that the use of Co-design within dementia care might not always supply the satisfactory results that were expected at the outset of a body of research, the following review of Co-design looks at how the practices occur, what state it exists within and how collaborative the approaches are. The framing of positivity that tends to follow the results of research is understood as a significantly common practice termed 'publication bias' the suggestion is that positive attributes are more commonly shared than those which are negative (Mohrer, 2007). According to him, this might be even more common in the creative industries. As Reiter-Palmon (2018; p.177) explains, "we have a tendency to believe that the effects of creativity are positive, leading to better individual outcomes". Therefore, it is refreshing to have the less publication-bias reporting of Hendriks *et al.* It also suggests that the perspectives in the preceding literature, should be read and understood in terms of potential bias within the reported projects and their discussion within Co-design practices. Most likely, the involvement of participants will have been framed with a positivist perspective. With this in mind, those projects discussed above are seen as an antidote to Hendriks *et al.*'s view but one which is not always 100% clear, effective or indeed holistic in practice or representation. However, the descriptive understanding of the practices has been used to inform a framework of co-design approaches and relationships of engagement (to, for, with, by) which shape the hopes and intentions of this PhD work.

### 3.5 Building A Framework for Understanding Contemporary Co-design in Practice

Co-design as has been stated has a history based in participative design theories and practices that evolved in the 1960's and that aimed to make the design process more inclusive of stakeholders and interested parties, clients and users. As such, there is a long history of co-design that achieves differing levels of 'co' working. The framework created for this PhD came from a review of co-design methods used in a selection of design for dementia projects over the last twenty years and questions them through a hierarchical system. The hierarchy places co-design within four categorisations: defined as design done 'to' people, design done 'for' them, design undertaken with 'people' and design undertaken 'by' them as non-trained designers. The levels of engagement produce a sense of order of engagement and depth of participation from the people identified as co-designers (participants/non-trained designers). Like Maslow's hierarchy of needs (1943), it suggests that there are levels of attainment that can be strived for and that when people fulfil their potential, then they can feel emotionally empowered or connected to a project, its possibilities and the possibility of (in this case) design techniques. Maslow's Hierarchy is concerned with psychological and attainment and sociological positioning that culminates in a level of self-actualisation that interestingly, includes creative activities.



Figure 3.6. Hierarchy of Needs (Maslow, A. 1943)

Arnstein in 1969 produced work on creating levels of engagement and resultant positions of prowess or power in his Ladder of Citizen Participation (1969). Both Maslow's and Arnstein's models suggest that to achieve the highest contribution and self-contained value in something, then stimulation and participation of the mind through proficiency, attainment of knowledge and application of capabilities and control leads to greater personal value. Arnstein's work suggests

transitions of power within the collaborative or inclusive dynamic of participation eventually changing to a position where, in the highest position, the citizen gains power.

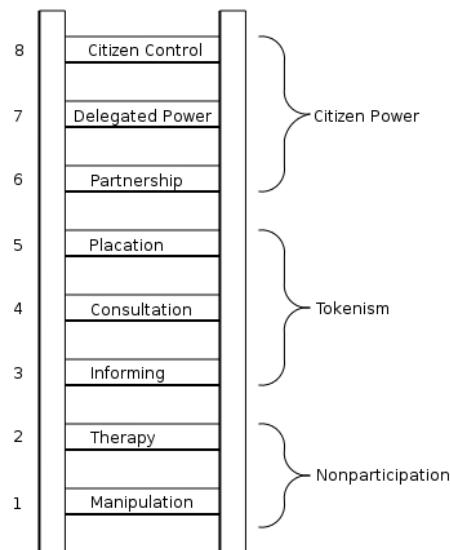


Figure 3.7. 'A ladder of citizen participation' (Arnstein, S. 1969)

The 'Co-design Participatory Power Pyramid' created in for the Literature Review (Chapter 3) adds to these kinds of models in a way that allows co-design to become central to the discussion and to consider the greater immersion of a person (collaborator, co-designer, person living with dementia, participant or subject) might be afforded by people conducting co-design research. Here, the model allows for the involvement through activities, actions, thought and depth of involvement to be considered. The model is based within the idea that design is a process, a series of activities and thinking that, when combined, result in a designed outcome. As a framework, it has used the simple but effective product design model of Milton and Rodgers (2011), where each stage is more commonly utilised en route to the production of a design, which means any co-designer must act within as many of these steps as possible in order to show their contribution and therefore, position within the hierarchical system. Here through action, evidence has been mapped to suggest to what extent the co-designers have been able to immerse themselves, contribute or even take control. The entire process is also concerned with control consisting of setting agendas, creative direction, fulfilling tasks, contributing to the group and providing support to peers. This is an acknowledgment that all of these projects have been undertaken in a manner that suggest the 'co' is an inclusive statement and that design should be an activity that is highly social.

Co-design methods appear to run through a spectrum of approaches from basic consultative approaches where a degree of interaction with proposed user groups informs thinking about and around a problem or opportunity, through to a designed 'by' model where the collaborative approach has created empowered people to act individually and with self-directed purpose within the collaborative proposition. In the 'by' model, the suggestion is that the Co-design has revealed latent skills and knowledge and has supported their application through confidence building facilitation and the introduction of design processes which started with significant collaboration. The 'by' framework is a change-based proposition where the participants within a collaborative method can feel ready and capable of arranging project outcomes without the need of the specialist-designer. The below Co-design Participatory Power Pyramid has been created to explain the spectrum and to explain how the dynamic occurs. It also charts the differences between 'to', 'for', 'with' and 'by'. As this is an explanation of the Co-design power hierarchy, the suggestion of the accomplishment of 'by' is only likely to occur through a 'with' project basis. This continues the evolution of the collaborative approach to a point of personal and collective empowerment.

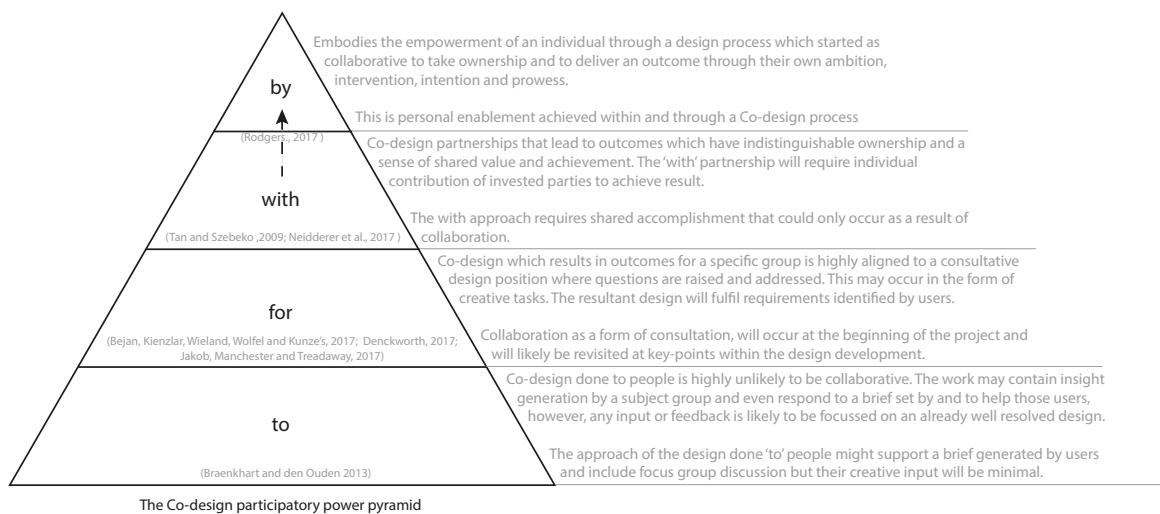


Figure 3.8 Co-design participatory power pyramid devised to understand different approaches and associated behaviours connected to differing forms of participation throughout such projects.

The participatory power pyramid follows the principle of Maslow's Hierarchy of Needs in that it identifies a preferred or superior level of fulfilment, in this case, one which identifies differing levels of collaboration and independence. The use of a the pyramidal or ladder systems can be seen as

difficult propositions thanks to the sense that complex situations become simplified to become categorised in sequential propositions (Maggetti et.al. 2012). The situating isolates components rather than narrating the interlinking qualities and likelihood to spill between different practices. Furthermore, a sense of progression up levels may appear to negate the levels below or diminishes their value. The challenge, however, is in how to represent what are evolving practices that are likely to alter future scenarios rather than a circulatory system, loop, ven or spider approaches where feedback interlinks and nuances might support more connected views. However, the pyramid used here is a suitable proposition as it is working towards a method that encourages self-empowerment in collaboration and independence in action that are perceived to be aspirational in co-design activities. This is suggestive of transformative and beyond common practices therefore describing a sense of attainment for the co-designer participants.

### 3.6 Chapter Summary

In this chapter, how design fits within the ongoing research agenda in relation to dementia has been explored. The intention being to define important aspects to be considered in ways of extracting valuable new ways of doing things, disrupting standard practices and provoking new possibilities. The work has discussed design work in health and social care and emergent trends whilst creating a focus that softens from the hierarchical control and the appreciation of complex 'wicked problems', in order to understand the ground-level experiences of people living with dementia. In understanding the greater need for collaborative processes to become more open and unorthodox and asking questions of existing co-design propositions and practices, the work further queries applications and outcomes and sets up questions about how co-designers need to think differently about how the process can become increasingly collaborative, less controlled leading to fluid and responsive approaches. The chapter also discusses the importance of relationships, emotions and moods in order to maximise participant stimulation, motivations, cognitive engagement and self-value. Within this, comes the requirement for design and designers to act with compassion and sensitivity and yet still with effective prowess in order to find routes for meaningful and valued impact through actions of achievement.

The situation, as outlined so far, for People Living with Dementia is that no singular solution will be found. Complex needs, support and requirements along with very individualistic experiences within

the dementia journey make this a 'wicked problem'. It concerns capacity to have support, to address social and healthcare problems, concerns relating to financial, accessing services, differing experiences of dementia journey timelines and impairments, ability for loved ones to provide support, personal narratives and personal capability. The result is a problem where no singular solution will be forthcoming, it is therefore important to address different aspects of their lived experiences and to help to make the act of living valued. This is why designers have many roles to play in terms of the curation of space, the creation of tools, and the provision of services that will help to alleviate stresses. This is because designers are adept at dynamically adapting their approach to the context, adapting and shaping propositions, refining them and producing valued intervention. In this review, it has become clear that research through design allows this to be put into practice.

What this proposes is the need for designers working within a collaborative design context to become part of an experiential research project embedded in the culture of the people they aim to work with. The importance of developing trust within the groups with which they aim to engage is important and the evidence suggests that this has to occur within a social setting that is inclusive and yet favourable to the participants. Interaction is likely to occur on a multitude of levels and design as a series of practices that occur over a prolonged period of time could be a good vehicle for participation that builds interaction and trust.

This literature review suggests that co-design methods are likely to have to adapt in duration, application and aptitude in order to democratise the collaborative process and to make projects for people living with dementia completely inclusive. This means that historical models will need to be influenced by substantial reframing, where the evolution of methods responds to the values, knowledge and approaches discussed within this chapter changing from 'to' and 'for' to 'with' and 'by' as outlined in the 'co-design participatory power pyramid' (Figure. 3.5). The next chapter will look to define a method that shapes this study and that considers what has been learned from this literature review, in particular, related to social inclusion, process inclusion and duration of participation where methods for direct participative and highly creative actions are devised rather than avoided.

## Chapter 4: Design Research and the Method of Enquiry

*"Design research can play a role in teasing out novel areas of opportunity for creating... scenarios and dialogues where the user involvement provides a radical expertise that may go across sectors and silos and be put into play. Here design has a role through its explorative and adaptive nature as well as its wide applicability and - at times - as a trouble-making, wishful and wicked approach to current needs and state of affairs."*

(Hansen, 2019; p.166)

There are two central tenets to designers' appropriateness and ability to work with in complex wicked problems, such as dementia, the first of which is the range of research skills and practices at their disposal. These action-imbued design approaches are aligned with an adaptive, responsive mindset, and form people-centred hypothesis-led experimental opportunities that develop and evolve quite quickly. As such, the essence of good design requires a research technique that is honed to looking at and responding to human behaviours. The key to this is flexibility, identification of possibilities, refinement of a coherent collection of methods and a wide recognition that a formulaic, single method may not, be appropriate or support the unpicking of the situation being explored. This is because, as Rachel Cooper (2012; p.261) says, *"research methods applied to the field of design are diverse and eclectic"*, and they need to be, in order to respond to or to unearth the human behaviours and motivations at the centre of socially driven design research (Milton and Rodgers, 2013). It is therefore recognised that common design research practices form uncommon methodologies in that they encourage unique combinations to develop. Responding to specific human centred situations, behaviours and motivations which are often informed or framed by much larger socio-political issues, design researchers are required to engage eclectic and wide-ranging methods that are likely to form integrated fusions. These fusions are often further influenced by other models from divergent interested parties. In the case of this work, those parties include health care, social care and charities. In the experienced design researcher's toolkit, such things as ethnographic and observational techniques, journals, probes and prototypes, pattern recognition and semiotic analysis, focus groups and collaborative methods, experience mapping and trend forecasting, task analysis and personas form an incomplete list of tools which commonly combine to create blended methodologies (Milton and Rodgers 2013).

The second tenet of appropriateness is explained in the form of soft-design-skills or social- skills and the importance of the interchange between the design-researcher the participants in the study.

Primarily in this exchange is the requirement to have and to nurture trust, to communicate and to respond in such a manner that all parties feel valued and included. This is viewed as a remarkably strong requirement within a socially driven design scenario. It is important that social interaction is a driving force where relationships develop and that within those relationships, acceptance, understanding and empathy cultivate a strength in shared intention. This perspective sits at odds with historic scientific research which would require a minimum interference and interaction with a subject group.

In this chapter and the following one, the method of research within this study is outlined and explained in terms of origination and evolution (Cruickshank *et al.* 2016). The changing parameters of the research method are discussed in terms of action in response to issues that arose. The outline of this method is therefore a point of origin and agreed proposition which through the act of conducting the research had to evolve in order to develop an appropriate method of enquiry. This, as Cruickshank *et al.* (2016) explain, is not uncommon, and supports a design researcher's ability to recognise fluidity in methods where alternate possibilities need explored in order to deliver the appropriate solution, when they state:

*"flexibility was also required to enable disparate contributions to meaningfully connect to each other. Finally, flexibility was essential to allow for the whole picture to change over the duration of the project."*

(Cruickshank, Coupe and Hennessy. 2016; p.50)

This qualitative cross-disciplinary investigation (Murtavoski, 2016) proposes the exploration of how design can be central to engaging and intervening within the 'wicked problem' of dementia. Central to the proposition is the investigation of how the acts involved in designing can be important in supporting people living with dementia to shape and enrich their lived experiences whilst promoting a very different consideration of what living with dementia might mean. In particular, the approach is interested in how design might facilitate individual and collective independence in terms of thinking, decision making, agenda setting, personal opinion sharing or personal framing. Through their input in a design process, people living with dementia might find

new ways of thinking about and representing themselves and their capabilities. The working practices engaged in this process explore personal and collective thoughts, ideas and desires which leads to the production of provocative outcomes. These outcomes are likely to embody the construct of "Design Through Research" (Frailing, 2015; Lunenfeld, 2003) and have been undertaken in the broadest attempt to operate within fully collaborative processes. Through, workshops, visits, discussion, actions, reactions and self-assured acts the processes of design exploration undertaken within this work utilises a blended but central co-design approach. The results are a number of outcomes, works or artefacts that fit within the area of *Design Through Research* in the manner explained by Milton and Rodgers (2013; p12.) as "*the taking of 'something'* (in this case the capabilities of people living with dementia) *from outside the design work and translating it through the medium*". The result being the production of outcomes that are the embodiment of the research and that exudes the importance of creative design actions, thinking and practice (Frailing, 2005). The research actions that have been undertaken led to the creation of co-designed outcomes that embedded in a 'Qualitative Research' approach (Ireland, 2003. and Robson, 2002). Here, observation, participation and collaboration resulted in a series of design projects where the method of workshopping (Ørnsgreen and Levinse 2017) was prominent. The workshopping method compiles a methodology where themes including 'interventions' (Brown, 1992; Halse & Boffi, 2014), 'action research' (Meyer, 2001; Muratovski, 2016) and 'Co-design' (Scrivner, 2005; Sanders and Stappers, 2008, *et al.*) were used to identify opportunities and to shape collaborations within dementia care and support.

The workshop practices in this method have engaged with environments and conditions that normally belong to the social care and charity sectors, wherein, design addressed emerging desires, interests and opportunities for extending care are addressed through participatory practices. These practices, which make use of the participants' desires and interests, introduce collaborative, design-led social interaction, to work alongside existing complex care plans. The methods employed in this study provide participation through stimulating opportunities which are intended to provide mutually beneficial outcomes between the researcher and people living with dementia. Whether framed as co-design or participatory design, the methods explored within this project through workshops have looked to "respect *the creative insight of participants to inspire and help guide the design process*" and "to probe participants for self-discovery, priming [them] for

*further participation, understanding current experience, and generation of future scenarios and concepts*" (Hannington and Martin 2017; p.62). The nexus of this work may also situate some of the outcomes within a context of 'design activism' that supports an attempt to disrupt paradigms of shared meaning, values and purpose, (Fauld-Luke, 2009) where "*creative practices among citizens... seek a transformative effect on their everyday outlooks*" (Julier, 2014; p.216).

In addressing the problems outlined in the Chapter 2, the potential of collaboration and overcoming historically restricted approaches of expert-to-subject activities of Chapter 3, this blended research methodology will aim to address the 'with' and 'by' perspectives to attain successful production of designs and design disruptions. The method will therefore use design and creativity to identify potentially powerful methods for working with people who are living with dementia and to share, as Cooper (2012; p. 263) puts it, an "excellent adoption of appropriate design research methods and the exciting new knowledge" this brings.

This Research Method has engaged:

**Research Through Design** utilising **Qualitative** approaches and evaluation methods which evidenced how people responded to and felt about the work they were engaged with. In order for these goals to occur, **Workshop** methods were undertaken in a **Co-design** approach. This has been by framed by a situation where projects were instigated by people living with dementia and encouraged enduring participation within all aspects of the design process. Workshops developed throughout the project journeys were devised to respond to the participant co-designers and to provide platforms for them to build upon their ideas.

Results were shared through the production of designs and the evaluation of those results incorporated observational field notes, commentaries during and after project practices by participants and carers, written evidence collected at events and in display of the designs. Further evidence of perceived value in the outcomes was generated through public dissemination and response to what the designs and collaborative practices had achieved.

## 4.1 Qualitative Research

Qualitative Research by definition is concerned with, how a situation is responded to on an emotional level, psychological position and within social context including quality of the lived experience. In relation to this PhD, the qualitative approach looks at phenomena through the lens of how evidence manifests through experience or as experiences. The primary condition of the work being that this is research into a real-world problem and interrogates actions which hope to positively affect the human experience of it (Robson, 2002). This includes and embodies situations where particular interventions change broadly experienced circumstances (Coxon, 2015). This research framework allows us to look at detail and to identify phenomena of particular importance but most importantly, how those affect the quality of the lived experience. As Muratvoski puts it, *"Qualitative Research... focuses on situations in the real world (in natural settings)... this type of research recognizes that the problem in question has many dimensions and layers"* (2015; p.37). For people living with dementia, the individual complexities of their personal journeys is aligned with how they navigate the real world whilst dealing with ever-changing scenarios. Herein, Qualitative Research allows complex, interlinking and over-lapping of nuances or influences that must be investigated and engaged with. Therefore, the qualitative discussion is likely to be supported with descriptive note taking and anecdotal insights or framing, that pay particular attention to the things that have been valuable to participants (Kenning, Treadaway, Fennel and Prytherch, 2018).

Within the project, a number of qualitative design research methods are explored. This builds upon the Social Science position (Marshall, 1997; p.18) where studies contain much more abstract concerns such as *"behaviour, human ability, relationships between people and thing"* which are *"intangible, existing only in the mind"* or in this case, relating to the mind and how relationships and considerations of wellbeing are as important as any artefact. But more than just the mental endeavour of a purely Social Science framework, design research allows for outputs that give evidence to the research process in the form of designs.

In Nigel Cross's Design Thinking (2011; p.28), Gedenryd's view that *"intramental"* cognition was not a reality but that cognitive action involves *"practical and interactive qualities"* where the *"full system comprises mind, action and world, or a combination of thinking and acting within a physical*

*environment*" helps to elucidate the kinds of influences of creative practice and the potential for people to shape designs through their own experiences. Introducing the combined qualities that thought and action might be studied and understood, and that these appear as manifestations of an outcome through a designed process, the intention is to find ways in which this becomes possible for people living with dementia. As such, the work within this study proposes the use of creative practice and the outputs generated from that practice to question the situation being explored, in this case, living with dementia. In doing so, the opportunity is to explore how the design process might develop relationships and interactions between participants and particular design subject matter, that in turn helps to re-write expectations and perceptions. To undertake these investigations, experimental practices are required and will often make use of different tools and techniques. – in particular, generating content that adapts to the participants. As Lunenfeld (2003) suggests, this is common practice and allows the designer to be agile. Seeing what is required and shaping the solution to fit the exploration is, to an extent, far more experimental in structure and form.

*"The space of design research is as much like the novelist's library or cook's kitchen as it is the scientist's laboratory or the marketers phone book"*

(Lunenfeld 2003: p.11)

Experiments allow for the testing of theories and ideas within a specific context. In scientific terms experiments are replicable approaches that have set parameters and within which alterations of a particular element or parameter can be tested and measured. In the scientific method, the experiment happens within a lab or highly controlled environment. In the social sciences, experiments allow for the testing of theories and ideas but are much more accepting of the fact that uncontrollable variables (such as human behaviours) are likely to exist in the situation and will sit alongside many adaptable conditions. Set within the design ethnographer context, the design research like this supports seeing and drawing understanding from the actions, reactions and interactions of human beings, where out-with rigid laboratory structures, much more layered and nuanced interplays can be analysed and brought into more complex reasoning (Ball and Linden, 2018). Therefore, the design experiment, in the social design or ethnographic context, will be less commonly replicable and binary. Lunenfeld (2003; p.12) expands upon this when he states "*design as research is necessary to deal with a moment defined by pluralism and enlivened by serendipity*".

The experiment in itself becomes a test to see what might happen in a situation when something unexpected, unusual or uncommon is introduced but within a context that understands that other variant factors might also play a role. This is why the description might be better put as an intervention into a situation where a number of variables and unexpected results may occur but also where a number of different approaches, tools and devices are required. These are likely to be used in progressive and iterative practices that pose a means of directly acting or intervening in the space being examined. These interventions are not seen as a pollution of the method but a means for continuing the process or actions of participants. Adaptive in delivery, the approach requires observations to be made in the busy space of what is occurring and is most commonly supported by notes written at the time or directly after. These field notes and observations require reflection upon the recently undertaken design processes in order to understand the situation. Here, insights develop into such aspects as occurrence and framing of what has happened and as a means for creating stimulus as to how the researcher/facilitator and participants might act next. All of which feeds back into a cycle of reflective practice (Brockbank and McGill 1998) that could easily become a never-ending loop of practice-led, learning, experimenting, delivery and review that leads to the next project and evolutionary undertaking.

According to Collins, Joseph and Bielaczyc (2004; p.17), in "*Design Research the enacted design is often quite different from what the designers intended*" by which it is meant that parameters outwith the control of the intentions of the originating researcher will change what was intended or expected. This adaptive quality makes design research agile and uniquely ready to uncover alternative possibilities or outcomes as it yearns for serendipity. In response to this understanding, the Design Research Methods used within this study have had to be adaptive, open to alteration and indeed, disruption by participants. The appropriateness of the projects and tasks or design activities respond to the subject, behaviours, participation and emerging opportunities. The approaches and methods therefore recognise the view that "Evaluation of designs can only be made in terms of particular implementations, and these can vary widely depending on the participants' needs, interests, abilities, interpretations, interactions, and goals." (Collins, Joseph and Bielaczyc 2004; p.19). In recognition of this, any particular approach in this study will be at best unique to each individual set of circumstances, parameters and decisions. "*The effectiveness of a*

*design in one setting is no guarantee of its effectiveness in other settings.*" Central to Collins, Joseph and Bielaczyc's ideas of Design Experiments (2004; p.18) is that something occurs and is designed and opened up for testing and revised for further use, testing and interpretation in further studies but with an understanding that the conditions and variables may dictate that it is not going to be successful in uptake or application every time.

## 4.2 Co-design Workshops

*"workshop means an arrangement whereby a group of people learn, acquire new knowledge, perform creative problem-solving, or innovate"*  
(Ørnsgreen and Levinsen 2017; po.71)

The principal method of investigation, participation and action within this research has been Co-design workshops. The workshop is an approach that allows for concise processes of exploration to occur and where the generation of data in various forms can occur rapidly. Workshops can occur as single standalone events or as part of a series of approaches. In development of this work, the workshop method was explored in a number of ways and will be discussed further in this chapter. Key to the method is the ability to gain collaborative and active participation by those people involved in the approach. Workshops can be formed as scripted and directed methods or open and adaptive forms. Within this work, the open adaptive form became the approach required though it was not necessarily the expected approach at the outset of this work. A number of reasons influence this position not least of all developing social relationships, trusted environments and buy-in. Sprange *et al.* (2015; p.2) assert that commonly, dementia leads to "*de- creased opportunities for participation*" which "*can in turn result in reluctance to participate in life and associated rapid deskilling on the part of the person with dementia*". Workshops offer the participant opportunities to participate and support them to make use of skills, even those they might not know they have.

Workshops are widely recognised as a means of working with people and how they form is thought by most to be quite apparent. However, the approach holds much complexity and requires skilled facilitators to make them flow. When used in the context of research, they become challenging. The training workshop might have a goal to instil certain capabilities or to develop certain skills, knowledge and understanding. In terms of research, the workshop is more commonly used to

unearth and unpick details where a rigorous and rigid process is being utilised within which certain questions are being asked and different approaches to how information is revealed occurs. As a research method, “*the workshop is, on one hand, authentic, as it aims to fulfil participants' expectations to achieve something related to their own interests. On the other hand, the workshop is specifically designed to fulfil a research purpose: to produce reliable and valid data*” (Ørnbreen and Levinsen, 2017; p.72). The products of the exercises and the methods of participation are likely to yield valuable information, insights and data that can be reviewed, analysed, sorted and hypothesised.

The relatively new framing of workshops as a qualitative research method is providing some interesting recognition in terms of position, intensity and integrity of research actions that are time constrained but highly effective in extracting valuable data or generating informed propositions (Ahmed and Mohd, 2018). The nature of the workshop as a social activity of engagement and interaction means that relationships have the potential to develop and the subject being explored keeps a human centric focus. As such, the collaborative interplay of participants and facilitator/researchers allows for a platform of trust that supports more open modes of communication. Through these channels of trusted collaboration, it is more likely that activities and participations become natural and support a willingness to partake through ‘diving-in’ as opposed to being restrained from action because of personal awareness and fear (Tarr, Gonzalez-Polledo and Cornish, 2017; Ahmed and Mohd, 2018). Of course, the workshop fits into broader modes of research practice and is central to such ideas as, focus groups, user-centred research, co-design research or participatory design research where participants exist in any kind of volume, *i.e.*, more than one. With this in mind, the workshop is very much anchored in widely recognised practices. It is the reframing of it as a method within these approaches that validates what is achievable within this kind of practice. Recognising the workshops can exist in various forms helps to identify differences in purpose and practice and helps to lean on the participatory or co-design framing. In that sense, it is the bespoke nature and adaptable methodologies explored within research workshops that identifies and helps to extract important, data, performances, actions, responses and practice for interrogation, adaptation, analysis and further investigation.

There are many ways to construct workshops with methods to do so freely available. Workshops are most effective, however, when they are designed with a particular cohort and/or area of investigation in mind (Hamilton, 2016). This helps to build focus, purpose and shared sense of togetherness whilst working in whatever task or area of investigation that is involved.

Within the workshop or, as within this study, a series of workshops, tasks are likely designed to reveal new data and to test ideas and may include activities such as, sorting, arranging, brainstorming, mapping and constructing. *“These are common in generative research, with participants contributing to ideation through codesign”* (Hannington and Martin, 2017; p.140). Creative and playful activities are likely to be used to encourage more considered and explorative responses, yet to some degree, it is arguable that in design workshops responses are still somewhat directed (rightly or wrongly) to the specific line of enquiry. Within these design workshop parameters, the opportunity exists to give non-designers access to design tools and systems and, to some degree, create a platform of training for where learning, development and research, work as components that collaboratively unlock information and insights (Hannington and Martin 2017). As such, the participants in a workshop get a reward in the form of new experiences and skills which are situated within the context of *“learning by doing in the ‘studio’ format”* (Lawson, 2004). The creative research workshops build upon the acquisition of new skills developed in participatory modes and recognise the requirement for tool-sets, briefs, trigger objects and further activities that encourage participant exploration that is framed by constraints often aligned with expectations of the research agenda. These structures, tools and activities, create the framework for controlled experiments which most commonly direct participants. In such understanding, the approach is very often aligned to a form of action research where under controlled experiments, ideas and actions are tried and tested, reviewed upon and adapted for re-experimentation. The reflection within this loop of planning, action, review and reinvestigation supports the rigour of a planned and strategic framework of investigation but can be restrictive in as much as deviation negates the process.

As a result, a different condition of research workshop is required and this is dependent on a highly adaptive, serendipitous approach. This in essence is the explorative design process that uses research throughout, engaging with the unexpected, imbedded with the happenstance of designer’s ways of exploring (Grocott, 2003). When the explorative practice-led design process is

central to a workshop driven approach, the opportunity to evolve projects, their reach and participant capacity within the creative process is likely to be common. As a recognised method within workshop approaches, the 'open format' (Ørnsgreen and Levinsen, 2017) fills this requirement, it allows for adaptability by both the facilitator/researcher and the participants, supporting deviation and adaptation to occur "on-the-fly". Espousing the design disruption approach of intervening and altering known situations or approaches, the open framework engages methods of 'shaking-it-up' in order to draw participants into situations that change relationships to the known situation. Or, as Ørnsgreen and Levinsen (2017; p.73) explain, *"Participants' habitual practices can be obstructed and innovation can be provoked through the use of unfamiliar practices"*.

Co-design workshops in the area of design for dementia, historically, have appeared to be founded within this open format through creative research approaches but have often fallen short in their engagement of a full design process. The most commonly shared outcomes have been less likely to result in any real or recognisable disruption, in the examples reviewed in *Chapter 3*, the dementia led co-design workshop was most likely to end with a defined brief or a set of objectives but very rarely has led to the production of tangible designs. The approaches have often finished within this condition due to time and funding limitations. In theory, more common co-design workshops can afford short and intense bursts of action where the completion of each workshop can be seen as the conclusion of research. This can ultimately result in units of conceived participation at which time they are valued by all involved as being proactive and positive but ultimately lead nowhere. These workshops embody incomplete design processes, where things might be proposed and, to a degree, given parameters and details but not acted upon and as such, produce little in the way of completed designs or impact.

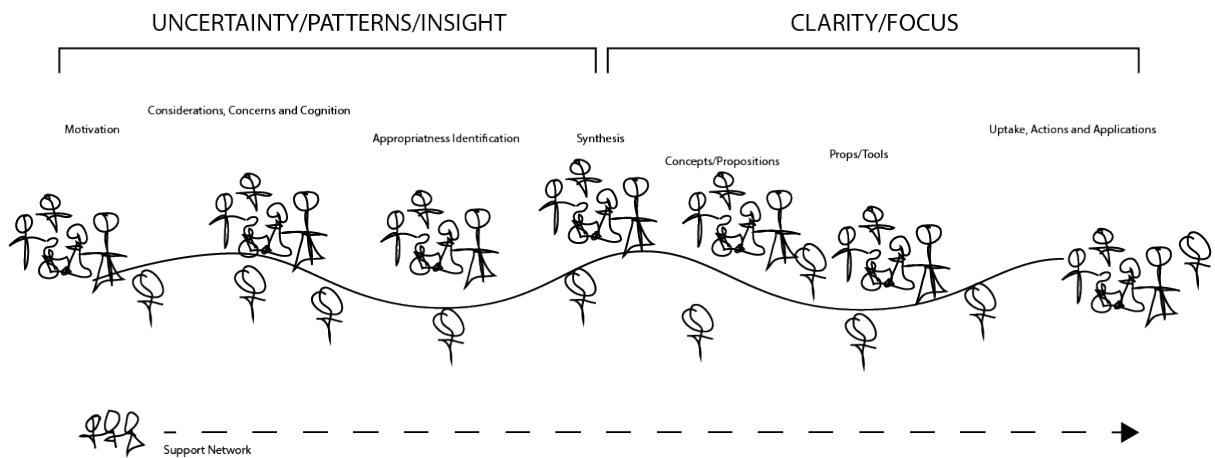


Figure 4.1. A proposed model for collaborative behaviours throughout the duration of this investigation suggesting shifts in prowess between the designer and the participants from project conception to project completion. Available support systems such as care providers are represented as a constant throughout.

The Co-design workshops in this PhD form projects that have adapted to become an evolving series of interactive collaborations, where each workshop builds on the previous one. Each time, more is added to the final design until the design is resolved and either enacted or given form. In this way, the design process is intended to encourage full-pathway interactions, design and making activities, discussions, provocations, frictions, agreements and results. By full-pathway, what is meant is that participants are engaged in workshops that support commitment in every aspect of the design process from 'phase zero' design research through to the production of designs for public consumption. The purpose of this is to both unpick latent creative talents but also to create objects that ask new questions and pose new ways of thinking about people and their capabilities whilst living with dementia. Therefore, the selected and designed approaches used for this research, to a degree, fall within Lawson's (2004) "*deskilling design*" whereby some rudimentary approach could be used to generate and articulate a design that responds to personal insights, thereby removing barriers to creativity, which include personal perceptions of inability. In order to achieve this, a suite of tools and processes are arranged to augment discussions and to generate real design solutions. The 'how' of the communication of designs becomes less important than the 'what' and 'why' that is expressed or communicated. Open and accessible approaches demystify the sublime design tools of drawing and form giving and circumvent them in order to ensure participant opportunity through rich and fulfilling engagement. Rodgers, et al. (2013) argue that the capacity for people to act as amateur designers or at least capable of undertaking tasks that constitute 'design thinking' approaches, is something that is increasingly democratised in this way. Delivered and explored

through workshop process where malleable opportunities exist, commentary and propositions become tools for achieving valued input, insights and outcomes. It is the methods in which these views are made accessible that becomes democratising and to achieve that proposition, it is most important that the methods are open, accessible and achievable. Importantly, it is also the view that, the purposes of willing participation, workshop methods should also be 'serious fun' (Rea, 1997) for all. According to Tarr, Gonzalez-Polledo and Cornish (2017), such a prospect will encourage positive and enthusiastic participation with a willingness to make things happen from those involved.

#### 4.3 Participation in and Supporting this Co-design Research

This PhD project is predominantly focussed on people with early onset dementia where participants were under the age of 65 and in early stages of their dementia journey. In this process, a clear indication of how the research is expected to occur is laid out in *Fig.4.1* where the key interactions are outlined as existing between the researcher and people living with dementia. In addition, the diagram places other relationships that must be considered within the approach, which includes environments, third sector care responsibilities and the inclusion of primary caregivers. Here, an understanding of the supporting infrastructure indicates a requirement for care in different ways and a need for a contingency when working with people who may have many different kinds of needs. This includes the third sector parties to provide support in and around the smooth running of the workshops, where specialist skills and knowledge is also required in case of an unforeseen event. These might include a person being disruptive or disinterested or needing assistance with something of a personal nature, for example, toilet breaks.

The inclusion of primary caregivers in the diagram recognises that they might have a role to play in the production of a project but also through engaging with preparatory work if and when required. The proposition is not that a primary carer might be central to a creative project but their potential inclusion should be accepted as a given as part of certain processes. Not least of all when consent is sought, as discussed in the ethical setting of this work, discussed later in this chapter.

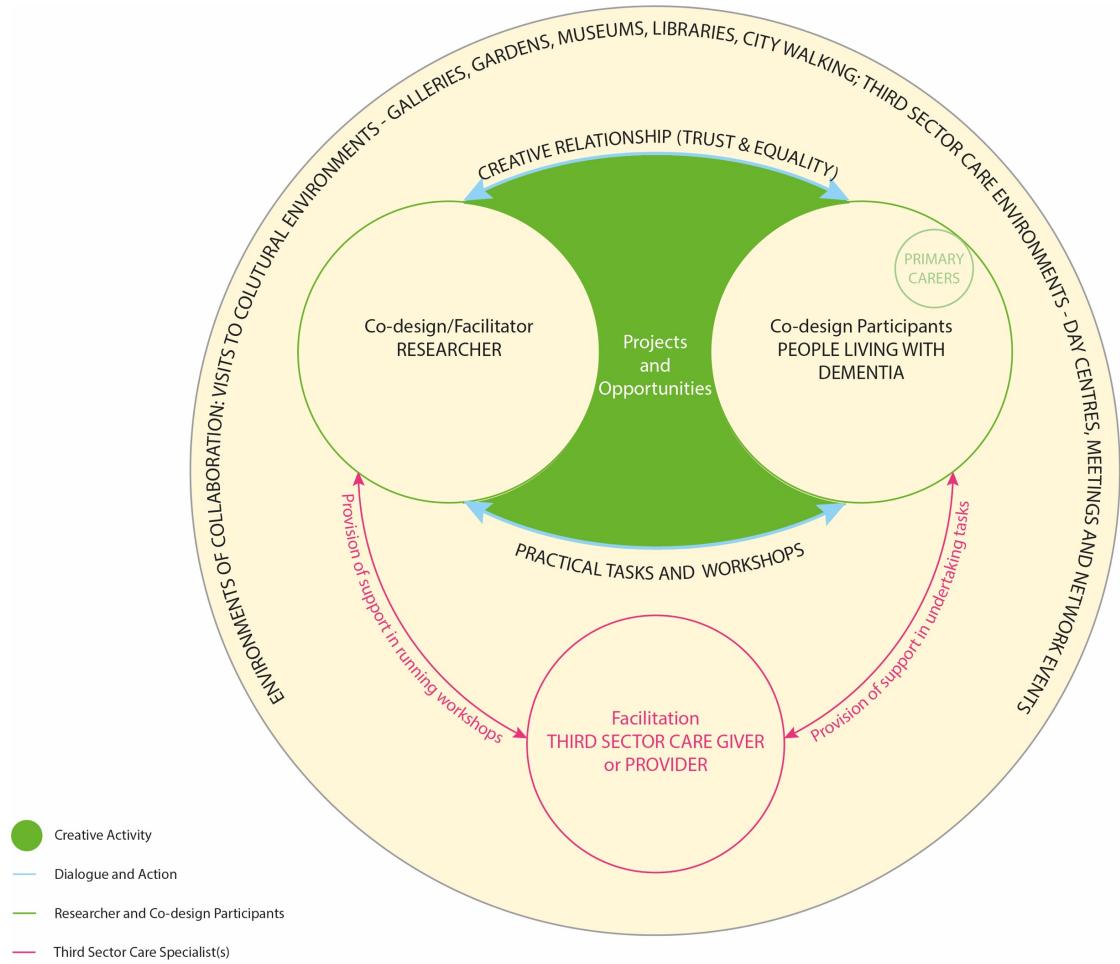


Figure 4.2. Diagram of relationships of participation in the co-design research method.

#### 4.4 Observational and Participatory Approaches in Initial Research

In order to understand the situation of creative care and to outline the appropriateness of this proposed method of research, preparatory enquiries were made. Observational research and shadowing of people in day-care support structures helped to illuminate the practices at a range of dementia care settings. The different environments offered solutions from reminiscence to art and music therapy. The environments also differed, for example, modernity of space, lighting and facilities were not uniform. This semi-ethnographic approach involved taking part in existing meetings, workshops, networks and day-care centres, on occasion being incorporated as a participant in activities and sometimes as a volunteer facilitator whereas on other occasions, acting as an observer secreted within an environment, invited to be there but not participating or interacting. The approaches were undertaken to inform the content and context of the proposed

co-design workshop-based research method as it developed. The process made use of photography and field notes and written records directly after the event, that would form the basis of reflective summaries and thoughts.

The culmination of this was the identification of working through processes which did not end with one task on one day. Instead, the process was to link events and actions over a prolonged project and an equally prolonged period of time. This worked with a desire to have creative projects align to a design process, which was more akin to Milton and Rodgers (2011) model of the product design process. This supported a creative approach which was discernibly different from art-therapy where, more commonly, the practice of expression in a short project delivers a solution that is of itself. Through the use of staged design actions, it is deemed that a more complete co-design model can be developed for people living with dementia to work within and through to generate outcomes that have wider significance than at the moment of initial conception. Ultimately, however, the process made use of conjoined creative practices which work with one-another to make solutions.

The research method for the following projects is, therefore, Co-design Workshops where an onus is placed on acts of proposing and making achieved through multiple interlinked methods applied within a design process. It should be noted that the creative methods chosen and developed to generate designs were the result of thinking about accessibility and capability, and that these approaches would be suitable for anybody participating in such a project without previously honed skills, e.g., drawing.

In the generation and curation of the workshops, many materials and approaches were therefore considered and selected including:

- Photography
  - Participant Photography - As part of the documenting and collecting process photography was perceived to be of significant importance. Charged with undertaking their own primary research, people living with dementia were able to quickly record content visually. The quality of the photography was of no great significance. Instead, the what and the why was to be key. The participants were each given a camera which

was part of the researcher's own kit. These digital cameras were provided with clean cards and the numbered cameras were handed out and collected in with note taken of who had which device. The collection of photographs was compiled in folders and used as a resource in the development of workshops and projects.

- Researcher Photography - When it was not suitable for the participant camera kits to be used, the researcher became a photographic resource and was guided by the participants as to what required capturing on any particular visit.
- Collage - Collage was a production tool that was widely used in this project to afford people who had limited time to create sketches or who perceived their drawing skills to be inadequate to give a visual form to their thinking. The approach could be merely visual or might contain notes and words self-generated or also collaged to create layers of meaning to their visual representation. As Jenny explains ,this helps to limit confusion or open interpretation reinforcing the meaning and contained values of the work that is ,or has been, produced.

*"We can find what is beautiful and note this either on the back or within the drawing. Even a few words can easily affect the meaning of the drawing; the many possible interpretations of any sketch encourage this."*

(Jenny, 2012; p17-18)

- Printing - Formats and approaches were by direct or mechanical application of inks or paints and affording repetition of form to easily occur. Working largely in rudimentary block printing, participation supported direct actions in inking and blocking. As projects developed, technical printing tools used included transparency and fabric printing on digital/mechanical systems.

*"Processes and functions intrinsic to print media inform the very strategy of art-making... structural and conceptual perspectives, the how and why of printmaking can hold many creative opportunities"*

(Garbowski and Fick, 2009; p7)

- Painting - The direct and expressive quality of applying paint allows for inventive, playful and yet known interaction in creativity to occur. A very natural experience for most participants, the application of colour with a brush to a design afforded an empowered sense of direct action.

- Discussion - As a socially charged activity, design requires the interaction of parties and enquiry and conversation is a key component. Though much of the conversation may not be recorded in the research data, it is what greases the collaborative approach and supports actions and outcomes as they are generated.
- Commentary - verbal and documented through the use of written expression, commentary is key to the design and feed-forward process where insight and values may be shared and often triggered by the designs or design propositions being expressed and explored. The ability to respond directly to that which is directly in front of a participant allows for in-the-moment analysis.
- Modelling and Prototyping - Incorporated within the facilitation of workshops, it was posed that methods for making ideas tangible would occur. The methods required to do so needed to be able to respond to the outcomes desired. Modelling required materials and template and on occasion tools specific to the job.

The research undertaken, through the design processes and incorporating workshops has been created to develop a collaboration which was consistent and which encouraged engagement at every stage. The incorporation of this required all parties to relate to, and to respond to, one another. Without agreement and actions at the prescribed design process stages, the intended collaboration would have been deficient and expected to result in incomplete design resolutions. This process of investigation was, therefore, inextricably entwined within the design process where the evidence of achievements could only be achieved through a co-design journey. In *Fig. 4.3*, the process of enquiry has been mapped to Milton and Rodgers 'Product Design Process' (2011) to explain the methods used and their relationship to participation in what could be recognised as a full-design journey.

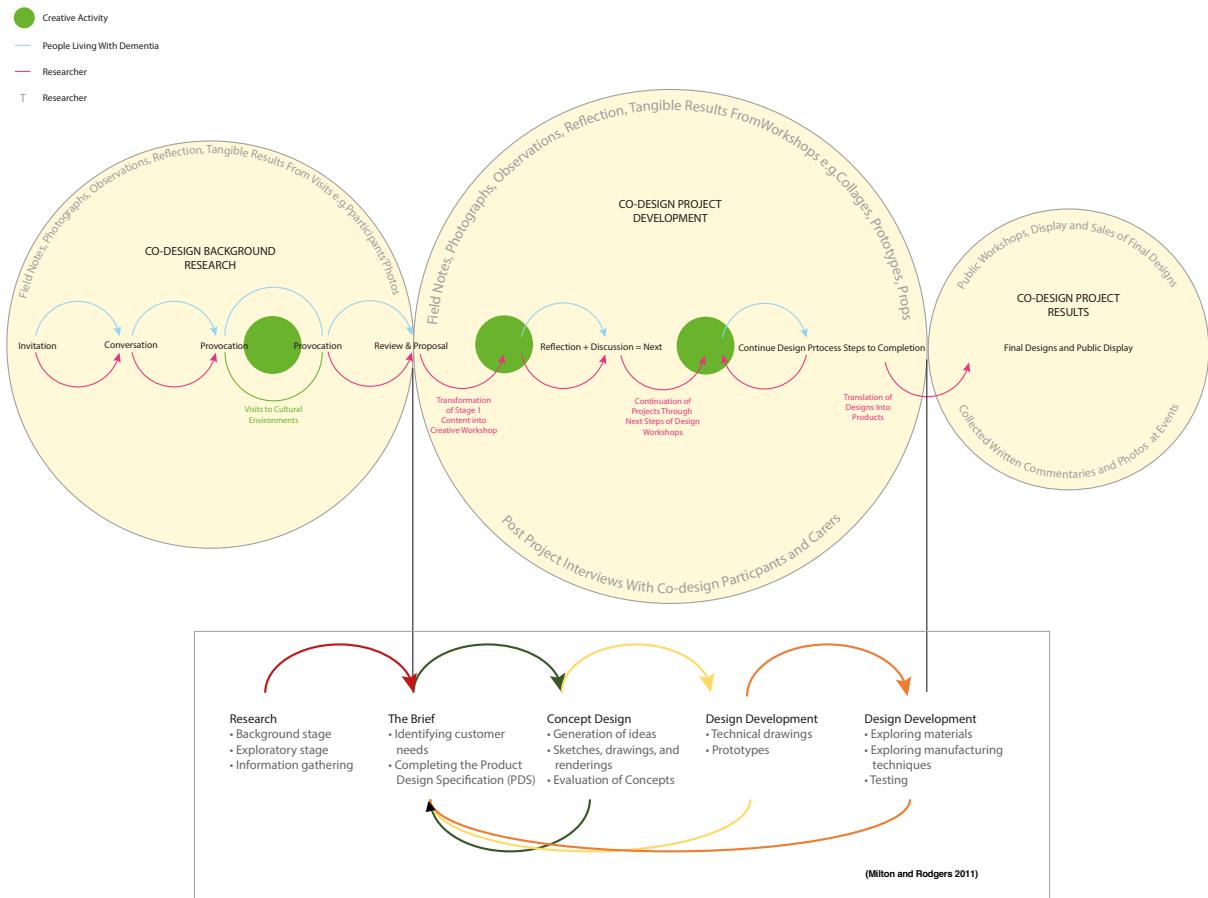


Figure 4.3. Method of co-design investigation mapped to Milton and Rodgers 'Product Design Process' (2011)

## 4.5 Settings and Facilitation Dynamics

### Environments

The research has been designed to work within recognised dementia care settings where scheduled events are supported by trained care specialists. These are third sector environments and organisations. The environments are designed to be accessible and suitable for a variety of people to use. They also supply multiple on-site support services including peaceful spaces in case any user required it along with councillors if needed. Accessible toilets, furniture that is robust and which limits the potential for somebody to injure themselves, suitable lighting, refreshments facilities and maintenance departments all had to be ensured. Some of the environments even had their own communications and research teams, which enhanced their offering.

Eventually, through trial and error (discussed in Chapter 5), it was discovered that the group or activity-based services that delivered periods and programmes of care would also become a significant resource within these settings. These existing networks, scheduled meetings and activities became central to facilitating the research within this PhD.

### Researcher Training and Vetting

In practice, workshops were initially devised to be run as stand-alone events and as such, training in working with people living with dementia was undertaken as were background checks for working with vulnerable groups. PVG (Protection of Vulnerable Groups) certification is now a necessity when undertaking such work in Scotland.

### Third Sector Staff and Facilitators

Third sector carers and staff provide invaluable support in facilitation of workshops. It is beneficial if they are interested in creative approaches but not a necessity. Their involvement in the research process (especially where and when the workshops occur within pre-existing groups), meetings and networks is invaluable. This kind of facilitation ensures that participants and their family members are reassured by the projects and their purpose indicating support and commitment from the organisation involved. The third sector representatives can act as mediators and communicators with families and can re-assure them that the situation is beneficial.

During workshops the third sector staff and care givers can perform roles which aid the facilitation of the workshops, this can involve working more closely with an individual or making sure that each participant has access to the equipment, materials and tools during the process. The support staff also provide a common link to the centre where the researcher is not based. This means that a sense of continuation of the project can occur. The staff can alert the participants as to when the next workshop or visit is happening and to remind participants of what has previously been done before the arrival of the researcher.

The relationship of providing suitable workshops therefore involves all of the Co-design Participants (People living with Dementia), Third Sector staff and environments and the design researcher.

## 4.6 Ethics

The ethical setting of this investigation occurred under the University of Lancaster framework fulfilling the requirements of the panel of assessors.

Ethics in academic research have been increasingly important over the last decade and although a requirement to be ethically responsible especially in a scientific perspective has been around for a long-time, the need to explain processes and expected outcomes prior to undertaking a project is relatively new in the design and the creative arts. A discussion of this aspect develops questions as to whether or not pre-ordained expectations are suitable for a subject which looks for the unexpected as part of its processes of activities. There has been significant discussion within the area of suitable ethics for designers, though this is still very much to be developed into academic settings and practices as well as other emergent design considerations (Dilnot, 2005). Further discussion of ethics and design by Monteiro (2019) suggests that it might be time for design to have a code of ethics which is designed for use within the creative industries and understands that unknowable ventures are undertaken with a hope to achieve unexpected outcomes. In this form, a proposition appears to be more closely aligned to the concept of the 'Hippocratic Oath' sworn by doctors before they are allowed to practise. Dilnot would argue that an ethics for design has to be flexible in nature and capable of moving between many modes of investigation and that must now cover the online artificial environments as much as the real world. Therefore, anything that might be suggested will either have to be immensely complicated or curiously simple. It may be that a proposition that never knowingly or intentionally does any kind of harm is open enough to allow exploration, supported by responsibility and to avoid risk averse practices through measured consideration of the situation at hand and how it should be navigated (Tsekleves and Cooper, 2017; Monteiro, 2019). Adding to the discussion, Lunenfeld (2003; p.12) expands upon why a fixed perspective cannot work within the undertaking of design research when he states "*design as research is necessary to deal with a moment defined by pluralism and enlivened by serendipity*".

Although ethics applications and constructs may be troublesome, it is a requirement of academic enquiry to work within the restrictions which are aimed at covering ethics across the institution and in consideration of doing so, key concerns had to be considered and addressed. Predominantly in

this work, ethical and moral problems within areas such as design for dementia were addressed through identification of private individuals and the subjects and through securing consent for participation and recording of actions. Further, obligations for care, suitability of settings and supporting individuals also required significant consideration as did the roles and responsibilities of me, the researcher.

This is where the expectation of procedural ethics, as commonly constructed within institutional settings, with a singularity and expectation of research and outcomes is not always the correct approach. It is clear that behaviour in working with people living with dementia is important but so too, is the use of behaviours and natural ways of being which are most commonly revealed through Situational Ethics (Rosenthal, 2019) that takes into account the full understanding of the situation being explored or *"all normative features of a situation must be viewed as a whole"* and further requires researchers to be adoptive and to act with compassion, understanding and recognising their own contribution to any given scenario as playing part in the research process. Thus, the development of an ethical approach by me, the researcher, required a proposal based within the academic system, but also required a recognition that the approach must be open to change and adaptation to fit with the investigation. In this case, working with people living with dementia focussed upon the fixed position of how data might be managed to meet the expectations of projects and of all parties involved. The most fluid dynamic within the approach required the ability to reshape or frame collaborative workshops so that they might respond to the emergent situations.

By accepting the need for a situational position in regards to face-to-face working and the evolution of workshops or collaborations, the ability to find unexpected outcomes and therefore informative situations or positions becomes more authentic. This means that the approaches do not force a position or proposition on to participants but invites their influence, postulations and insights.

In preparation of this research, consent was applied for and received through Lancaster University's Ethics Committee.

The application identified workshops as the central method of research practice and identified issues concerning data collection, storage and dissemination. In support of this application, AHRC

recommendations and guidelines were reviewed and adhered to. The result shaped how people would engage in design projects and respect their rights to remain anonymous and to opt out of participation. The process also defined how data would be collected, stored and shared.

The approach limited what was to be collected and reduced ideas of what might have been valued in order to find a workable solution. As such, photographic records and audio recording, field notes and collected written commentaries along with the generated designs were seen as appropriate methods of data collection. Video recorded content was eschewed due to the complexities that this might bring.

The writing of the workshop intentions left enough wiggle-room to facilitate changeable scenarios and focussed on the agreement on the kinds of approaches, management of risk and working with confidential information along with those previously stated.

The description of how people chose to be involved (which follows) clearly shows that, in a process that is supposed to support individuality and personal decision-making, the ethical controls of the university and the partner organisation has the potential to automatically close down selection and so strip people of their personal autonomy. This is despite the basic objectives of this work, which was working with people in early stages of early onset dementia and to give them some degree of self-empowerment.

### **Consent**

A common and sometimes troubling perspective is that people living with dementia are not capable of providing consent alone. Building on the experience of undertaking this work, this is a view that could be challenged but in order to be risk-averse, participation consent was required of both the individual and their primary care giver (family member). In practice, the judgement as to who can provide consent existed within almost committee-like gatekeepers involving the centre or networks wherein projects were to occur, the participants themselves and their family members or caregivers. This appeared to be counter intuitive to the ideas of personhood (Kitwood, 1998; Mitchell and Agnelli, 2015) and self-efficacy and of Alzheimer Scotland's 'Charter of Rights: For People Living with Dementia and their Carers in Scotland' (2009). Within the practice of this

research, it can be agreed that the participants were personally invited to take part. However, it was evident that they did not have the final right of say, and that other parties would control their agreement to participate. This situation was also dictated by adherence to the Lancaster Ethics Committee approval system.

### **Personal anonymity**

All participants have been respectfully anonymised so as not to be identifiable, to respect of their privacy, and in accordance with participant agreements.

### **Supported Responsibility**

Responsibility for running the projects lay within settings where dementia care already existed, a result of which was buy-in from professionals in the field and the ability to make use of their expertise. The projects were undertaken with continuous support of trained professional carers associated as employees or volunteers with Third Sector organisations and in particular, Alzheimer Scotland using their networks and environments. The professionals engaged to supply these kinds of care and support ensures that at no stage of the research practices would there be either uncertainty in roles and responsibilities or a burden to provide specialist responses to unexpected scenarios or disruptions. This was important, in particular, should participants wish to remove themselves from activities, became disruptive, disinterested or upset in any manner.

### **Personal Responsibility**

In order to commence the research, significant training was undertaken. This incorporated dementia care and facilitation training through Alzheimer Scotland, Protection of Vulnerable Groups certification (Scotland), and training and certification with Generations Working Together. Through these training and accreditation exercises, suitability for design research in the field of dementia was reinforced and responsibilities for behaviour along with an understanding of how to respond to difficult situations has been developed.

## 4.7 Generation and Collection of Data

Figure 4.4 below is an extract from the ethical consent form produced for the Lancaster University's Ethics Committee this extract sets out the intended procedures for collecting and anonymising data. The intention was to utilise the products of the workshops to represent achievement and capabilities and to illustrate the recorded actions leading to their creation. These products of the collaborative design approach have been supported through semi-structured interviews, field notes, open conversations, audio recordings and photographs. These practices were deployed in different situations and have been structured to be dynamic, responsive and constructive dependent on how and when they are applied. For example, field notes were used to capture a conversation, a happening or particular approach occurring during the workshops, visits or task-oriented situations. The field notes approach required short term memory recall on completion of the workshop and were supported by reminders captured on notes on a phone during the event.

Semi-structured interviews and audio recordings occurred on the completion of projects and were open to shifting discussions of what had been done, why and how. The semi-structured approach allowed for the discussion to develop organically and reminded the researcher to come back to points identified in preparation of the interview.

Throughout the data collection and in accordance with good practices, communication of an individual's name or representation has been altered to preserve anonymity.

As the project developed, it became clear that this preserved anonymity appeared counter-intuitive to what the project was engaging with. The project set out to champion capabilities of people living with dementia, to develop personal and public esteem and to present at times ground breaking achievements of the individuals involved. To remove the names of the individuals who might have created wonderful solutions or products would appear to undermine their achievements and sense of pride and accomplishment and furthermore remove their right to be credited with such outcomes. However, for the purposes of working within the rules and guidance as set out by ethics committees the ethics rules in Figure 4.4 were adhered to.

#### Recording of Data

During the workshops data will be recorded through field notes, photography and semi-structured interviews (questions attached); and in the form of the artefacts generated in the making process of each workshop. Audio recording will be used as a method of recording data during the workshops.

#### Note taking and semi-structured interviews

During the workshops any note taking interviews (semi-structured approach – questions attached) or conversations will be recorded through a first name only basis. If two or more participants share the same first name the use of a numeric additional identifier will be used.

#### Use of photography for academic publications or other dissemination

The focus of photography is based upon wide shots of the group and close up ‘actions of doing and making’ where the focus is not upon an individual’s face. At anytime, when an individual’s face is recognisable pixilation will be applied to protect anonymity

#### Use of audio recordings for academic publications or other dissemination

Any recordings that will be transcribed will be treated confidentially; as such the data will be used and shared in the following ways.

- Participant’s names will not be used in any conference or academic papers. This work is part of an on-going PhD study and will likely form the basis of papers for academic conferences and publication and the production of a PhD thesis.
- Audio - It is possible that short extracts from the audio transcriptions may be used in sharing the project through web-based platforms, in conferences and public disseminations and the PhD thesis. In extension audio transcriptions are likely to form part of the wider conversation of the project. Participants have been advised of this in the Project Information Sheet and each participant must grant their permission through a consent form (supplied). Any audio transcription in which the commentaries or actions of the participating group are shared will be used in a manner where no names, ages or location identifiers are used.

Figure 4.4 Data collection information as provided to ethics approval and participants.

## 4.8 Researcher Position - A Discussion of The Outsider

Undertaking this research required overcoming considerable fears and doubts and to challenge a personal feeling of “do I have the right to be there?” Personal inferences, expectations and prejudices informed a sense of being an outsider and perhaps even of being incapable of doing anything of great value in regards to the problem of dementia. It was the perception of the researcher that after all, this is the medically ringfenced physical and mental decline of an individual, which at first glance, appears to be the most important point for that person. Therefore, it was difficult to consider that any proposed action-led intervention would really be of value. In particular, the works that were being proposed did not look to find any kind of cure, or a significant method for slowing the progress of a dementia journey and so as a researcher, a constant doubt of value, purpose and validity in working in the field created a degree of angst. This was further informed by the work being situated within the charitable support system where many individuals have very

deep and personal motivations for working with the organisation or indeed volunteering within the various care processes. As such, the sense of being an interloper within this care setting was almost tangible. I have my own personal histories with dementia through the experiences of grandparents and within this personal framework, the research has led to a form of self-reproach where I have been able to reflect on my involvement in caring. The positioning of a researcher in any field can be a challenge but in an emotive and widely experienced situation such as living with dementia the thoughtful, considerate and value actions of the person involved in the research process has proven to be a real challenge. In undertaking this work, it has been evident that the ownership of dementia as a body of research, investigation and action has become an interesting and challenging proposition. Many parties are involved in care provision, all attempting to intervene in a multitude of ways - supporting physical and mental stimulation, through to raising money and providing resources, and through to the clinicians and scientists dedicated to finding cures; being part of this world can feel very inclusive and simultaneously exclusive. Undertaking this research has therefore challenged personal positioning and historical experiences and has led to a sense of outsideness. The outsideness sets up a challenge to a personal sense of value, purpose, worth and right to be involved and challenges the researcher's skills to find answers to any related issues. It became clear, however, that through the initial observations and supportive approach that gaining confidence of participants and feeling part of the group would prove valuable.

*Vignette:* On one visit a participant had become uninterested and despondent. She was not happy to be involved with the group and had taken Umbridge with the care support staff. She was reacting out of character including using swear words. I offered to talk to her and persuaded her to join me in undertaking a drawing exercise (artistic approaches are important to her). Quite quickly she settled and her anger dissipated, she soon re-joined the group and took part in their activities. By gaining common ground and providing support I managed to build confidence and show my value to the group and that particular individual.

## 4.9 Chapter Summary

This qualitative study is focussed upon responsive workshops tailored around excursions and explorations of cultural venues with people living with dementia. In this approach, Co-design is the central consideration of the workshop approach where iterative developments and staged design developments aim to engage participants in the fullest collaborative design method possible. The approach was expected to result in designs that would imbue this process and which told a story of the approach. In undertaking the workshops, reviewing participation in the process, understanding the collaborative dynamics and analysing the outcomes, a number of methods were employed to collect and generate data which included, photography, field notes, semi-structured interviews and public display and recording of public responses.

What the following two projects communicate are the ways in which investigations occurred and the changes that had to occur in optimising working practices and delivery of workshops in order to derive a suitable productive solution. The communication of the project explorations in Chapters 5 and 6 explain how planned approaches failed and how they had to be reconstructed to align with emergent possibilities. The results of this are highly engaging design research explorations. The projects also display how collaboration over time can develop Co-design that is highly sociable and inclusive.

The focus of collaborations contained within this work focus on a specific group of people with early onset dementia where participants are under the age of 65 and in early stages of their dementia journey. As a result, the work develops collaboration with people who have dementia who are not usually engaged at a stage in their journey where coping with and management of conditions is seen as most important. The approach here changes this focus to present ways to keep people active, socially engaged and appreciated for their capabilities.

## Chapter 5: Co-design Workshops Part1 - Failing to work *with* People Living with Dementia

The series of co-design projects featured in this PhD have involved many attempts to work with groups of people living with Dementia and sometimes with their primary care givers (carers). This chapter discusses initial approaches and ideas. It outlines how they failed and leads into Chapter 6 which explains how more effective co-design workshops occurred. This comprehension further underpins Chapter 7 where a framework for how designers should approach designing for early-to-moderate stages of early onset dementia in a collaborative fashion is posed.

Within this chapter, an explanation of how initial intentions and framing had to be adapted to achieve the fuller collaborations and associated activities discussed in the next chapter, '*Co-design Workshops Part 2: working with people living with dementia*'. This discussion shares how failing to instigate the initial plans led to adaptation, retrial, further adaptation and eventual reframing of the work. Here, the trials, pitfalls and successes of running this series of co-design research events shares the complexity within this rewarding method of enquiry. Resulting in more precise methods for undertaking collaborative workshops, this chapter starts by discussing the initial hopes, intentions and methods explaining how they informed the consequent achievements by those involved. The discussion of the early project struggles reveals an unenlightened starting position aligned with an over-ambitious proposition that could only be overcome by immersion within the situation. The shaping of the programme of workshops demonstrates a design approach where iteration informed and shaped future solutions. This aids the reader in understanding the final accomplishments in the following chapter that were achieved through progressive distillation of methods. Situated within five years of continuous collaborations with people living with dementia, the more successful components (in terms of delivering designs and design solutions) form the concluding part of a much longer co-design research project. The discussion naturally develops a view that continuous refinement and adaptation are synergetic with a fully adaptive co-design approach.

This chapter also responds to Moher's (2007) postulation that researchers should be morally obligated to share the negative results, or in this case experiences, along with the positive to overcome 'publication bias'. The chapter elucidates the tenacity required to direct research and to find appropriate ways of working, where 'learning from failure' enriches and streamlines the eventual process driven outcomes in the following chapter.

## 5.1 Initial Observations of Group Activities shaping Workshop Approach

As previously stated, to understand the existing nature of charity delivered workshops, a series of largely observational and sometimes participatory investigations was held. Within the settings and premises run by the service providers, varying group approaches were reviewed. These included singing groups, arts tasks, discussion forums, reminiscence group activities, coffee and chat groups, through to research and activism led participations. The groups consisted of a number of people who had been at different stages of their Dementia journeys and who displayed different engagements as a result. The observations allowed for a better understanding of the ways people are stimulated and engaged in tasks. The studies revealed the capacity for people to inform situations where the likes of SDWG and EMELDAN were proactive, embracing a strong willingness to change, shape or influence the dementia experience. No matter what aspect the observational research was reviewing, an over-riding component was a willingness for PLWD to get involved. In task driven and particularly arts driven tasks, the participants displayed enthusiastic engagement - diving in and getting involved.

When observing the more therapeutic tasks, such as those witnessed at the Alzheimer Scotland Resource Centres, the Open Door and the Eric Liddell Centre, little was expected of the creative and participatory actions other than what was done directly there and then. These tasks were of the moment and for the moment in order to fill time. The largest issue stemming from these observations and supported through secondary investigations, was that all too often, the most direct tangible creative ventures in these settings had been fixed within an '*art for art's sake*' context. In many of the activities and

outcomes, the creative nature of what was created was seen as a therapy or pastime which limited the value of tasks undertaken. This kept them within the closed confines of the environment in which they were created. The closed loop of creative care appeared to display no wider impact than that directly experienced by the participants.

On reflecting upon what had been observed, it was considered that introducing design activities that could provide more publicly meaningful outcomes could be a valuable investigation and opportunity for PLWD. The proposition was that design practices might stimulate authentic, applicable design intentions for the real world, where the outcomes could be valued by people outwith the restricted environments of Dementia Care. Initially these were posed to PLWD groups and expected to occur through a willingness to partake and through a self-selecting capacity to engage with a list of free co-design workshops.

## **5.2 Initial Research Proposition: Intergenerational Activities and Opportunities**

As part of the early intention of this work it was also hoped that a platform could be proposed and developed for intergenerational working where young and old people could be supported in undertaking collaborative practices.

In preparation for this proposal, training in Intergenerational Facilitation was undertaken through the Generations Working Together network. This Scottish network provides training and resources in order to encourage and drive intergenerational activities. Through integrating an intergenerational approach, it was hoped that sharing of skills would likely be a valuable proposition for young people and PLWD. This view was informed by the knowledge that many young people are likely to have personally experienced dementia through a relative or loved one. It was further enhanced by the observations at the Open Door where two of the facilitators were brothers in their early teens. The brothers were fifteen and seventeen years old respectively and had been involved in the Open Door through their grandmother who had dementia. The

seventeen-year-old acknowledged that he hoped to study medicine and was aware that being involved in such a group was beneficial for his future.

With this intergenerational view-point being considered, it was proposed that design solutions, interventions and events could be created where collaboration across the ages could direct creative solutions. The work aimed to challenge the observed, traditional approach where dementia support groups are closed off from the world around them. The thought was to explore how design activities might support intergenerational relationships that would be mutually beneficial and that engaged with the locale in order to affect positive societal impact.

This societal impact was to be documented and reviewed through the development, application and production of design outputs shared in local community settings. An objective of the proposal was to reveal ways of working through intergenerational collaboration that highlighted and valued the skills and knowledge that each participant possessed. It was hoped intergenerational understanding could lead to insightful societal change, suggesting new ways of affording marginalised citizens power to affect change.

### **5.3 Trial and Failure in Developing Interdisciplinary Events and Approaches**

For the better part of a year, workshops and scheduled events were imagined, posed, scheduled and rescheduled. The series of workshops had the aim of undertaking design projects that would get people thinking and creatively responding to the local environments in which they lived or regularly visited. The propositions had the design intent of generating something that could act as a sign post, system or new product for the local community. Here the idea was to explore the idea of what a community is and how PLWD might engage with, inform and design for those communities. The hope was to explore the proposition that PLWD have creative capabilities that could be valuable for people outwith dementia care/support environments.

Under the title ***Designed with Me***, which suggested an inclusive collaborative proposition, a series of workshops were promoted. The suite of workshops invited people to take part

in sessions where they would set briefs and respond to propositions or opportunities. The intergenerational workshops were based upon a programme of six participatory 2hr sessions. The workshops were designed to utilise accessible creative practices such as collaging, mapping, modelling and brainstorming. It was a fundamental of the approach that PLWD would not be stigmatised and their views not disregarded. Ultimately, the project had the intention of exploring individuals and their capabilities, making them primary protagonists in any design actions. Central to the approach was that the participants would explore localities together, in a variety of integrated ways, before identifying where they might be able to propose new designs or designed interventions.

#### **5.4 Testing of Proposed Design Workshops**

In preparation and development of the workshops, the planned processes were the subject of a test event. Working with 8 Masters of Design students under the age of 25 from Edinburgh Napier University, the project, its intentions and the proposed activities were tried and tested. The process garnered insights from the group identifying the time skilled designers required for each proposition. This quickly revealed that even with expertise some aspects took much longer than anticipated. Though completely at odds with the experience of the intended co-design participants, the students were richly placed to de-compose the suggested methods and to make or provoke alterations to the ways in which the possible workshops might be delivered. Their input refined the workshops tasks and time expectations.

#### **5.5 *Designed with Me* Workshop Propositions**

This first series of independent workshops were organised for the Eric Liddell Centre (ELC) in Edinburgh where dates, times and space were booked and time was set aside by its Dementia Support Team. The ELC commitment to the project was in the form of space and staff-time for free which provided evidence of its belief in the intended approach. The independent nature of the workshops refers to the situations in which the events were set.

These did not form part of any existing groups or networks and were open to people who had not used the dementia resources at the ELC before.

The series of workshops were promoted through various Dementia care contacts that had been developed for this PhD including the Eric Liddell Centre, link workers, other private care providers and Alzheimer Scotland. Verbal presentations of the workshops were supplemented with posters in venues and through the various online networks and locations connected to younger generations. To develop the intended intergenerational approach, the local High School (Boroughmuir), Edinburgh Napier University, Young Scot, The Scouts, Generations Working Together, and the Duke of Edinburgh Awards Scheme were engaged with. These organisations offered and supplied support in promoting the workshops to younger generations including creating incentives to do so.

To further support the project and to offer a route to additional information the *Designed with Me* website was developed. [www.designedwith.me](http://www.designedwith.me) and was designed within the guidelines set by the National Dementia Communication Group - DEEP (2020). This meant that inclusive design was used to ensure appropriate message transmission. To be open and to encourage inclusion the web-based content was conversational instead of directive. The intention was to minimise a sense of participants being studied and to maximise a message of wanting to work with PLWD and other proposed participants.

Figures 5.1 and 5.2, which follow, show how the workshop propositions and series structure were communicated.

*The activity driven projects of **Designed with Me** have been created to give you the opportunity to think about local sites and opportunities for you to design interventions. You aren't expected to be a designer or have any artistic skills; just a willingness to try stuff and do things with the support of others.*



#### **Share - Collaborate - Play and Create to Improve Your Community**

Map My... is the first in a series of 6 intergenerational workshops being run at Eric Liddell Centre (Morningside, Edinburgh) during the Summer of 2016. The workshops have been designed to allow young people and people living with dementia to challenge their local environments. The first pair of events will be creative activity filled, brief generating sessions. During these intergenerational exchange and collaboration workshop you will work with someone older or someone younger to find opportunities to creatively intervene in the local area. The first session will be on **13th July 2016** from 10:30am and each workshop will last for about 2hrs.

**If you are between the ages of 16 and 25** and would like to explore your design and creativity through collaborations that identify issues or opportunities for design solutions, please apply to take part now.

**If you are a person living with dementia** and want to be proactive in informing, influencing and changing local communities or environments, through design explorations and working with young people, then please apply now.

If you would like to take part please contact Euan Winton by email:  
[EWinton@Alzscot.org](mailto:EWinton@Alzscot.org)



Figure 5.1 Initial independent workshop call poster including desire to run an intergenerational aspect



#### Workshop 1: A Local Picture

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Where: **Eric Liddell Centre, Morningside, Edinburgh**

The first workshop uses collaging to understand what people think a place is and how it is represented. This approach gives us an idea of what people think the place is like from their own perspectives or in this case shared perspectives.

**Duration:** 2hrs

**Tools:** Supplied + Your Hands + Your Eyes + Your Thoughts

**Materials:** Will be Supplied (unless you want to bring pictures you have taken or collected and that you are willing to cut up to create a new vision with)



#### Workshop 2: Map My...

Date: \_\_\_\_\_ Time: \_\_\_\_\_

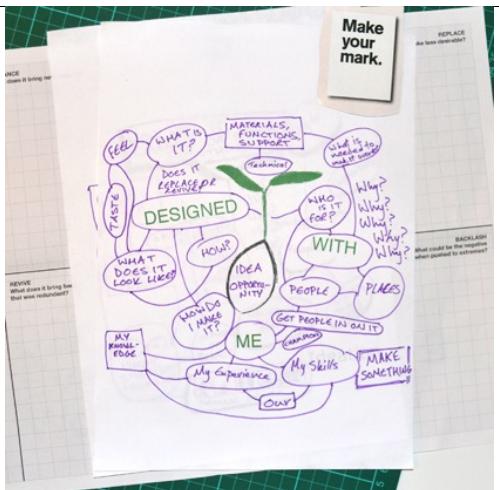
Where: **Eric Liddell Centre, Morningside, Edinburgh**

Using the process of mapping you will look for the 'Good the Bad and the Ugly' of local environments. Through a walking and talking tour supported by maps that you will be encouraged to draw on and write upon, you will look for positive, negative and un-considered elements of the local environment.

**Duration:** 2hrs

**Tools:** Supplied + Your Hands + Your Eyes + Your Thoughts + Your Walking Shoes

**Materials:** Will be Supplied



#### Workshop 3: Ideation – Coming up with ideas based on previous research

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Where: **Eric Liddell Centre, Morningside, Edinburgh**

Building upon your image making and mapping of the local area you will develop ideas in collaboration with your partner based upon what you know. A design champion will help you through the process. By the end you will have at least one idea for taking a next stage.

**Duration:** 2hrs

**Tools:** Supplied + Your Hands + Your Eyes + Your Thoughts

**Materials:** Will be Supplied



#### Workshop 4: Prototyping

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Where: **Eric Liddell Centre, Morningside, Edinburgh**

Taking your idea to the next level will involve prototyping, there are lots of ways to prototype an idea and your skills can be very useful. The biggest asset you will bring is open to new ways of doing things and to try new ways of making your ideas tangible.

**Duration:** 2hrs

**Tools:** Supplied + Your Hands + Your Eyes + Your Brain + Your Partner

**Materials:** Methods will be supplied

Figure 5.2 The poster/web information created for the first four of the planned six independent workshops.

Although every effort was made to create a series of independent workshops under their own identity, the approach proved unsuccessful. A limited response from young people was achieved, where only three young people positively committed to being involved. Even more disappointingly, no PLWD expressed a wish to be involved. At this time, additional effort was made to utilise the groups and networks that had been involved so far. Alternative dates were proposed and further promotion through presentations at events were undertaken. In addition, a meeting was made with a local link worker to make new connections. The outcome was equally unfruitful and it became apparent that this was not going to be a successful approach.

It was noted that alternative approaches to engaging participants was required and a reconsideration of the structured workshop approach might have to occur. It became evident that it would be particularly difficult to realise the intergenerational intentions of these proposed workshops. The intended workshops were clearly going to be difficult to gain participant uptake or to garner relevant support and therefore difficult to deliver. This resulted in a review and the understanding that the intergenerational aspect was deemed significantly less important than getting PLWD to engage within co-design activities. Accepting that there had been very little interest from younger generations, PLWD or their carers was difficult, but it forced the research proposition to explore alternative opportunities.

## 5.6 Changing the Research Approach

*"John Constable remarked, painting is a science of which pictures are but the experiments. Both abstract art and representational art require considerable skill on behalf of the artist, even if only telling the experiments that work from those that do not"*

(Evans, 2011; p.90)

To reinvigorate the research, reflective consideration had to be given to what would be feasible within the limitations of a PhD body of work and as a single researcher. Essentially, a refinement of purpose and complexity was required. As Evan's (2011)

identifies, this is in keeping with the creative process where trial and error inform the shape and style or success of final deliveries. More than this, it aligns creative or design practice with design research in as much as both are intertwined and the search for the appropriate solution is experimental. Within this process of review, the complications of who was to be involved in the project and for what reasons came sharply into focus. By reflecting on the failed workshop experiments, it became apparent that the primary concern was building relationships with PLWD. It was not enough to have been a recognisable part of the furniture in existing settings. These were safe environments that the PLWD knew and that had developed within recognised structures delivered by care providers or charities. Considerable thought was required about how the project had failed to stimulate participation, fundamental to which was emerging issues surrounding the creation of a new independent set of workshops, even though they were based within recognised care provider settings.

Previously, there had been noted desire by PLWD to be involved in the proposed workshops. However, converting interest into participation proved very difficult. The PLWD's lack of action in the form of participation revealed a reticence to get involved with something unknown. To initiate some kind of design research within the field, there was a requirement to further engage with PLWD and to develop new interactions that might support project 'buy in'.

Following the required personal review of the original research workshops, a redefined approach was made:

1. The research should focus upon the provision of workshop-based design and problem-solving opportunities for people living with Dementia.
2. Work within already existing groups and networks to integrate any workshop methods within the scheduled events.
3. Eschew the intergenerational aspect to focus upon PLWD.

This resulted in a design-research proposition that augmented the approaches of already existing and successfully populated dementia support settings and that could become intrinsically linked to these projects. The proposition continued to develop co-design workshops where there was an intent to make use of the latent creative abilities of PLWD and their personal knowledge and skills (Kelley and Kelley 2015). Central to *Designed with Me* was the application of a co-design approach that focused on the research intention; where PLWD are highly valued and their inputs and collaborations are held in the same esteem as any other participant and collaborator. Within this PhD investigation, the prowess of participants was to drive a situation where they were more than suppliers of input and opinion. Instead, they became instigators and originators of the thinking, commonly directing tasks and projects. Within the process, all participants were co-designers helping to propose possibilities, to choose solutions, provide services and to make things happen. As discussed in the literature review, co-design is often fixed within the foreword to a project or design. However within this work, there was a hope to use the approach to focus on non-designer informed 'change' (Brown, 2009; Heath and Heath, 2011). This change, it was hoped, would have relevance beyond the secluded dementia care settings as a result making a difference in the world around participants and beyond.

## 5.7 *Designed with Me*: Change of Approach Leads to Action

*"Those who take the direct path limit their ways of thinking about and creating"*

(Jenny, 2012; p.8)

Building from Jenny's (2012) acceptance that the creative journey achieves the richest experience when it deviates from the direct path and responds to the emerging situation, this research process accepted false starts, changes of direction and new ways of working. These were embraced in order to achieve outcomes that, most importantly, could be valued by PLWD and that appeared to work with collaborators rather than forcing a method upon people. During the early phases of research, a number of relationships with coordinators and caregivers was developed. These contacts allowed access to care groups and Dementia networks and were used as preliminary sounding boards for the

project. Ongoing discussions with these contacts helped in the reshaping of the approach where their input revealed reasons as to why it had failed, including the 'fear of the new', a view that its easier 'not to bother' and the role played by primary care givers in acting as gatekeepers. This aligned with a perceived understanding that these carer-gatekeepers might block or withhold participation of PLWD in what is an unknown situation. Craig (2017) recognised that gatekeepers exist from a medical perspective within dementia care and interventional actions. However, within this research, the evidence of gatekeepers became highly relevant throughout. The role of the contacts in helping to make a success of the work cannot be underestimated as they themselves proved another form of gatekeeper. One of these contacts, Ruth McCabe of the Alzheimer Scotland and coordinator of EMELDAN, extended an invitation to undertake a design research workshop during a day of discussions on 29th November 2016. This timely approach identified Ruth as the first '*project champion*' who, through personal interest, hoped to help move things forward. A project champion in the form expressed by Howell and Sheab (2000, p.15) is "defined as expressing confidence in the innovation, involving and motivating others to support the innovation, and persisting under adversity". Ruth McCabe, through her interest and actions, became the first person to intervene in order to progress the project and as such, did not act in the more common recognised position of a '*project champion*' as project leader, but from a position of an empowered project supporter without whom progress would have been highly challenging. Ruth's invitation allowed for workshop participation to begin, at the same time, informing a rethinking of the project. This rethinking included how collaborative PLWD relationships might develop. These were very much focused upon the *project champion*'s empowered ability to support, promote and give space within existing meetings or groups to undertake the workshops. During this session, a simplified participatory workshop approach involved asking for individual insights and opinions through specifically designed revelation postcards.

## 5.8 *Designed with Me* - Workshop 1

The first of the invited workshops for EMELDAN provided a platform for the participants to inform and start to make propositions. In this change-inspired scenario, the group developed the basis of a brief and set proposals through collective togetherness, that occurred in the first instance with PLWD. What they achieved and decided during the course of **Workshop 1** and following workshops continued to develop and alter the intended research-working model.

Again, working under the *Designed with Me* project identity, the workshop started by exploring the attitudes and opinions of PLWD to ascertain what are pressing societal issues and what is important for them as people living within society. They collaborated in groups and undertook discussions before answering by writing on the back of a set of stimulating postcards.

This initial stage was undertaken to generate a design brief that would be co-authored by the PLWD themselves. The initial purpose of **Workshop 1** was to develop a working relationship with PLWD and to create a starting point for future workshops. The group, all of whom had had a diagnosis of Dementia, were invited to respond to everyday questions or statements by filling in answers on the back of a set of purpose designed postcards. The questions invited personal and collective opinion utilising the terms "I" and "We" the purpose of which was to solicit each participant's opinions and to stimulate thinking and talking about their thoughts, hopes, wishes and desires. The provocative postcards invited opinions by stating:

- I'd really like to fix...
- We really need to improve...
- It would be great if we could change...
- I would bring back...
- Imagine if we could...

A presentation which was more akin to upscaled projections of the cards was used to explain the process and to outline the intention of the day. The group was informed that the approach was about gaining the thoughts and wishes of people living with Dementia and allowing them to present areas for collaborative exploration. It was explained that the workshop, was the first step in a journey looking to exploit the potential and practice of co-design. This was to be a means of raising awareness and developing the voice of PLWD. It was explained that the practice was hoped to make them enthused and infused throughout the design process (*i.e.* formulation of brief, concept generation, development and design delivery). The aim of this workshop was to engender a situation where PLWD identified areas of potential where design could make a difference. It was also hoped that any design proposal emanating from the workshop could ultimately have further value and impact in the local community. With this in mind, the postcards used to prompt the group of PLWD were openly ambiguous. The open nature of the postcards invited wider thinking, collective discussion and agreement.

This initial workshop stimulated a lot of conversation between participants, all of whom had Dementia. The result was free-flowing collective thinking and views peppered with personal insights, tastes or interests.



Figure 5.3 The five design research postcards used with PLWD at EMELDAN

The session lasted 1hr and although there was a set of five postcards, only three were addressed during that time. The rich conversations that occurred were allowed to develop, so time limitations defined how many statements could be responded to. The cards were handed out one statement at a time and presented in large format through the projected content. The presentation of each statement allowed for direct questioning and answering to take place before the groups commenced their own discussions and written responses.



Figure 5.4 Workshop 1 design research postcards responses

Facilitation of the workshop occurred through a fluid, engaged and responsive approach where various roles were undertaken; at times as a group member, at others as a scribe or on occasion, as a provocateur. The facilitation required guidance to set the activity following which, little was needed to stimulate participation and progress. The activities were embraced by all the participants and supported them in providing a variety of responses. The attention of the facilitation became concerned with keeping to a timeframe that supported the discussions and let them run their course, whilst keeping them restricted enough to achieve discussion of a minimum of three cards.

I'd really like to fix...	We really need to improve...	I would bring back...
My husbands email communication community Embarrassment by people Ability to talk and Understand	Illness - not to be acceptable	Respect
Improve public awareness of what is dementia and the need not to be embarrassed	Crossing the lines relating to dementia or worry about problems (for example)  Dementia - e.g. - concern about the stigma of the "illness"	Conversation. Concern for others.  Holiday flying  Bring back not working from home.  Ban laptops from 5pm onwards.  lets have conversation and being together!
Television and other tools of communication for telling and sharing, developing understanding. Talking	Respect.  more thought.  more money.	Respect from society at large - just everyone.  Local branches of banks  Outdoor play and exercise  Going on holiday
My memory ability to remember more things	People and how they can be.  How they react to me and situations  Time and friendliness	Bring back sunday as a day of rest 'Different'  Back to localities not globalisation  Time to think  Time for silence  Get rid of cars  Street games
My memory - my ability to recollect things especially short term things.  Left handed now struggling to write	Understanding people and giving support	History... world has become different place  dementia  "time to think"  'Street games' - 'every day of the week'
A miracle cure!  A counsellor to listen to me	Awareness of the public of what is dementia  More groups like this  Stigma	Walking places stopping overuse of cars
Pronetak patch is good cure but don't stay on  Link after 1st year should continue	Midlothian don't do enough dementia friendly things  Support for people - starting from education and going right through - active support for me to talk about how dementia affects and what I can do about it.	Dog  Helping with the horses  Going to the hunt balls
a cure for dementia	Bus service not frequent.  Driver more careful - allow time to sit down  Assumption that everyone has access to/wants to use Facebook etc.  More money and easier access given increasing number of branches closing	Street games  Places to play  Creating places that work and where people come together
Sometimes looking back something comes to stir the 'history' - e.g. Sunday's something different	Nothing my life is wonderful	Going into the world and seeing it for good
		1

Table 5.1: The postcard commentaries from Workshop 1.

From this first workshop, a number of possible project ideas began to emerge. The considerate and carefully planned approach allowed participants to make explicit their thoughts and considerations. The participants' comments, collected on the postcards, were analysed to identify common themes, thoughts, wants and desires. A number of key themes emerged including:

- Participants wanted more respect and greater communication

- More appropriate social spaces to meet and mix with others
- Strong desire to make Sunday special again

The method allowed for a distinctive, design-research approach where, from the outset, PLWD developed the conversation triggered by the postcards. These conversations led to the participants forming the outline of a brief and in the following workshop these helped to solidify their own brief, therefore making the PLWD the instigators of what would occur. One particularly powerful piece of feedback from one of the participants that was offered after the first workshop was: *"You made us think more than we are usually asked to do and it is good for us to have to think"*.

### 5.9 *Designed with Me* - Workshop 2

The second co-design workshop focused on the wants, needs and desires expressed by PLWD in the first workshop. That is, participants wished to see greater opportunities to make more time and space for social inclusion, understanding, personal esteem and empowerment, and to be nurtured and supported. These key themes were arranged into a PLWD-framed proposition for the second workshop: *"Redesigning Sundays to make them special again, where fun can occur that supports respect and communication"*.

The second workshop supported more open and diverse groups of participants. During the lunch that followed the first workshop, the carers or partners of the individuals involved wanted to know more and to understand what had happened during that first session. They were interested in the activity offering their own insights as the discussion continued whilst expressing a clear desire to be involved in next workshop events. The Workshop 1 participants agreed that they would like to broaden participation to make the process increasingly inclusive. As such, the second workshop brought together both carers and PLWD to expand upon and propose responses to the brief generated in the first workshop. The larger group (28 participants) assembled in the second workshop allowed for greater involvement, understanding and thinking of all the concerned parties, which supported a sense of togetherness in the discussions and activities.

The previous lunchtime discussion within the participant group influenced Workshop 2's café theme which referenced the commonly known Dementia Café environments (Greenwood et.al., 2017). Within these settings it is common for discussion to take place and for concerns to be raised. Dementia Cafés visited and observed in advance of the workshop proved to be appreciated and supportive environments but were often quite hard to distinguish from a meeting. They largely consisted of places to gain information on current research situations and care guidance along with access to professional advice. In the attempt to theme the environment, more of a conversational and fun space was created where particular importance was placed on common café motifs.

The conversational environment asked participants to sit at tables that were dressed with table cloths. At the centre of the table cloths, were biscuits sugar, milk and fruit to be consumed with the coffees and teas that were being served. The participants were split into smaller groups of 5 or 6 and each group was invited to utilise the environmental setting. This placed great importance on the table cloths which were to be used to document discussions and to act as collection spaces for imagery and thoughts (Fig 5.5). The participants were invited to make marks, scribble details and stick images down on the tablecloths in the form of a collage to encourage discussion and communication of their collective viewpoints. Arising from the tablecloth documents were a number of project ideas which shared the focus of each group's attention, their discussed wishes and to some degree, their expressed desires. The table cloths, therefore, formed part of the setting and restructured the more formal meeting approaches into something a bit more radical, rebellious and disruptive. The setting was supported by documentation that looked like a discarded notebook and formed a set of actions for participation. These were discussed and gone through step-by-step during the course of the workshop. The motifs were linked to a café culture where creative people might be brainstorming or be struck with instant ideas that must be expressed there and then. At the end of the café, the individual groups talked through, with the wider group, their scribbled, collaged and sketched-upon tablecloths which now formed an artefact of their collective position.

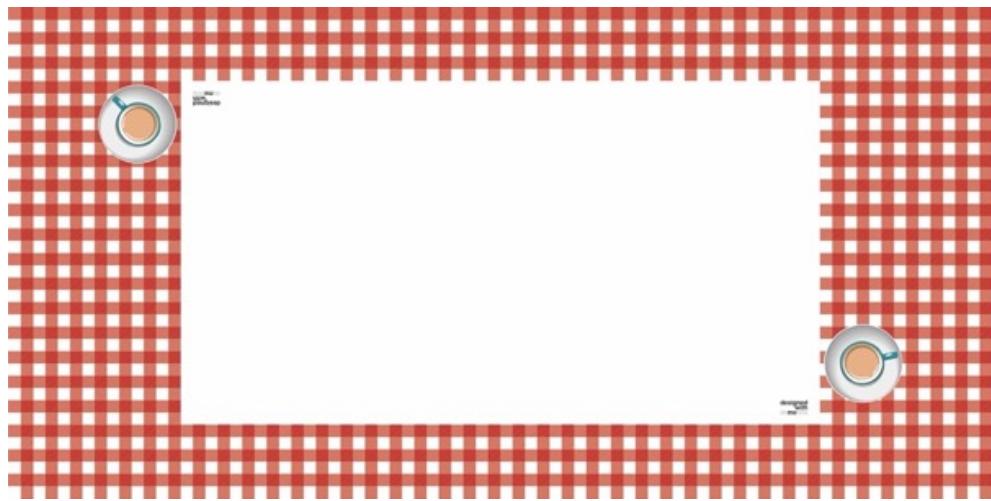


Figure 5.5 Dementia Café tablecloth design.



Figure 5.6 Dementia Café tablecloth sample of feedback

The tablecloths were collected for interpretation and were documented before being arranged for easier reading in a graphic format. The ideas proposed in the second workshop, from left to right in Figure 5.7, are "Family Day", "Water / Boats", "Younger People are a Tonic", "Local Communities and Big Events", and "Encourage Interaction".



Figure 5.7 'Making Sundays Special Again" visually collated initial ideas from Workshop 2.

The workshops that occurred were created to lead towards a project outcome chosen by and directed by participants and especially, by those living with Dementia. This first co-design workshop focused on the wants, needs and desires expressed by PLWD. Here, participants wished to see greater opportunities to make more time and space for social inclusion, understanding, personal esteem and empowerment, and to be nurtured and supported. These key themes were then arranged into a proposition for the second workshop: *"Redesigning Sundays to make them special again; where fun can occur that supports respect and communication."* In Workshop 1 a number of points of view were collected that allowed for this brief to be set. Workshop 2 defined parameters and suggested the attributes of importance. This unearthed problems that greater public understanding could help to overcome.

**Vignette:** One couple discussed the importance of social inclusion, acceptance and understanding. Here the wife of somebody living with dementia explained that her husband (who had been a doctor) often has to be pulled away from talking to children. On one occasion she had felt very uncomfortable as a parent dragged their child away from him at a park whilst remonstrating with her that she needed to control him more. She explained that throughout his career he found it normal to talk with children and he couldn't understand that the parent didn't want him to talk to their child.

Learning from the discussions, notes, scribbles and collages ideas were codified and arranged (fig 5.8). Following the first two sessions and this analysis, a news print was produced to detail what had occurred and to outline the outcomes. The newsprint discussed why co-design was underpinning the approach and how this was going to inform future practices in the PhD research.

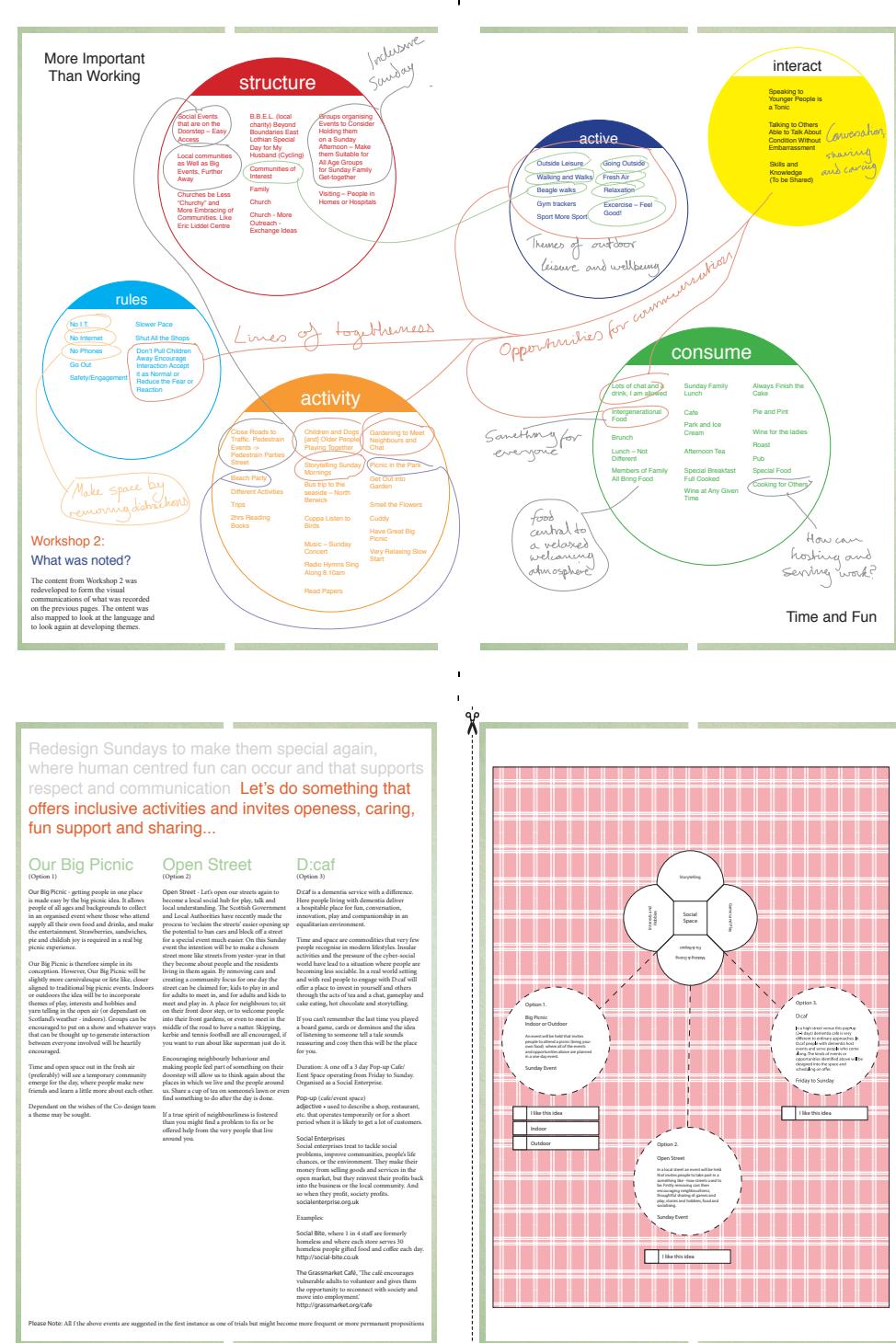


Figure 5.8 Sample spreads from the Workshops Newsprint (Appendix 5)

The newsprint (Figure 5.8) was designed to communicate the previous approaches that had been taken; where cumulative ideas became propositions for future exploration and action. This work was presented back to the group at the next EMELDAN meeting, where it was well received (Figure. 5.9). Disseminated through the presentation at the EMELDAN meeting and the newsprint the propositions emerging from the first two workshops were:

- “Our Big Picnic” - allows people of all ages and backgrounds to congregate in an organised event and make the entertainment.
- “Open Street” - will become a local hub for play, talk and local understanding to make the street more like streets from yesteryear.
- “D:Caf” - where PLWD deliver a hospitable place for fun, conversation, innovation, play and companionship.

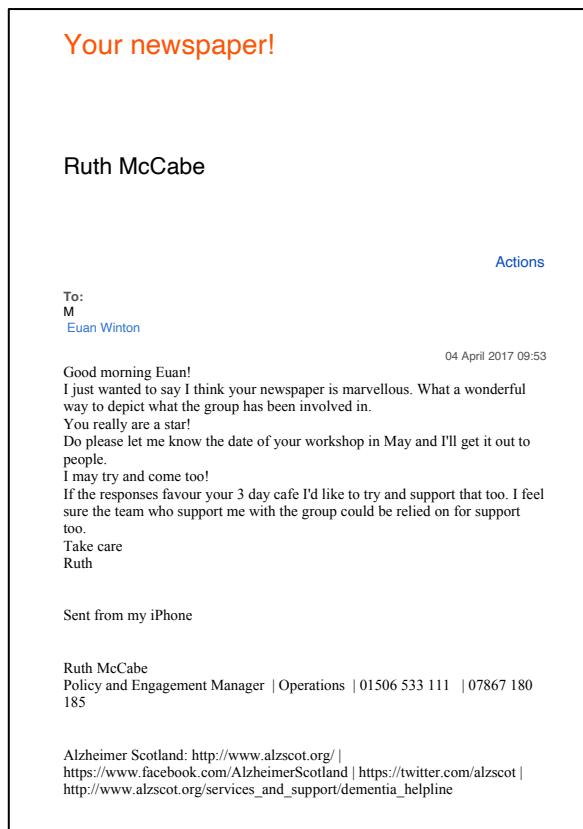


Figure 5.9 Workshop 2 Feedback from EMELDAN

Within the newsprint, there was a double-sided page of simple tasks that could be undertaken by carers and PLWD. A stamped, addressed envelope was included with the

newsprint and it was requested that this be sent back with the completed form the intention of which was to use the feedback to help develop the next workshop. The next workshop was planned and scheduled to occur outwith the bi-monthly meetings. This was to test whether or not participation in stand-alone workshops might be possible now that working relationships had developed. It was also considered appropriate in order not to detract from the core purpose of the regular EMELDAN meetings. It was hoped that, now that there was an existing working relationship, a stand-alone event could be stimulated. Unfortunately, the planned Workshop 3 did not occur, indeed only one person responded.

The individual who responded was a carer whose husband had recently gone into full-time residential care and who wanted to support activities for other people. However, she ultimately hoped to keep herself included in ongoing activities. In lieu of the planned workshop, a meeting with the respondent occurred. This informative session supported insight of the being a primary care giver and proposed a need for activities that included carers. In particular, she stated the need for inclusion even after the point in which she was no longer primary carer for somebody else. She stated that for her the brief to the idea to redesign Sunday was particularly powerful, asserting that "*Sunday has become the loneliest day of the week*". She went on to explain that it is a day for families and then friends. This alienated position was further underlined by the fact that she had become removed from historic, personal and social networks through the need to care for her husband. For her, once the caring role was removed, the day became even lonelier. In this scenario, it was not merely that during the process of caring she had become isolated but also as a legacy of having been a carer, she remained isolated. As such, finding ways to regain and reaffirm who she was was difficult and yet, she was finding the idea of rethinking what Sunday could be as "*uplifting and exciting*". In this investigation, she could see potential for new personal opportunities. This was a view that was reasserted in a subsequent discussion with another former carer, Pat, who stated that she had felt exactly the same since her husband had died.

As such, the brief and outline proposals for ways to *Redesign Sundays* offered a set of propositions that move beyond those who are living with Dementia or even those who are currently carers. The proposal affords connections to be made for people who need further support as a result of having been a carer and could provide opportunities for new meaning or purpose to be acquired. This kind of proposition aims to fulfil a new kind of support system, where people who find themselves between who they once were, who they became, and who they are now as they try to connect with society and the caring network of which they used to be part. Further to these sentiments, the group had articulated that any new proposition should provide opportunity for widespread inclusion and interaction with all aspects of society.

*"Dementia needs to be spoken about openly in the community, and people with Dementia need to be able to meet other people in a social space where they can talk and have fun."*

(Thackara, 2007; p.68)

The Designed with Dementia service intervention focussed upon the three core propositions. The project gained interest from the Eric Liddell Centre in Edinburgh who hoped to make the Redesigned Sundays a new offering hosted by them and fulfilling their newly developed strategic aims. The centre hoped to provide a more prominent and wide-ranging set of services enhancing the role of the centre in the locale. In particular, it wished to renew its relevance to a wider demographic and especially to families with children. The proposition to Redesign Sundays to it appeared to be of great significance and united their current provision with its strategic aims. Having already developed a relationship with the ongoing research, ELC approached the group to make a joint bid for funding. Although unsuccessful in gaining the funding, the project already proved to be producing results that were deemed to be of value to the wider community. By proposing new ways of working and delivering solutions, PLWD were starting to create viable working relationships with external organisations. In this sense, ELC proved its belief in what was being proposed by both seeking funding and offering 'in kind' support in the terms of space, facilities and time-investment from its core staff and promise of shared facilitation with Dementia support staff. Furthermore, ELC hoped to use Redesigned

Sundays as ways of building Edinburgh's Morningside into a Dementia friendly community and to stimulate training in being a Dementia friend.

## 5.10 Learning, Affirmation and Further Development

Though stymied by the lack of engagement outwith the EMELDAN by PLWD and their carers, somewhat positive affirmations were made in regards to the potential of collaboration and the practice of co-design with such groups. Much was learned about facilitation, time allotted to tasks, periods of concentration and buy-in beyond existing care settings. In particular, lessons were learned from the failed attempts to invigorate or develop independent workshops. It became clear that collaboration and buy in by PLWD required situations that were existing, known and therefore deemed secure, and preferable to them. Creating new settings and situations proved unlikely to result in positive outcomes. Instead, existing groups, networks, meetings or activities, where trust had been developed over time, proved more fruitful. It appears that existing situations, networks, groups or meetings supported a sense of trust where all parties genuinely felt safe or reassured about undertaking new tasks. Consequently, developing relationships and opportunities within existing groups became essential. Recognition of this also supported the view that no matter how much planning, working within guidelines and use of recommended communication approaches or trying to invent new places for experimentation would be productive. To arrive at this point of understanding much time had been consumed and to a degree, lost. A recommendation for anybody attempting to undertake similar approaches to engage PLWD is that it is more fruitful to work within structures that are already well developed.

Affirmed by the experimental design research postcards utilised in the first EMELDAN workshop, it was clear that people with PLWD in early to moderate points in their experience with Dementia were more than capable of generating intentions. This informed the future research position where PLWD would largely set or shape the focus and direction of what could be explored through design activity. In particular, the research evolved to have the intention of developing project outcomes that were

instigated, developed and then produced through a co-design approach within existing support groups. The approach was considered a suitable and achievable direction based upon what had been observed and achieved within Workshop 1.

### **5.11 Limitations, Experience, Acceptance and Renewed Challenge**

The suggested success of the *Redesign Sundays* approach were significantly limited and consisted, at best, of a 'for' in the co-design Participatory Power Pyramid (Chapter 3, Fig. 3.6) narrative where, despite a significant amount of creative activity, task completions and rich conversation, the results still had to be shaped and formed into something more conceivable by me, as the design expert. This work was therefore limited in its apparent ability to provide an equal, collaborative platform. It required substantial energy and promotion from a design researcher/expert position to generate solutions and to attempt to cajole the participants into action beyond the initial workshops. This is not to negate the rich collaborations and insights generated through the participations in these workshops of which there was plenty. However, the results became nothing greater than front-end proposition-making in a design process much like those in the historic models (Chapter 3, Fig. 3.2).

At this stage, the acts of positively engaging with people who are living with dementia in creative explorations was viewed as being highly positive for the study. After nearly a year of inaction through an inability to gain collaborators to work with, the mere engagement of people and their carers was a relief. The design propositions were great and the value espoused by the participants through comments of enjoyment and value in the process were significant. The ownership of the project by the groups of PLWD after the first workshop was also encouraging, particularly when they invited their carers to be involved in the second workshop. These results suggested insight into some of the key attributes being explored, such as:

- developing and reinforcing capabilities of people living with dementia

- identifying benefits of working with people living with dementia in a design-led manner
- the affording of design skills and processes for people living with dementia in terms of self-actualisation, ownership, creative prowess and empowerment

Although these were by no means breaking boundaries or achieving full buy in to co-design in terms of the higher desires of 'with' and 'by', the work had provided valuable encouragement for greater exploration and hopes of more fulfilled co-design practices but was stymied by the extent to which the participants were willing to be involved.

On reflection, this experience fuels the provocations of Hendricks *et al.* (2014) about co-design. The protracted process of gaining some form of traction with people living with dementia reinforced their assertion that "*To involve people with dementia in a research and design process is not an easy thing*". More importantly, they assert that if the hope of co-design is to result in a sense of equality in a project where reciprocation occurs, it is not going to be possible with people living with dementia. Instead, the view is that the designer will retain the power due to participant inabilities. The results of the initial investigations appear to continue to support this position. However, this is only if the measure of value in the process is about judgement of level of participation and control. If this view of value is refocussed to consider the actions and engagements that occurred within the research process as the key outcome, then concepts of wellbeing might be addressed. Then, the value is not about what the designer gets but what the participants might receive. In these initial forays, the evidence of this kind of value is evident in the statements of enjoyment in participation or the steadfast statement that being asked to think is good and breaks common conventions in dementia.

## 5.12 Learning From the Failed Project Approach at this Stage

Hendricks *et al.* (2014) have indicated that there are significant challenges in undertaking co-design with people living with dementia. This chapter is starting to respond to the assertions they make and identifies where that their statements are too generic.

1. *"The cognitive limitations of a person with dementia may make PD [Participatory Design] too difficult"*

Finding: Limitations are likely to be methods of engaging PLWD and the extent to which these appear to be 'fit for (the collaborative) purpose'.

2. *"The results of PD sessions are difficult to be translated to the wide variety of forms of dementia"*

Finding: Not all of the projects need to be transmitted or transmuted to other groups. The solutions might be actively achieving results of importance for those directly involved in that moment in time.

3. *"It is unclear whether the people with dementia, their caregivers and relatives are reliable"*

Finding: The reliability of content will respond to the parameters of the investigation. It is worth noting that a carer might answer or act for the PLWD when it is not required.

4. *"PD may be too stressful for the person with dementia"*

Finding: As a designer/researcher a responsibility is to minimise areas likely to cause stress and to think of alternative ways of accessing views. If an alternative solution is not possible, then being proactive in encouragement and responsive to problems should be expected. The designer/researcher should be caring and empathic in their interactions.

5. *"The differences between the designer and the person to design for are too big to speak about equality in participation"*

Finding: Equality can come from different aspects and if the view point is changed from the designer perspective to the subject perspective then equality might come as simply as being able to share views and to achieve enjoyable communications. Two people sharing a moment can be deemed as equal, despite influencing conditions.

6. *"The process of PD can be a burden for the designer"*

Finding: PD (or co-design) should be seen as a process with differing expectations or pressures to standard consultancy or product design. Here, the transference of knowledge, skills, ability and the revelation of knew participant informed positions are the valued design outcomes. The results stemming from these are an extension of the process and therefore, the “burden” appears capable of achieving more than other processes.

#### 7. “Minimal utterances are given too much importance”

Finding: In the above projects, significance was given to utterances but these were folded into a research process which allowed those utterances to develop further through investigation, conversation and actions.

### 5.13 Chapter Summary

In exploring the approach to running events and workshops as first proposed in the research, an understanding was developed that the approach would not work. This invited reflection and a reshaping of the project. What followed were project developments that were encouraging. Ways of working with existing groups developed as a central requirement.

Participation by PLWD through responses to the provocations demonstrated value in the outcome of these initial engagements and supported a renewal of purpose. The learning from which provided a refocus of probable engagement techniques and a more concentrated direction in which this could occur. Chapter 6 shares engagements that develop a new perspective and the alignment of the necessary components which made the following projects with people living with early-to-moderate stages of early onset dementia possible.

## Chapter 6: Co-design Projects

### 6.1 New Collaborators at the Alzheimer Scotland Bridgeton Resource Centre

During the development of the EMELDAN group work (Redesign Sundays), it became clear that making use of other long-standing groups was important. Working with Alzheimer Scotland, a number of potential collaborating partners were identified in Glasgow, Stirling, Perth and Dundee. These were existing Alzheimer Scotland Resource Centres across the country. Though it had been hoped that a number of Resource Centres might support collaboration, it became clear that Bridgeton Resource Centre (BRC) in Glasgow was going to provide the most significant opportunity. Recommended by Lindsey Kinnaird and Joyce Gray of Alzheimer Scotland, the centre was seen to be dynamic offering a good range of groups to work with.

The BRC allowed exploration of a different socio-economic environment from that experienced in Edinburgh. Bridgeton is a historically industrial and residential town in Glasgow's East End. Here, the textile industries and weaving manufacturers formed a significant part of the historic landscape as did the local Tramworks. The area is less affluent than where previous workshops had been held and there is a significant prevalence of religious influences on the local culture and environment. Football and historic divisions also form part of the local narrative. The Bridgeton area is also located very close to significant cultural institutions of Glasgow including the People's Palace, The Kelvin Grove Art Gallery and Museum, The Barras Market, The Olympia CCG, Bellahouston Park and the Tramway Gallery. The different environments and surrounding culture supported the next phase of this research work but again, proved that contingency and adaptability in the research approach would be required.

### 6.2 The Alzheimer Scotland Bridgeton Resource Centre: Scene Setting

As previously discussed in Chapter 2, Alzheimer Scotland's Resource Centres form a part of their ongoing support network across Scotland. The Resource Centres support PLWD through information and socially focussed activities and provide respite for those involved in caring. In recent years, these information hubs and spaces, have been undergoing

transformation in how they deliver the experience of their use and design plays a significantly important role in this.

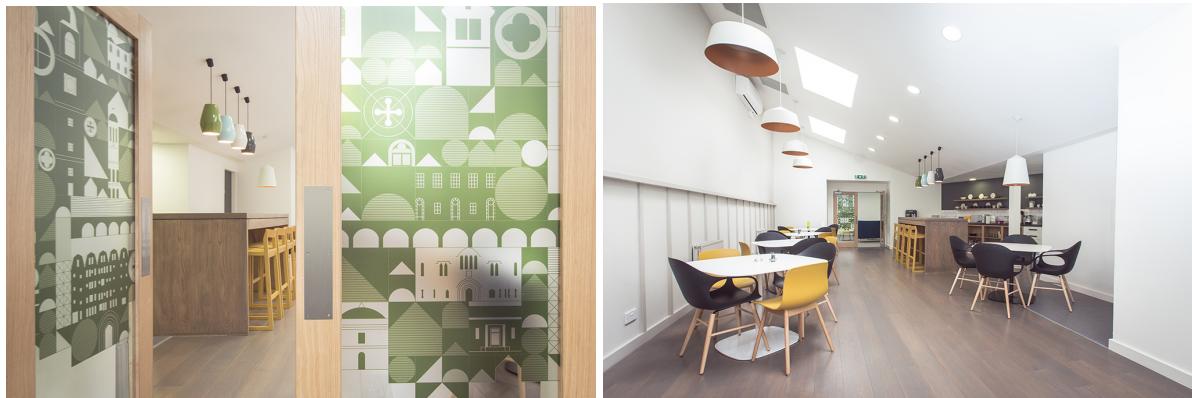


Figure 6.1 Alzheimer Scotland Kilmarnock Resource Centre by designed Graven

The BRC, has been developed from designs first implemented at the Kilmarnock Resource Centre. This prototype centre was designed by the consultancy, Graven, in order to create a destination that was welcoming, modern, bright and thoughtfully arranged<sup>1</sup>.



Figure 6.2 Alzheimer Scotland Resource Centre Bridgeton designed by Graven

To appreciate the workshop environment setting of the creative practice that follows, it is important to set the scene where the bulk of the design activities occurred. Like the Kilmarnock Resource Centre, Bridgeton has been given the Graven treatment. It is

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<sup>1</sup> discussed further in Appendix 4.3

situated in a former shop on the corner of Dalmarnock Road at Bridgeton Cross. As a former corner shop building, it is a bright space with a large open plan aspect. The use of vinyl on the windows acts to generate internal privacy and light diffusion whilst allowing for the brightness of the space to remain consistent. Internally, a series of bespoke wall benches in soft but wipe-able upholstery creates supported seating space whilst white round tables, and ergonomically considered chairs are positioned to create sociable additions to the benched seating. In the centre of the space, is a high island for housing crockery but that also encourages people to stand and talk round. Along the back wall, the kitchen and sink are arranged and in the back-right corner, is a booth with dining table. Above that table, there is a screen where images and a variety of content can be shared through the use of an iPad. The floors are a combination of light wood and carpet. To the left of the entrance doorway, the localised graphical city scape treatment brings the surrounding environmental representations into the space. The lighting is largely supplied by modern pendant fittings of moulded plastic in an array of hues. The environment is, therefore, one which sets a degree of influence in terms of modern aesthetics and visual approaches and appears conducive to the kind of creative practice discussed in this chapter. The environments provided a setting and the constraints for which the workshops were to be developed.

### **6.3 The Research Group: the Friday 'Day Opportunities Group'**

Working with the staff of BRC, the most appropriate research group was identified and approached. The group was formed of people who were living with early to moderate stages of early onset dementia that had been attending the Day Opportunities Group (Day-Opps) at the BRC every Friday as part of their ongoing support. In attending these sessions, they had been used to undertaking arts-based projects and generating artefacts that are in display cases within the space.

The Day-Opps group attend the BRC every Friday and on the last Friday of each month, the group goes out to local cultural venues in order to be guided through new exhibitions

or to be talked through aspects of collections. During the initial investigations for *Designed with Dementia*, visits occurred at the Tramway (twice), The People's Palace, The Transport Museum (twice), Kelvingrove Art Gallery, The Scotland Street Museum and a walking expedition to see some of the Billy Connolly 75BC Murals on the streets of Glasgow. These cultural excursions are often guided by local site representatives during which discussion sessions are supported. Craft or entertainment elements augment these discussions and have helped to inform appropriate design interventions. The encouragement during these events aims to stimulate conversations about the group's own relationships to what they are seeing.

In the first instance a visit, to the Day-Opps at Bridgeton was undertaken to meet the current group of service users. The group was made up of people who were all under the age of sixty-five and had a diagnosis of dementia (early onset). Initially, the proposed participant group consisted of five PLWD - two men and three women. During the process of the first period of investigation, one person left the group (as they had relocated residence) and one new member joined.

#### **6.4 Participation and Permission**

The visit allowed examples of proposed workshops to be shown and to discuss with the group the hope and intention of the work to be carried out. The group was asked about its willingness to work with the project, to support member's understanding and a set of permission forms and information documents were provided to the group<sup>2</sup>. The forms were taken away to be reviewed by the individual participants and (as was required) shared with their families and/or carers.

Ideologically, the approach was taken that a person living with dementia had the right to choose what they became involved with. However, with the knowledge that carers often act as gate-keepers, the participants were urged to share and discuss the proposition before deciding. The approach sought both oral and written agreement to participate,

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<sup>2</sup> Appendix 1.2

which was achieved. The participatory group members were regularly asked to review their respective positions by agreeing to be involved in further series of collaborations over the various periods of research. This meant permissions were sought on the start of any new project. The outcome was that all of the participants and their family or carers agreed to continual collaboration of the PLWD. There was one exception who was not allowed to be photographed during participation though permission was granted for them to take part and actions noted. The continued process of permission seeking defined the end of one body of work or project and the start of another. Often, this correlated with changes to participant groups.

Because of the nature of Dementia and the journeys that each PWLD would experience with their own disease, the membership of the collaborating participant groups saw changes over the course of the research. The selection process and make-up of the participant group occurred outwith the project parameters, based upon age and cognitive function adjudged by the professional care providers. The group morphed throughout the phases of research with some people dipping in and out where others remained for far longer. The result has been a participatory group that started with five members but that subsequently allowed fourteen PLWD to co-design products and services.

## 6.5 The First Meeting with the Co-designers

The first meeting with the group, allowed the ideas of the planned workshops to be presented. The pre-programmed series of workshops were designed to interrogate the local environment through the eyes of somebody living with Dementia. These were largely based upon the first set of workshops developed at the outset of the research project and were discussed as *Designed with Me* propositions. However, through the discussion that occurred at the meeting, it became apparent that the approach was too prescriptive and disconnected from what the group already enjoyed. It was clear that a pre-programmed approach was not necessarily a good fit.

One of the issues was that the pre-planned workshop-based, approach depended on a large degree of local experience or knowledge and assumed that all parties were local to the centre. The nature of how people travelled to and used the resource and their attendance patterns proved to be at odds with this position. Many of those who attended the centre were not from the locale and travelled from all over Glasgow to attend the service. As such, working very much within blocks of time on the days that they attended was an absolute requirement. Again, this reinforced the knowledge gained from previous attempts at doing new things - in particular, working within what is known and trusted. This was not only the centre itself but the group make-up and its schedule.

Instantly, it was understood that learning about the group and their individual interests was key to the development of a more organic, natural and relatable approach. Talking and, in particular, listening, formed a significant part of the first visit with the group. What the group does, and how it does it allowed for its ownership of the experiences to come to the fore. During the meeting, it became apparent that the cultural visits and investigations the group undertook each month were going to be particularly powerful opportunities. These visits to local galleries and museums often included access in ways that most attraction visitors would not usually have and often encouraged creativity. The group shared artefacts and outcomes of previous work. Members told of how visits to these places had been collectively pulled together in order to create a visual record of what they had done. Creative practice was very much being used to generate artefacts that recorded their cultural activities. Furthermore, their work was not site specific to Bridgeton. They were much more concerned with Glasgow in a broader sense and context.

Building upon these kinds of visits, the work undertaken in this process, and the collaborative approach that grew within the various outcomes, has looked to create valuable design opportunities that reflect upon what has been seen and has led to new designs being generated. On occasion, with the site and a topic in mind, the activities that were designed within this study also preceded visits.

At Bridgeton, the re-evaluated research position required adoption of a fluid approach to exploring project purposes and intentions, the focus of which was always to drive collaborative actions. This proposition required a relationship of non-judgemental acceptance of each other that would support exploration, experimentation and trust. The situation was such that the group members listened to what had been proposed in terms of collaboration within design explorations, but it was their choice and for them to collectively offer an invitation to work together. This was very similar to the EMELDAN situation where PLWD took the lead in initiation of the Co-design collaborations. The thinking here was that the power to choose was theirs. The conception of the project generated by them, reinforced the position of doing 'with' rather than having things 'done to' them. By placing the power and intention from such an approach in the hands of the collaborators there was tangible development of trust. From the first meeting, the group afforded an invitation to participate in the next programmed visit. What followed through regular participation in events and visits was an immersion in their programmed experiences, which built acceptance and trust. In time, a relationship emerged which was essential to the future of the research collaboration.

## 6.6 Listening to Future Collaborators

Particularly important from this first meeting was that the creative capacity of the participants played an important role in what they do at the Day-Opps. As such, they were already attuned to doing arts and crafts projects that somewhat responded to events and visits. In discussion, it became clear that it was common for the care support team from BRC to plan tasks and provide opportunities for being creative. This again helped the group members to make connections between what they knew and what they were used to with the proposed co-design workshops.

With the almost instant recognition that any future project would stem from the group, based on its collective interests and experiences, focussed listening became important. This required recognition of how people responded to and talked about emerging situations and topics. It would be within these periods of sharing that opportunities would

evolve. Arguably, this allowed for a fuller design process, making it much more of an act of designing 'with' PLWD. Listening, learning understanding and responding to the group was essential. For example, during the initial meeting, '*I got chatting with one participant who shared the importance of photography to his niece, however, it was also clear by the interest he had shown in her work, as a football photographer, and the depth in which he talked about her work that it was important to him also<sup>3</sup>*'. This discussion was the kind of interaction that fuelled practices adopted within the projects, namely incorporating PLWD valued input in instigation of any proposition. At the end of the first meeting, verbal agreement to collaborate had been achieved (documented permission was collected in due course). The Day-Opps encouraged an invitation to attend their next cultural visit, to the Tramway Gallery, Glasgow. Taking on board the discussion that had been had with the gentleman regarding photography in which he also stated, "I used to love photography, but nobody'd give me a camera now", a suggestion was made that cameras would be supplied for the visit. This would allow the individuals within the group to document the things that appealed to them. The visit and the participants actions proved to be the launch activity for the projects that followed. Importantly, the process and subsequent approaches responded directly to the wishes of the PLWD participants.



Figure 6.3 Billy Connolly 75BC Mural near BRC

<sup>3</sup> From field notes (2017) taken on completion of the first visit to Bridgeton Dementia Resource Centre in Glasgow

Within the first discussion with the group participants, they had explained that they had been out on a walk that morning to see one of the Billy Connolly murals (*Fig. 6.3*) that had been painted on the side of a building not far from the BRC. These four murals termed 75BC were selected and painted to celebrate the seventy-fifth birthday of the comedian and Glaswegian cultural icon, Billy Connolly. The group's less than positive response to this informed the first project.

## **6.7 *Designed with Dementia* - 75BC Fabrics and the First Truly Successful Series of Collaborations**

Working under a renewed title, *Designed with Dementia*, the project development leaned heavily on a workshop approach where the activities proposed responded directly to the individuals involved. From here on, these people living with Dementia are referred to as Co-designers. The group and the individuals involved as co-designer, informed, shaped and sometimes, changed practices during the course of the projects and workshops creating a range of interesting design artefacts. The first of these was a collection of textiles which were inspired by the 75BC street murals and the 75BC exhibition at the People's Palace, Glasgow and the American artist Tschabalala Self's exhibition at the Tramway Gallery, Glasgow. During this project, the five PLWD Co-designers photographed the exhibitions and content they saw. The photographs became a reference point for a range of visual representations of Billy Connolly.

**Stage 1** introduced the group to undertaking primary research, during the visit to Tschabalala Self's exhibition at the Tramway Gallery, Glasgow. The co-designers were given a digital camera and asked to photograph the artworks, focusing on their composition and their structure. Each participant was asked to photograph what appealed to him or her. Their photographic investigation was rooted in the conversation noted above.

Each armed with a digital camera, the co-designers set about eagerly photographing the exhibition from different perspectives, selecting what to photograph and how. One participant was particularly adamant that only two of the artworks appealed to her and those were photographed because of the vibrant background colours.

The exhibition consisted of large textile-based human forms and portraits. The group was guided into and around the exhibition by the gallery's outreach worker. On completion of the tour, the co-designers were given time to explore the collection for themselves. On entering the gallery, each of them was handed a digital camera and asked to document what they liked. Prior to this the group was shown how to use the cameras and informed not to worry about selecting or editing what they had shot. They wandered around with the cameras taking their own photographs and making decisions about what appealed to them. When asked about photographing one artwork one of the co-designers insisted it was not for them, stating, "No. I know how it's been done, and it's been done well, but I don't like it". They then made very selected choices explaining them as they did so. The opportunity for the individuals to wander around taking photographs appeared to give each person a sense of individualism that encouraged them to look closely before taking photos. Amongst the group, good humour and discussion of the pieces was evident. The task appeared to reinforce the visit, introducing a layer of discussion based upon what they were collecting. On completion of the task and whilst returning the camera, another co-designer - who had previously been quite quiet - said "I really enjoyed that, it was good".

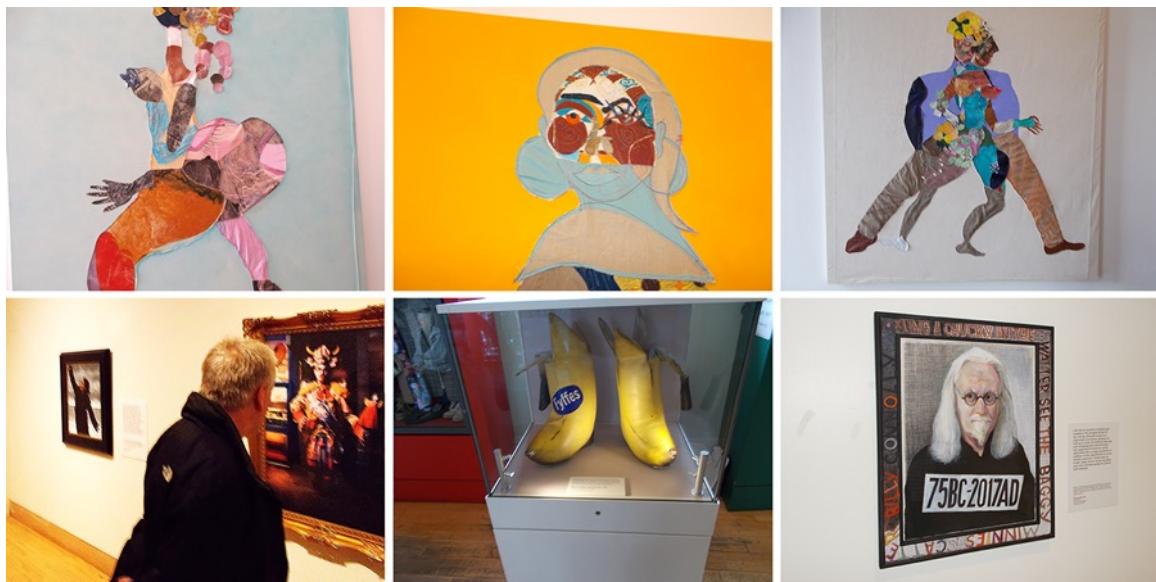


Figure 6.4 Tschabalala Self artworks (top) Billy Connolly at the People's Palace (bottom) all of which were photographed by the Co-design collaborators (PLWD)

**Stage 1 Part 2:** Having previously visited one of the three Billy Connolly 75BC murals in Glasgow, discussions had already taken place with the group regarding the three murals and what the group felt about them. They were not convinced by the murals and reacted with distinct negativity in particular to the 'Big Yin' by Rachel Maclean. They didn't recognise this representation of Billy Connolly and thought it disassociated the public view of him. As one participant said, "I don't get it" and another revealed, "I don't like it". This discussion led to a follow-up visit to the Peoples' Palace in Glasgow where again armed with digital cameras, the group photographed artworks and artefacts of significance that were more closely related to their vision of Billy Connolly. Here they were able to get up close to the original Billy Connolly artworks that became the murals on the sides of buildings and to see others that were submitted by the public through an open brief (Fig. 6.4).

Following the Tramway and People's Palace visits, a suggestion was made to the group to combine what they had been exploring through a tailored and responsive creative workshop. The one-hour workshop considered the visits and the work of the artists that the group had seen. Building upon the preceding Billy Connolly murals tour that the group members had undertaken themselves, the process pulled together discussion,

photographic investigations, art-based explorations that had taken place during the visits, and their own personal insights. This workshop became a Stage 2 in their design process, as described by Kelley and Kelley (2015), where the group could make sense of what had been seen, organise what they had recorded and discussed, and most importantly, explain how they felt about these things. By being the creators of new 'research' materials in particular through personally curated photography, their thoughts and decisions would shape the content for the next phase:

*"to begin the complex challenge of Sense-making. You need to recognise patterns, identify themes, and find meaning in all that you have seen, gathered and observed."*

(Kelley and Kelley, 2015; p.23)

**Stage 2** incorporated the results of the group discussion and reviews of the visits including the photographs taken, to inform the design of a project kit. Their primary investigations created the parameters for this next phase of action. The rich investigations that the group had taken part in informed what was to follow and allowed the content of the design actions in Stage 2 to be framed. Their primary investigations identified Self's use of layering of scraps of materials stuck and stitched onto canvas to create highly expressive portraits and figurative artworks. Their photographs and chat pinpointed elements of layering, pattern and colour as being important.

The photographs of the artworks that were displayed at the People's Palace and the Big Banana Feet which were on display in the museum helped the co-designers to identify and articulate what they saw as being true to their idea of Connolly. They reviewed the alternative ways in which Billy Connolly had been presented and had identified the depictions to which they felt more closely allied. This approach made true to the Co-designers, the Kelley and Kelley (2015) position of seeing, gathering, and recognising how collected parts might come together.

Devised in response to the Co-designers framing of their investigations, the Stage 2 project kit was devised to allow quick, accessible methods for creating visuals. The kit

repurposed Tschabalala Self's artistic process where different scraps of fabric formed different body parts. Based upon more widely recognised images of Billy Connolly from highlights of his career (informed by the group), four historically significant pictures of trademark outfits and poses were converted into outlined graphic illustrations. These were then printed on the reverse side of a collection of patterned laser prints. The laser print patterns were of textile designs inspired by Tschabalala Self's medium of choice. The choice of patterns reproduced in the laser prints were significant, as they originated from modern and historical textiles produced in Glasgow. This anchored the designs locally, supporting an imbedded link to the local surroundings of BRC. In total, fifteen different patterns were utilised. A range of patterned heads, legs, bodies, hands, feet and clothing were cut into small portions (or scraps) to be assembled. The component parts were offered to the group from which they selected the elements they wanted to use. As part of the kit design, a guide to how the parts should be re-arranged was generated. The designs were then systematically reproduced in a sequence, although freedom of choice in regards to pattern and arrangement were entirely that of the individual. The serendipitous nature of how the original source patterns, aligned with the form of the Billy Connolly component cut shapes, supported diversity in choice affording opportunities for a range of colours and pattern glimpses with which to work - though, not every piece created contained a highly decorative or colourful pattern. What was important in this process was choice in form giving.

The workshop invited the co-designers to collage their own designs for their vision of Billy Connolly from the component parts. During the workshop, the five co-designers generated individual artworks. In the hour of action that comprised the workshop, five of the co-designers created two completed artworks each. The fifth participant, due to a previous appointment, was only able to produce one artwork albeit that it consisted of two representations of Connolly.

During the making of the individual collages, it was observed that each participant's image revealed personal tastes where component part selection was particularly important to him or her. In one example, one of the Co-designers stressed the desire for

the right hand and right boot to match but that "*the hands and the feet shouldn't match*". This was a clear personal choice of the participant and an articulately expressed creative decision relating to the organisation and arrangement of the constituent parts.

Throughout the process, very distinct and clearly considered decision making was evident. Continuing to make judgements and to explain what they were doing, the same Co-designer stated "I've used too much blue, I need another colour in, it's too much the same". Another Co-designer was adamant that they were not interested in making the image in the form of a human figure. Instead, they explained "*I'm waiting until everybody has got their parts and then I'm going to use the parts I want*". After this, they proceeded to select multiples of figure parts to create their own more abstract patterns. This Co-designer took great joy in collecting and arranging the vast array of surplus parts into their own creative outcomes.

The rest of the co-designers produced very close facsimiles to the original designs. These were, however, highly individualistic in terms of pattern choices and colour combinations. Throughout the process, all the co-designers were assertive in directing what they wanted, what would work and what wouldn't. Rejecting in no uncertain manner what they did not want in their designs. The result was similar representations of Billy Connolly that were nonetheless highly individual in colour arrangement and pattern relationships.

Learning from attendance at previous workshops and observing the capabilities of PLWD, the kit design contained some particularly small parts. These challenged the perceived wisdom of dexterity and sight issues associated with Dementia. As such, this went against the guidance in designing for people as directed by organisations such as DEEP (2020). In particular, the approach tested the co-designers in regards to elaborate pattern and the very small nature of some of the pieces. It should be noted that the individuals within the group were younger people with a diagnosis (under the age of 65) and that they were not so far along their own personal journey. However, the parts and precision with which they worked proved to be no problem at all. During the process, it was noted that on at least three occasions, individual co-designers, when small pieces fell on the floor, managed to identify them and picked them up. It was suggested to one of these individuals that there

were others available and not to worry about the one on the floor to which the response was *“but that’s the one I want”*.

The design workshop led to bold visual outcomes created to the particular tastes of the Co-designers. These were in the form of abstract representations of Billy Connolly. The individual Co-designer’s images were often produced in pairs on the sheets on which they were being arranged, which was an unexpected outcome. At the outset of the workshop, it was expected that each representation would be produced on an individual sheet. The group, by their individual actions, took control of what would be generated and created arrangements that led to the next phase of the design process.

In order to achieve the greatest value for the outputs from this workshop, predetermined expectations for their use had to be adapted. Informed by participant actions the design intent remained fluid enough to react to the choices of the group and their arrangement of the new artworks. What became apparent was the potential that existed within their unexpected visual arrangement. The artwork outcomes from Stage 2 consisted of multiple sheets displaying combinations of human figures collaged into patterned silhouettes along with two highly abstracted forms. Throughout that process, unexpected arrangements occurred, driven by individual decision making. In particular, the abstracted images shared a creative aspiration by the Co-designer who created them and articulated that she *“always collaged throughout my life, I used to make cards for people, I know what I’m doing”*.

In this project, the Co-design decisions and actions displayed the often-leading roles played by the PLWD. Here, decisions, discussions and actions have informed the direction of the project. Adapting regularly to these choices, behaviours and actions the research intention or proposition within all the workshops was regularly re-evaluated in order to react to the potentials of the outcomes generated. The applications of the visual outcomes as designs, were driven by the design conversations that occurred. On viewing the *“Big Banana Boots”* images alongside the abstracted arrangements (one of many unexpected outcomes), it became apparent that the new images had the potential to

become patterns in their own right. Given that textiles initially informed the project, it was by happenstance that the idea of creating a repeat textile pattern for a new local fabric was developed (Fig. 6.5).



Figure 6.5: Designing the Billy Connolly figures (left) New Bridgeton textile fabric design proposals and selection (right)

**Stage 3** Identified a skills gap that would be difficult to overcome without more time, specialist equipment and training. In order to keep with the momentum of the project and in order to support the consistent interactions achieved so far, it was important for the design-researcher to provide technical expertise. This facilitation occurred outwith the workshop settings. Although appearing to happen at distance, the translation of the visual designs into patterns was a process necessary to progress to the next stages of co-designing. Thus far, in this collaborative project the process of co-designing had developed through the actions of, and reactions to, the workshop co-designers. That is, every participant's creative input had been valued and taken into consideration throughout; achieved through mixed methods including, discussion, action, photography and collaboration between all parties. In this sense, collaboration has been based upon discussion, agreement, accepted disagreement, fun and support where there is no judgement (from any party) in regards to the quality of the contribution being made. In Stage 3, responses to the designed outputs that the group had created were made. New arrangements were created through repeating the group's original Billy Connolly designs. Here, spacing between original elements and the figures were maintained in their original state to retain authenticity. The only aspects reconfigured were the surrounding blank space and alignment or rotation utilised to make repeating patterns. This important aspect of the work was discussed prior to its being undertaken and represents a process

where design specialists with particular skills and knowledge are needed. The revealing or sharing of these pattern arrangements appeared to reinforce the sense of collaboration. The options created a sense of value (within the group) in what they had created.

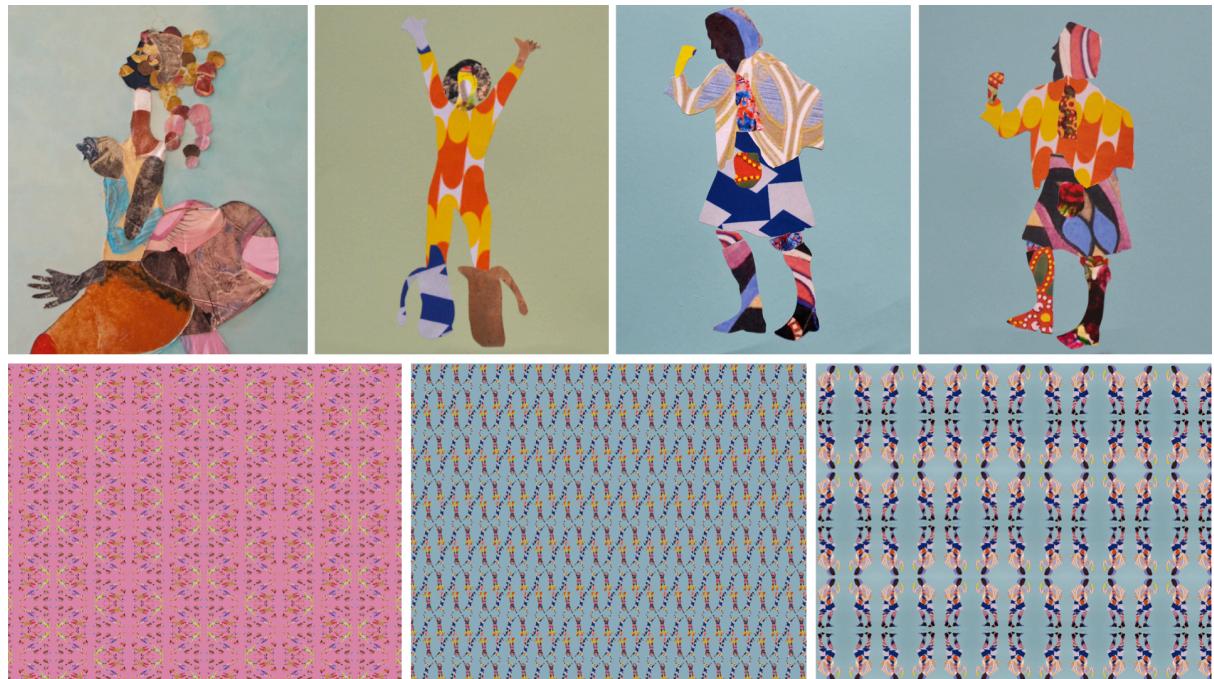


Figure 6.6 Tschabalala Self and Billy Connolly collages (top) and New Bridgeton textile fabric design proposals (bottom)

**Stage 4** consisted of a workshop of discussion between the Co-designers leading to them making pattern selections and undertaking a process of editing selections. The workshop utilised the space in the BRC environment to allow for printed copies of their patterns to be displayed. For an hour, the group was asked to stand, walk about and personally review what each co-designer was looking at. This process was reminiscent of the kinds of visits that the group undertook as part of its cultural excursions. The next step asked the group to gather around each set of prints to decide what it was going to have produced as textiles. The standing and walking process appeared to stimulate the co-designers to talk and to use their bodies to articulate and animate the process of decision making. Large expressive arm movements, in particular, often supported these enthusiastic discussions. In this process, there was an intention to identify three patterns that would be digitally printed on cloth.

This process was largely restricted by the available funding for the production of their prototype samples. The group selected four. Once the four textiles had been selected the co-designers agreed on the production scales for each pattern (Fig. 6.6). Five variant sizes had been printed for each of the patterns. They then made decisions so that the collection of new patterns was agreed. Consensus was then sought as to what the reproduction size should be. This edited selection was then produced as prototypes in heavyweight cotton using a commercial digital textile printer. The process supported a collegiate agreement of the designs and the way in which they were to be reproduced and further exhibited the ability of the co-designers to take control and steer the project. One of the co-designers expressed how the importance of their tastes had emerged in the project when they expressed their liking for the pink abstract fabric. The discussion of this included the point that although not a fan of pink, *per se*, the pink fabric was the one that appealed to them. It came as quite a revelation when it was revealed that this was that individual's design to which they remarked, "well I do like it". What followed was the retelling of the previous statement about how they had always liked to collage. This appeared to be important and self-reaffirming, expressing part of their individual identity and personal biography (Greenfield, 2012).



Figure 6.7 Co-designers selecting patterns and scales for digital print on fabric

The following workshop, **Stage 5**, stemmed from a group discussion as to how the fabrics might be used. This discussion had occurred at the completion of the selection process. Where the next production stage in the process was explained. The group was then encouraged to talk about where and how fabrics play a role in their own individual lives. From this an agreement was reached to explore home furnishings.



Figure 6.8: The four textile fabrics (top) and the textile designs being applied to products (bottom)

**Stage 5** started with an introduction to the newly printed textiles and video footage of the production process. Based upon the discussions within the group during the previous selection meeting of how fabrics are used, a range of household objects and furnishings were chosen to be turned into templates to which the new fabric designs could be applied. The range of interior products chosen included a lamp, a light, cushions, a rug, bed linen, a sofa and a lounge chair. These were based upon IKEA's ubiquitous collections.

In preparation for the workshop, the selected items were turned into new line art drawings and laser cut out of card to make frames. The frames could be filled with the cut outs creating internal jigsaw like pieces that would become templates for cutting and sticking patterns to. An acetate top layer then allowed for the outline of the original furniture to appear over the frames. Within this approach, the co-designers could move the frame over different samples of the patterns and to devise efficient mock ups that could quickly be adapted.

In the workshop, the Co-designers were invited to use this template systems to propose ways of applying the newly designed fabrics. The templates formed a prototyping kit for the design of the pieces and were open to adaptation dependant on the will and wishes of the Co-designers. During the workshop process, each participant chose a minimum of one key design to produce. Some got on to doing a second while two other Co-designers collaborated in the design of two new rugs. The resultant designs were produced in largely individual processes through personal choice making, selection and application of the fabrics. As this process occurred, group discussion continued and through working with, talking to and engaging with each other the co-designers generated final decisions.

During this stage of the research, a new co-designer joined the group and one left. To incorporate the new member into their co-designed project the existing group members informed the incomer about what they had been doing and how the fabrics had come about. With this knowledge, the new member wilfully got involved in the process of designing the home-furnishings range with the rest of the group.

In review of the workshop in **Stage 5**, particular emphasis is drawn from two of the co-designers. All of those involved in the process delivered successful propositions or prototypes but the activity itself appeared to resonate in particular with two people now being singled out for discussion.

The first co-designer began by working on the lounge chair, where he desired a very simple covering for the entire upholstered area. He applied a covering of the blue kilted fabric. At this stage, the method of how to use the templates was shown to the group again which changed the participant's thinking and approach. He desired a rethinking of the fabric covering arrangement and organised the design such that the back cushion remained the same but the yellow textile was introduced to the base cushion. As part of the design kit, some other un-patterned materials were supplied, allowing for plain options to be applied where and when the Co-designers required them. This Co-designer decided that this was what he wanted for his design, where he made the choice to create

a cushion to go on the chair made from a sky blue fuzzy felt. Using one of the template jigsaw pieces they utilised the cushion template form to create the desired look.

The outcome of this work was that this individual showed a great deal of adaptability and problem solving where awareness of other co-design products informed use of the pillow (Figure 6.9).

This first Co-designer is a quiet individual and is very rarely as vocal. However, he regularly expressed joy in what they had done and articulated what was their preference. During the process, this participant also designed a lamp and collaborated with another co-designer to generate designs for two rugs.

The second co-designer highlighted in this process was the new group member. Being new to the group and the project, he did not have the same opportunity to have ownership of what had previously occurred. However, he eagerly got involved with the task at hand. This new co-designer is particularly non-verbal, limited in his ability to hold conversation or find the words that would aid his participation. By the time of this workshop, he had been attending the group for more than a month and had taken part in another quick Travel Postcard project. As such, the participant was used to working with the other co-designers and displayed enough confidence to get involved in the whole process. It had helped that the group had informed him of what had been done and that there had been a tangible result in the form of the textiles. The new co-design participant paid particular interest in creating designs lampshades for pendant lights. Here, he layered up a variety of quite raw arrangements of the materials sometimes tearing them to get the desired proportions of pattern. During the process he was animated, fighting in order to find decision affirming words and displayed a sense of being thoroughly engaged. This resulted in two unique designs (Figure 6.9). The lack of sophisticated verbal communication was no barrier in this process, although there was a clear want to explain the design decisions made and approaches used. On completion, the co-designer appeared to display pride in what he had achieved and showed a sense of ownership of the designs, this view was reinforced in a later workshop.



Figure 6.9 The lampshades designed by the new Co-designer and the lounge-chair designed independently by another Co-design participant along with the rug he designed with another collaborator

In this phase, the group collectively created a range of products that made great use of the materials they had designed. The processes explored allowed for iterations and supported decisive finishing points where the co-designers were happy with their designs. These were then collected through photographs to be developed further in the form of real products.



Figure 6.10 Cushion Production by the Group at BRC

Stage 6 involved the creation of the group's first real products. As an intention of the process was to take the work beyond art therapy, it became important for some realisable design outcome to be achieved by each of the individual co-designers. The focus of the previous workshop informed this proposition. It became apparent that the group should explore some sort of manufacturing technique. Taking the simplest, realisable product, the cushion, it was decided that each participant would design, and to the fullest possible extent, make their own. These were to be designed for, and used within, the Alzheimer Scotland Resource Centre at Bridgeton. A range of plain backing fabrics were acquired and the sample printed textiles were made use of.

*Vignette:* The discussion of the cushions led to one participant using paper to explain how the envelope approach to making the cushion cover would work. She picked up two pieces overlapping them. Another co-designer then helped to show how the flap opened to put the cushion in.

Based on this insight a set of foamboard templates were produced for the workshop which would support the production of envelope style cushion covers.

Each participant was initially asked to make material choices, pairing plain coloured backing materials with fronts to be made of 75BC textiles. Then, using the three supplied, template-forms, the Co-designers took it in turns to help chalk out each other's patterns.

Following this phase, the group helped to stretch the materials and aided in cutting them. Collectively, they collaborated in the production of five sets of cushion parts. These were pinned together, with help from the facilitators, around a cushion pad. This one-hour session encouraged full body movement and interaction, encouraging the Co-designers to move around the workshop space, laying things out on the floor, chalking and cutting on table-tops and wrapping the pads whilst sitting down. The activities themselves required fine motor skill engagement and good hand to eye co-ordination. Going against the prescribed notion that people with dementia should not be handed sharp or potentially dangerous tools, the use of scissors and pinning was encouraged under

observation (or to a degree of supervision). This struck a chord with the members of the group, some of whom explained that they had undertaken such craft activities and had been skilled in dressmaking most of their lives. The cushions were then taken away for stitching assembly on a sewing machine, with firm instruction from the group as to how this should happen. This construction guidance provided a further example of how people feel joy in sharing their experience and knowledge within these kinds of co-design activities, suggesting a reinforcement of personal and social value.

The cushions were stitched and returned to the group in time for the next meeting. The result was that the cushions that were produced became part of the furnishings at the BRC. Where it was relayed by Heather Ruddy, Leader of the Friday Day-Opps Group, that although the co-designers were happy to share their cushions throughout the week they want their own one back on a Friday and that even when two cushions were very similar each person wanted their own one.

The diagram below is a representative map of participation, leadership and prominence of role within the Co-design process that naturally occurred during the development of the 75BC project. The peaks represent actions by the PLWD Co-designers and the troughs were those actions undertaken as part of the facilitation and responsive workshop planning. Each workshop or visit lasted between 1-2hrs. Where contributions were more equal, opposing peaks and troughs explained the combined participation and influence. The diagram helps to explain the predominant participatory behaviours of everybody involved in the Co-design process and helps to visually narrate what became a highly action and response driven design conversation. The diagram also helps to illustrate where design expertise, knowledge and skills drove actions and where the same knowledge facilitated translation of design concepts into processes of production. Key to this process is the long-term relationship of continual back and forth interactions where content or knowledge was not extracted to be exploited. Alternatively, the collaboration and interdependency continued throughout the design and production of Co-designed content. This process underpinned the approach throughout the research forming a framework for considering the projects that followed.

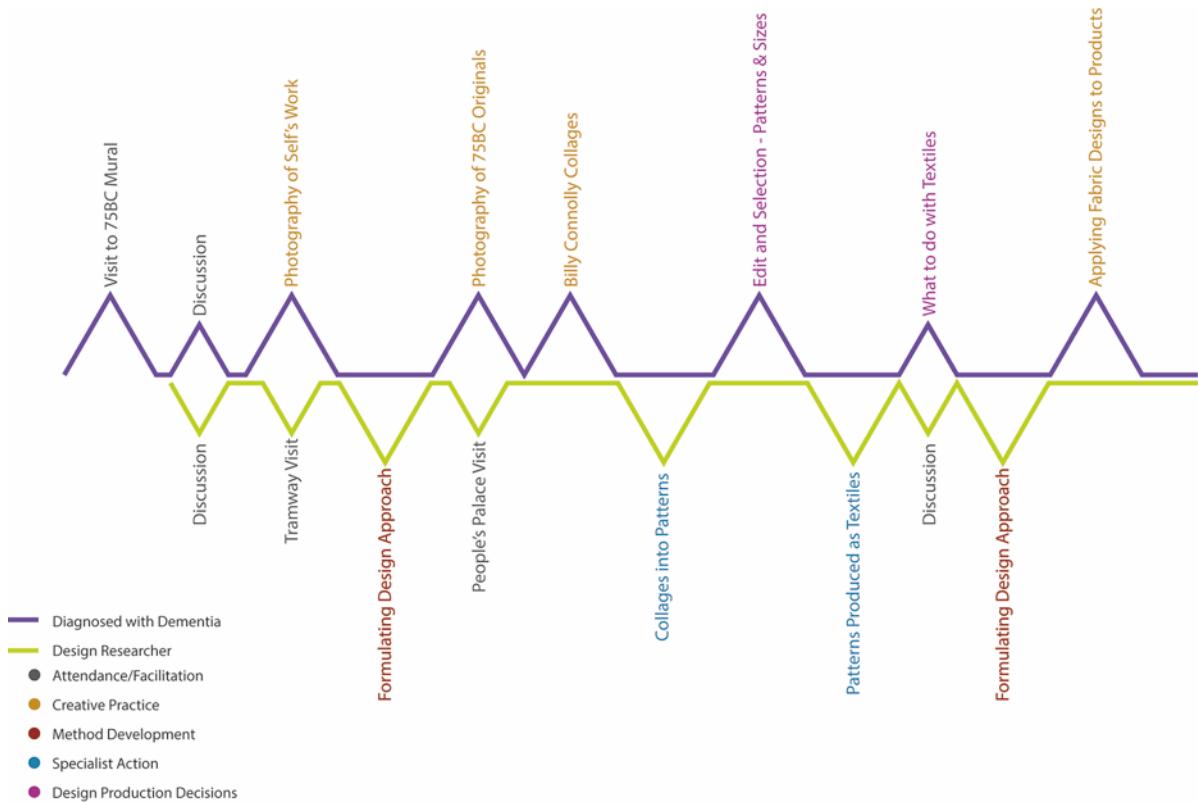


Figure 6.11 Diagram of the 75BC textile Co-design journey

**Stage 7: Exhibition - co-design Development of the Campus in The City Toolkit.** As the project came to its co-design action-based conclusion an invitation to present the work in an exhibition was received. The event, 'Campus in The City (CITC)', is a Lancaster University public platform that invites people from the local community to come in and see what research is being undertaken at the University and to see how it might be relevant to the public. Housed in a redundant shop, the exhibition allowed for the display of the fabrics that had been produced by people living with Dementia. This required the production of the patterns on new cloth, cotton drill and silk. In support of the display of these cloths, some of the furnishing designs were made as three-dimensional prototypes. A version of the lounge chair and table lamp were made, as were two lampshade designs. The event was used to highlight the capabilities of PLWD and to act as seeds for further discussion by the local community. Given two days within the month-long event, the *Designed with Dementia* project was afforded an opportunity to highlight the work and to produce a public participatory event, where they could play with and learn from some of the techniques the group had been using. Recognising that this further moved the work

beyond art within a restricted concealed environment and made it design experienced in the public realm (Cross, 2011), the opportunity was put to the Day-Opps for discussion before being accepted.

In preparation for this event and coinciding with discussions that were ongoing at Bridgeton, a system for printing onto fabrics was explored. The exploration of the block printing approach was based upon the textile prints that had already been undertaken by the Day-Opps Group. Through the Burn's workshop, the group experienced a different form of pattern printing that was of a more direct nature. This process introduced more traditional printing approaches which each group member explored. The theme the group was looking at was Rabbie Burns<sup>4</sup> to coincide with Burns Night.. This 'quick and dirty' project was devised to allow the group to make a quick memento and to get very hands on in the process of doing so.

Prior to the Rabbie Burns Workshop, discussions had been held within the group regarding favourite Burns quotes and poems and reading some of Burns' works. From this, a number of themes and representations were noted and these became the initial elements for a set of stamps. The stamps were produced for this workshop which was supplied with paints, paper and cloth. Using a block printing approach, the co-designers experimented in making marks and using the range of materials supplied to them. The stamps were exploratory prototypes to see how the group might react to and adapt them and allowed them to experiment in making their own compositions. The approach was limited in its tangible success when compared with the 75BC outputs, though it gave plenty to explore in regards to the approach for '*Campus in the City*'<sup>5</sup>. As such, they were undertaking the task as both co-designers and evaluators working under a different form of co-design. The group played with and used every aspect of the stamps that were provided to them and noted where problems occurred, including 'glooping' in tight cut elements of the stamps and issues created by over complicated text. The most effective

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<sup>4</sup> Rabbie Burns or Robert Burns (1759-1796) is widely regarded as the national poet of Scotland. Burns night is a key event in the Scottish Calendar and is celebrated worldwide on 25<sup>th</sup> January.

<sup>5</sup> *Campus in the City* is a Lancaster University initiative to demonstrate the excellent research undertaken at the university. Its aim is to bring research into local settings allowing local citizens to see and learn more.

outcomes proved to be a Burns portrait and a Rose design. It was also noted that the stamps were not easily removed once pressed down and that this led to smudging and dirty fingers meaning that a key modification was to add a handle. Questions were also raised as to whether or not the materials the stamps were made from would work for the event. In their participation, the team of PLWD refined how it was to be made, the materials, the structures and their method for use.

*Vignette:* A co-designer explained that she couldn't pick the boards up very easily and that she could do with a handle. She stated it would make it easier to hold it whilst she painted the stencil too. At that time another explained "that just wont last" whilst pointing to the foam board.



Figure 6.12 Burns block printing workshop at BRC (Pics 1 and 2). Printing stamps from Lancaster Campus in the City and images from the public event.

Taking on board the comments and feedback from the group, a set of stamps was generated for the 'Campus in the City' event, the content of which was based on local Lancastrian buildings celebrities and sayings. In particular, the celebrity images and the text-based approaches were informed by the guidance and use of the prototype Burns kit. The stamps for the event were produced on wooden panels as opposed to the foamboard Burns prototypes and wooden handles were attached.

Stage 8 involved no group participation from BRC but did consist of the *Designed with Dementia: Lancaster* exhibition and public participation event that it had helped to shape. The Lancaster event was presented to over two-hundred members of the public over two days. During this event, there was an open invitation to all visitors to not only browse the designs but also to become active makers in the space. Here, ninety-six creative pieces were generated by the visitors and retained by them as mementos. The creative activities involved printing of tea-towels and cushions using the kit developed in the Burns workshops. Tailored for Lancaster, the designs were rooted in local places, personalities and sayings. The recorded public co-designers ranged from ages of one to ninety-three years old. There were some people living with Dementia in attendance and one who had travelled specifically to the event and whose carer brought her to get involved in the making of her own designs. Much like one of the 75BC Co-design team this kind of creative work had been a central part of her life and the opportunity afforded time to engage with such a process in a different setting.

During the exhibition, commentaries were collected through stamps and written commentary, notes of conversations were recorded in field notes and photographs of the designs created by each individual were taken. The joy of what had been created by people living with Dementia was evident, as was a general surprise in the products and fabrics. Importantly, the space where people were encouraged to make something also created a hub-like environment where people of all ages participated in making their own designs in a socially inclusive environment. One visitor spent two and a half hours conversing and making her design during the event and raised her own concerns that her [brain] was "not what it used to be". The space in welcoming families and people of all ages proved the potential for Dementia shaped creative hubs to offer something unique in the high street.

The Lancaster Exhibition, in terms of affecting the world outside the BRC by the Co-designers, was important for the group and the project. This became the first opportunity for the members to express their creative prowess externally and in doing so, built value

in themselves and their work. The outcomes of the event were shared with the Day-Opps Group through a post-event review consisting of discussion and display of the photographs.

**Stage 9** in this final stage of the 75BC project was to look at how products adorned with the fabric designs might be taken into the high street as commercial propositions. This will be discussed further at the end of this chapter. However, it was at this point that the final adjustments to the fabrics were undertaken. In the hope of creating some kind of commercial output that would benefit the Day-Opps Group and the Co-designers, the permission to use the remnant designs of the contemporary designers was sought. At this stage, one designer decided that although the project was of interest to her that she would not like her scraps of content to be used in any commercial proposition. Timorous Beasties, the renowned Glasgow design practice, was supportive of the project and happy with the way in which its work had been used. In order to ensure that no infringement of work occurred, the objecting designer's patterns were replaced with alternatives which did not infringe anybody else's designs.

To: Winton, Euan <e.winton@lancaster.ac.uk>

Hi Euan,

Thank you for getting in touch and letting us know how Timorous Beasties has inspired your project.

We support your project as it is a worthwhile cause and if you ever need any samples for projects in the future we are happy to help.

As we were not involved in the project we can promote the designs as something we were a part of in a creative sense.

We have no objections with you selling your products and supporting your project but again because we were not involved in the project, we wouldn't be able to sell the products on our website or in our shops, etc.

All the best with your PhD research!

Best regards, Dana

**TIMOROUS BEASTIES**

Figure 6.13 Email from Timorous Beasties

## 6.8 Travel Postcards

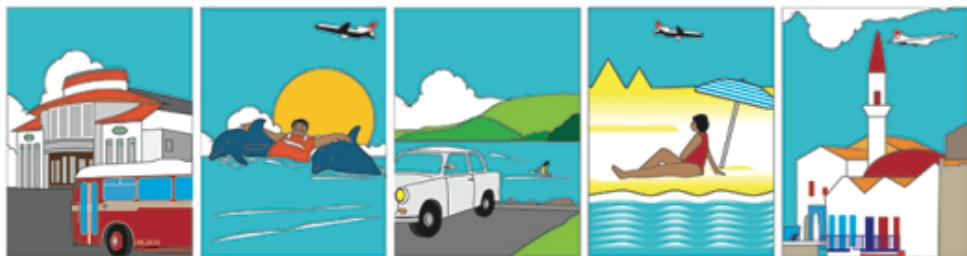


Figure 6.14 Favourite or dream trip postcards for the Riverside Transport Museum, Glasgow.

Following on from the initial investigations undertaken by the group for their 75BC Fabrics, the next project to be undertaken was a much smaller and quicker challenge.

Designed around a forthcoming visit to the Transport Museum, Glasgow, a quick investigation was undertaken with the PLWD who had been actively involved in the 75BC project. This smaller project took place during the course of the larger project and was completed quickly. As such, this piece of work represented the kind of interruptive design project that regularly punctuates a practising designer's larger project. This was embraced as an opportunity to do something different for a short period of time.

Promoting the understanding that a designer rarely has one project occurring in isolation. Instead, a practice is usually undertaking a number of overlapping or parallel projects some larger than others and all of differing durations. This encouraged the group to think and perform in a manner more akin to a real-world practice to test mental or multi-tasking capacity.

Again, the process followed a discursive design approach that was punctuated by active workshops. Designed to support the forthcoming visit the project explored personal travel experiences.

**Stage 1** engaged discussion around favourite travel experiences and had a nostalgic consideration of travel. What was proposed was that individual co-designers would discuss their favourite travel experiences and whilst doing so, would collage a prototype postcard through a collection of supplied images that had been informed by previous conversations.

**Stage 2** formed a Postcard Collaging Workshop. At the start of the workshop, the co-designers were given a travel ticket that would allow them to get to any dream destination of their choosing. The approach recognised the cognitive capability of the group to understand that this was an action that had a degree of role playing inviting the use of their imagination. Continuing to explore the approaches that designers use when tackling a challenge, the role playing (IDEO methods cards, 2003) encouraged internal questioning and acted as a tool for people to think about their historic experiences; touching on a form of reminiscence, but much more attuned to the designer's approach of using individual attained knowledge. On filling in the ticket, the group discussed where their ideal journeys would be to and how they would like to travel. The breadth of answers pertaining to destinations showed just how important the individual's framework of reference was. Two people identified overseas travel as being important and related to holidays that had been undertaken recently or were to come in the future. One of whom talked of an impending trip to Lake Como in Italy where another recalled a recent (past 10 years) trip to Egypt. Another reminisced about a trip to Loch Lomond with her Father in a white car when they were a child and talked of swimming in the loch. The fourth member of the group had no distinct destination in mind but wanted the sun and the ability to swim with dolphins. Whereas the final member was more concerned with travelling by bus up the West Coast of Scotland.

To develop their themes the members of the group were supplied with a number of nostalgic printed images to collage their destinations and modes of transport. The nostalgic narrative was chosen to sit alongside the historic collection of the Riverside Transport Museum. The supplied materials were to be used to form a postcard. During the following discussion of the postcard project, the group revealed the thought of the postcard as a dead technology that "nobody sends" anymore. They discussed the habits people had of sending postcards and how finding postcards, stamps and where to post them was a ritual for the first day of the holiday. The suggestion made by one participant was that "you got it out of the way so you could get on with the holiday". Another stated

that "it's not the same now, you just get a text". By the end of the activity, every participant produced his or her own sketch outline or wire frame of a postcard.

**Stage 3** was an interpretive undertaking by the researcher. The wireframe designs generated by the participant collaging session and supported by the key comments collected as they made their prototypes were used as the brief for the creation of a set of postcards. The author of this work undertook this task. Using the computing software, Adobe Illustrator, drawings were produced as more professional representations the content of which was very much directed by the actions and conversations that had been undertaken in the workshop process.

The conversations and the process helped to trigger memories in co-designers' minds. In particular, one member talked of the bus he had worked on in 1968 and the places he had stopped at before recounting "ML2610". When asked what this was for example the number plate of the bus he responded "no that was the serial number of the bus I worked on".

**Stage 4** delivered the individual postcard designs to the Co-designers for them to keep. Consistent with the attempt to get the group's designs into the public realm again, the transport Museum in Glasgow was been contacted to see if they might be interested in selling the postcards within their Museum Shop to no avail. However, this further concentrated thinking about how public presentation of materials might occur.

## 6.9 Reconfigured Research Group

The initial projects undertaken with the Day-Opps Group occurred over a year from 2017 to 2018. During this time, one member left and another joined the Co-design team. Throughout the project, there were periods where members might dip in and out of the group due to other commitments, however, they tended to be consistent in attendance, participation and make up.

In the time between the completion of the 75BC project, the running of the Lancaster Exhibition and the next phase of collaboration, the group changed significantly. In April 2018, the first phase was completed and it was agreed with stakeholders, including co-designers and the BRC, that a new phase would start again in August 2018. Only one member of the Co-design team remained and he was the participant who had joined midway through the original work. The reasons for the reconfiguration of the group included a change in the nature of some co-designers' Dementia and one participant becoming older than the sixty-five years old age limit of the group.

This meant that a new relationship had to be developed with the new group and that trust had to be built up again. Thankfully, the experience of the one member who had remained was a powerful testimony to the new group. To inform the new group of what could be expected if they were happy to get involved, examples of what the previous projects had achieved and delivered were shared. During this discussion, the continuing Co-designer fought to find the words to say he had been part of the team and in particular displayed great pride when he told the group "I did that [cushion]".

When going into the meeting with the new group, a certain amount of uncertainty was experienced and concern had developed that the original group had been keen co-designers whereas the new group was a new unknown. With this in mind, it was particularly encouraging to be greeted with a big smile and handshake by the one remaining original team member. The warmth he exuded was gratifying and surprising. By his approach it appeared as though the project and the social connection had been significant to him. The three-month gap between workshops appeared not to have been an issue and he asked personal questions that showed interest and memories as to why there had been a break, in particular asking, "How is your new baby?".

The group expressed interest in taking part in similar projects and again, members took forms and information away with them to assess the propositions and to declare their individual consent. With verbal agreement forthcoming, an invitation was extended by the group to join it in its next excursion.

## **6.10 *Designed with Dementia: Stained Glass Explorations***

In the first instance, two external visits occurred to the Charles Rennie Macintosh Scotland Street Museum in Glasgow and St. Mungo's Museum of Religious Life and Art, also in Glasgow.

**Stage 1** - visit 1 formed a primary investigation through a visit to St Mungo's Museum.

Here, stained glass was explored through a guided tour across three levels of the museum and contained discussion and explanation of styling and detail. During this visit, very much like the 75BC project, images were made and collected of the designs and artworks that were observed. However, the photographs taken on these occasions were guided by the co-designers rather than taken by them. The tour revealed that much of the highly detailed glass designs were not stained but painted. During the visit, the group took part in designing their own versions of stained-glass using stained-glass colouring pens.

**Stage 1** - visit 2, consisted of a similar visit, this time to the Scotland Street Museum in Glasgow which was designed by Charles Rennie Macintosh. This was of particular importance at the time, as Glasgow School of Art had just had its second, and most disastrous, fire. On commencement of this stage of work, the fire was in the minds of the Co-designers' and as such, was central to conversations that occurred. Much of the discussion had developed around Mackintosh and his influence on a range of design practices including products which incorporated stained-glass. This further developed the conversation from St. Mungo's where the 'Glasgow Style' and Macintosh's approaches to decoration, elongation of figures and blocked details were also apparent. The tour guide explained Macintosh's style as being contemporary to some of the works created by the stained-glass window makers that were being viewed and he identified these recurring motifs in many of the stained-glass designs.

In response to the visit, a collective discussion was held and the decision made to explore stained-glass designing as a group. The first group collaborative lighting design project was identified as being an opportunity to create a lamp in the style of Mackintosh.

**Stage 2** consisted of the workshop making the Mackintosh inspired light. The workshop was the first design activity that the new Co-designers had undertaken and developed the creative relationship within the group. In this workshop, the five co-designers cut windows into printed Mackintosh designs in order to apply lighting gels to the reverse side of the prints. In this process, support was given in the cutting out of the areas selected for the application of the gels, this was due to the intricate nature of the elements selected and the need to use a scalpel to do so. In the final designs, the gels became representative of the key stained-glass element that would highlight design details through light. The group then framed the prints using card and by gluing wooden framework to the rear of each of their designed elements. The design of the light was based upon a cube, which was inspired by one of Macintosh's lighting designs. Each of the five Co-designers designed a side of the cube which included the underside. On completion of each of the collaborators' designs, the parts were compiled and manufactured into the new light fitting. The forming of the light created a moment of revelation, in particular when the bulb was turned on, which provided evidence of collective capability within and to the group. In conversation about the project fourteen months later, the project still resonated with them, as one participant noted, *"What I liked when we did the... you showed us the picture of the Rennie Macintosh upturned cup and saucer but then when we were actually doing it. It was really interesting and then when you put the wood round the picture and the frame kind of thing it all fitted. You used the different coloured paper and stuff. It was good".*

The approach allowed for personal details to be revealed, supporting one participant in feeling capable of sharing skills and knowledge.

*Vignette:* One woman took charge in directing me as to how the wiring of the plug for the light should happen. She joked about the time I was taking to do it. Eventually, taking the plug out of my hands to do it. She also explained "I used to be an electrician" and went on to state that she had taught her daughter how to wire her house.



Figure 6.15 Stage 2 Inspiration, design making and outcome.

**Stage 3** was a workshop inspired by a review of the visit to and photos from the St. Mungo's Museum where the museum surroundings had also been photographed. At the time, lamp-posts in the vicinity of the museum had been commented on by the group and had been noted as containing symbols from Glasgow's Coat of Arms. Here, the co-designers shared a poem that revealed the coat of arms constituent parts and what the symbols meant. The poem reads as follows:

*Here's the bird that never flew.  
Here's the tree that never grew.  
Here's the bell that never rang.  
Here's the fish that never swam.*

With this as stimulus, the workshop used collaging as a means of producing stained glass window designs. This time a variety of line illustrations and graphic forms were reproduced on printed acetate sheets and supplied to the group in a range of sizes. The collection for parts allowed for the co-designers to choose and arrange desired components as long as they shared a relationship to the coat of arms poem. Once they had cut, arranged and pasted their desired components, the Co-designers used

permanent markers to colour their final designs. Due to the material quality of the acetate the colouring of the designs allowed the compositions to become detailed stained-glass prototypes and reinforced the appreciation that much of the glasswork the group had seen before had colour painted onto the glass. As 'quick and dirty' prototypes, the outcomes were taped to the windows of BRC allowing the daylight to pass through them and again creating a moment of revelation.



Figure 6.16 Stained-glass compositions designed around Glasgow's Coat of Arms and quick and simple window testing.

**Stage 4** - parts 1 and 2 comprised of another excursion this time to the Mitchell Street Library in Glasgow and a subsequent feedback session. This visit was undertaken by the group and its care support team from BRC. The second part of this stage consisted of a feedback session to inform the development of the next project phase. The Day-Opps Group explained what it had seen in the form of the archive and in particular, old buildings of Glasgow which shaped the theme of the next workshop. During this Day-Opps Group led session, they talked about what Glasgow landmarks they identified as being iconic. Informed by this discussion and the ongoing explorations in stained glass designing, a plan was conceived with the group to design a shared view of Glasgow

**Stage 5** consisted of a workshop where the buildings and iconic signs of Glasgow (selected by the group) would become the basis of a light banner/stained-glass window. The task was to encourage the Co-designers to select and colour elements from Glasgow

and its past that would suggest vibrancy and fun times whilst reflecting a sense of the city. Picture sorting formed much of this process where they collectively arranged the banner composition. The contents of which were printed on acetate sheets. In this process, the group used magic tape to align and adhere the constituent parts. This was of particular importance to one of the co-designers who revealed that she had been a book binder and that this had reminded her of previous skills and knowledge. In advising the rest of the group as to how to tape things together, the participant revealed a sense of personal knowledge and value, creating for herself a temporary position of expert demonstrator. The final composition was recorded digitally to be printed as one single transparent banner.

*Vignette:* In the incident regarding the taping together of the imagery the participant effectively pushed me aside. She was convinced that I was part of the problem and that she would be better at doing the task. This moment was undertaken with real humour and ribbing of me as the facilitator especially as she felt she was leading me and treating me (in a fun way) like a child.



Figure 6.17 Co-designers arranging the content of the stained-glass window for Glasgow, a painted sample from the banner in production and the backlit panel with design in progress.

**Stage 6** consisted of a workshop where the Co-designers painted on the reverse of the acetate banner. The group painted with acrylic paints using brushes, in doing so, using a more authentic stained-glass approach. The process of mixing and applying the paint invited experimentation and layering up to achieve their desired effect. On completion of the day's workshop, there was, again, a moment of revelation when the artworks were

applied to a LED backlit panel. This aspect of the process was highly valuable and through further experimentation, one of the co-designers overlaid the two panels that the group were working on creating an unexpected outcome, which the group preferred. The overlaying of the two banners created greater colour depth where overlapping occurred and integrated the different aspects to which each group had paid attention. This again related to the original visit they had undertaken where colours and the richness of the tones was deemed highly important. Although the work itself has never been publicly displayed, the process informed other design projects that followed and the image created became part of a number of products designed for public consumption, which will be discussed later in the chapter. At this stage, it was not lost on the collaborators that the methods they were being exposed to were introducing new things to them and supported keeping things interesting. Here, one of the co-designers explained with their own humour "each week we are learning, we might not always remember, but we're learning".

### 6.11 Floating Heads Plates

The collective participation and actions of the group continued to build their portfolio of designs which became relevant to the broader achievements of the project and the Co-designers. The togetherness and willingness displayed, helped to identify new opportunities and displayed a sense of ownership by the group. This became particularly true in the project that emerged from the next visit - to the Kelvingrove Art Gallery and Museum in, Glasgow. This smaller project followed a similar pattern to the previous postcards project, in as much as it was to be a short additional project sitting alongside the larger stained-glass body of work.

**Stage 1** consisted of a visit to the Kelvingrove Art Gallery and Museum in Glasgow. The purpose of the visit was to visit a new art installation where pottery had been blown-up in historic war zones. The process had been filmed and photographed and replayed within the gallery alongside the exploded artefacts. The fragility of the ceramic pieces and their fragmented forms were arranged to generate questions in regards to collateral damage.

The group was unimpressed, as expressed by one participant, "I get it, I just don't like it" or another who stated "nah, it's not for me". There was a general sense that it was too serious and largely uninteresting. In juxtaposition to that exhibition, the group noted the large ceramic heads that hung in the adjacent stairwell. These were the 'Floating Heads' by Sophie Cave. The group photographed these noting joy in their appearance and playful nature.



Figure 6.18: Floating Heads by Sophie Cave at Kelvingrove Art Gallery and Museum.

**Stage 2** formed a workshop that responded to the commentaries and photographs that the group had taken and offered. A number of ideas based on the Floating Heads installation at the Kelvingrove Art Gallery and Museum were to be explored in this workshop. Different materials and process had been considered and were going to explore the forms in both 2-Dimensional and 3-Dimensional forms. These ideas were very quickly abandoned the moment one of the co-designers decided to start drawing her versions of the faces of the floating heads on ceramic plates. This Co-designer had taken the approach of diving in and acting on impulse. She picked up one of the plates that had been brought, a template and porcelain marker pens as the materials were being unpacked. Instantly she started to alter the template and to draw directly on a plate using the hacked template as a guide. Quickly the other co-designers got on board with doing their versions of the same thing. The hour-long session was transformed from 'workshop intention' to 'design intention' by the Co-designers. By inadvertently disrupting the planned approach, the project became the group's own, where its members experimented with hacking templates to create their own designs.

Four of these were selected by the group to become a set. It was important that the facilitation process allowed this to happen, rather than redirecting the efforts of the members of the group towards the original plans. In facilitation, it was of particular importance to embrace the unexpected outcome as this was singularly *their* design process. This provided a sense that the Co-designers were both stimulated, knowledgeable and empowered. They appeared to be building on their confidence and their right to make decisions or to direct design practices, reinforcing a notion that the control in all of the workshops rests with the Co-designers. The empowerment is best explained here by the understanding or prowess displayed by co-designers to disrupt a planned process in order to develop a better design solution.



Figure 6.19 Floating Heads inspired plates the result of the disrupted workshop process.

## 6.12 Table Top Gardens

During the duration of the research project, many visits had been organised by BRC for the Day-Opps Group. These were used to build upon existing design projects or as stimulus for new opportunities. During the collaborative design journey these visits created interesting segues and allowed for more than one project to develop at the same time, just as the previous Floating Heads project is testimony too. At this stage of the Co-design relationship, new visits were arranged to garden spaces. In this next stage, the two visits were proposed by the researcher.

**Stage 1** consisted of two visits to garden spaces, one of which was the Hidden Gardens at the Tramway, the other was Pollock Park and House, both in Glasgow. The process of a primary photographic investigation was again used at the two visits. This time, the group had been informed that they were going to design their own table top gardens. During the visits, each participant wandered around with a camera documenting what was important or interesting to him or her. The Hidden Garden is a small modern garden arranged in a contemporary, stylised theme, whereas Pollock Park and House form part of a historic estate arranged in the style of their time. The two contrasting environments supported a broad range of tastes and stylistic interests. The collection of the imagery here was attuned to the personal responses that each group member had. The group was becoming used to this approach and needed little instruction as to what was required. The social interaction between the co-designers as they undertook the task showed a willingness to share insights and personal preferences to discuss knowledge and to relate what they were seeing to their own lived environments.

**Stage 2** formed a workshop that introduced a stage of planning where the co-designers designed their own miniaturised table top gardens influenced by what they had photographed and supported with contemporary gardening magazines. The use of collage as a visual design method was again put to good use and resulted in distinct personal designs to be translated into real table-top gardens. These outcomes also acted as a shopping list for the plants required to deliver the outcomes.

**Stage 3** was a workshop that challenged the Co-designers to translate their 2-dimensional plans into physical table top gardens. In this process, the co-designers brought their own skill and knowledge of gardening into a planting of their designs. The plants were provided in accordance with their predetermined designs and the interpreted materials required to complete them were also supplied. These included a variety of decorative stones. The co-designers wilfully explored making their table-top gardens in the allotment at the Alzheimer Scotland Allotment at Bellahouston Park. Here they sat in the open air around a picnic table building their creations. The environment made for a different atmosphere for creative practice removing the group from the usual setting of BRC. On

the day, one Co-designer was unable to attend and so, her fellow Co-designers made use of her collage plan to create her design. This step reinforced the idea that the group was involved in a design process that involved investigating, planning and making. The transformation from plan to product provided evidence that ideas could be collaboratively materialised within the group.

The process of making the table-top-gardens elicited much conversation and drew out the Co-designers' personal knowledge as keen gardeners. Conversations about what the gardens would mean to the Co-designers and where they would be used were full and engaging. One participant expressed that her Table-top-garden would be used as a table centre piece in their garden for other people to enjoy and discuss; "*Mines is going on my garden table 'n' it can be a focal point, a talking point*". Another had identified a space in her garden that had been prepared for its arrival; "*The part of the garden 'ave got it in, we've got grass there and roses there but it just sits between us 'n' our neighbour who's round the corner... there was nothing there... it just fits there great. It still gets light 'n' a bit of rain 'n' whatever, when it needs it but it's certainly still growing fine*". These creations were discussed, during and after the workshops in a manner that highlighted significance and personal esteem along with a continuing sense of value.

### **6.13 Designed with Dementia Pop-up Shop, St. Enoch Centre Glasgow**

During this PhD investigation, much thought had been given to how the designs generated might be shared or made public, an aspect that would further cement the notion that these design ventures were distinctly different from therapy. Throughout, an idea of producing a pop-up shop was loosely held, underpinned by a belief that the shop would encourage public engagement on the high-street. The shop became a firm idea as the Co-design workshops developed, during which time it was proposed to the Co-designers themselves. The first group of research co-designers from BRC agreed to the idea. When it eventually became feasible, thanks to the number of potential designs to be made available to the public, the proposition was also put to the new Co-design group. With complete agreement from all, the process of looking for a venue led to an offer to

use the community shop at the St Enoch Centre in Glasgow. Here again, we found invaluable the contribution of a project champion in the shape of Nadia Wilson at St. Enoch Centre who was highly amenable to our approach and who provided the shop free of charge. Set within the second floor of the Centre, the store was publicly accessible in a widely visited shopping destination. The centre itself has an annual footfall of 20million visitors which almost guaranteed visitors.

For four days in June 2019, the *Designed with Dementia* shop opened to the public selling 73 designs in the form of 835 individual products to the public and at the same time displaying the creative capabilities of people living with Dementia. The products available included; table-ware, tote bags, mugs, coasters, aprons, ties, miniature sculptures, and pencil cases. The aim was that the *Designed with Dementia* pop-up-shop would clearly illustrate how design had played a key role in empowering people living with Dementia. The shop display was arranged with photography, written description and audio-visual arrangements to explain the Co-design venture and the depth to which people living with Dementia had authored the designs on sale. This showcase explained how the Co-design process had helped to value and stimulate their decision making, support greater social interaction, and create opportunities for personal achievement, whilst engaging those individuals to work as part of a larger creative collective. During the four days, hundreds of visitors explored the objects on sale, many of whom made purchases. During the shop, invitations were made to leave comments and thoughts on what visitors had purchased or seen. The collected comments included statements such as:

*'The designs are so thoughtful and individually made'*

*'This shows people living with Dementia can contribute greatly to society, in a very beautiful way!'*

*'I'm impressed as a designer myself I think these designs should be on the high street!'*

*'Insightful, educational, inspiring, very positive and we need to talk about key issues more'*

*'It's amazing how much things have progressed in 20 years since my dad. Good to know things other than medical care are being looked at. It's about the person'*

(Multiple comments: recorded notes from the *Designed with Dementia* shop)

*Vignette:* The value of the products as publicly valued and desirable was best illustrated by a customer who was in his mid 20's and dressed in a style best known as hipster. He wanted to buy two of the cushions but only had card for payment. He said he'd be back. This was early in the day, it was thought that we wouldn't see him again. However, at the end of the day as we were closing he returned cash in hand to make his purchase. At this point he expressed that they would make a great talking point in his flat.

As well as the public, the shop was visited by many of the Co-designers involved in the projects and their families. Through discussions in store and through reflective feedback it was clear that they felt significant value within the design projects that had been undertaken. In a post event reflective discussion, a Co-design group shared the following:

Respondee 1: *"I thought that was absolutely brilliant."*

Respondee 2: *"It was, it really was...I didnae think, I thoroughly enjoyed making whatever, but I still didn't think it was good enough to sell kinda thing"*

Respondee 1: *"And it was"*

Respondee 3: *"It definitely was"*

Respondee 2: *"It certainly made you feel quite good"* (laughs)

Respondee 3: *"It's good for your morale and good for your confidence. "*

Respondee 1: *"That's the thing about it is what you value you canna buy."*

Another member of the group on visiting the shop wrote of how the experience had changed their beliefs and perceptions; *"Brilliant never thought Dementia people could do this. I did and I've got Dementia".*

The profit generated by the shop was gifted to the BRC and the participant Co-designers to continue their creative explorations. As such, the shop, which contained designs

created by people living with Dementia, provided a platform for them to generate their own income, to challenge public perceptions and to encourage people to share the narrative of capability. The commentaries collected and stories noted helped to affirm what was being achieved through this public interaction.

The pop-up shop approach also allowed for a form of design and Dementia research network to develop where two other PhD students shared aspects of their research, including transforming some of the content into Co-designed objects. This deepened ongoing discussions of design and Dementia helping to promote their projects and the range of methods being explored by researchers in the field.

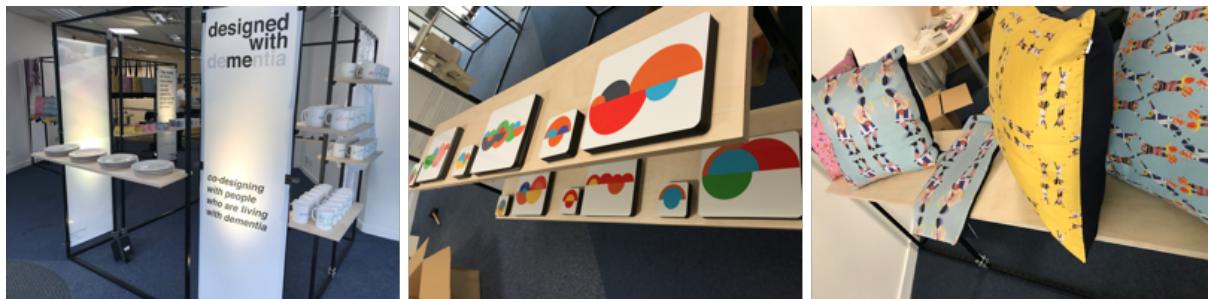


Figure 6.20. *Designed with Dementia* pop up shops

#### 6.14 Bellahouston Allotment Sign

Building upon the Stained-glass Window for Glasgow and the Table-Top-Gardens projects, the sign for the Alzheimer Scotland Allotment at Bellahouston Park came from a brief set by the project co-designers. Their proposition was that a sign should be produced by the researcher as a final marker for the series of projects we had undertaken.



Figure 6.21 Initial lighting models by co-designers as tests for allotment sign

Considering, the feedback of the perceived value and purpose of the other projects along with the beautiful and wonderful outcomes that had been achieved by working together, it was agreed that we undertake this final project together. A particular influence on the discussion was the Macintosh inspired light they had created together. The brief they devised was to design a new sign for the Bellahouston Allotment that would become iconic in the environment and that might include lighting. However, they stipulated that any light used must be solar-powered. Furthermore, the sign should be robust and significant in the landscape.

**Workshop 1** consisted of colour, light and pattern generation. Each Co-designer was given a light-box to work with and a series of cut-out leaf and flower forms with which they would arrange patterns. They were also given sheets of lighting gels to introduce colour into the design mix. The Co-designers copied each other in order to create panels of light instead of cutting up the gels which created a cohesive overall light form. To finish the workshop the group arranged and rearranged each light-box in order to test ideas and to discuss what the sequence of the units should be when brought together to make the sign. These prototype units were excellent in encouraging remixing components and for allowing the group to configure their final collaborative design. However, one particular issue was how textual content would fit into the design.

**Workshop 2** required significant pre-workshop action by the facilitator encompassing transposition of the final Co-design composition into one visual layout. Here the expertise of the facilitator arranged the components and textual information in a manner that would allow each participant's design to work within the larger design. With a completed layout in place a large 1:1 scale paper print-out was taken for the group to see and make comment on. At this time the group undertook a materials exploration. Originally expected to be produced in metal, a range of potential production approaches were brought to the group. The approach included explorations of material tactility where various metals, wood, plastic, glass, and concrete samples were handled and discussed. Here, explanations of properties, values and construction methods were shared with the

Co-designers for them to decide what they thought the final solution should consist of. The material explorations led to the selection of concrete and coloured glass (which was eventually substituted with acrylic).

**Workshop 3** continued material that explorations included making moulds to explore the pouring of relief-based designs and the textural quality of the concrete. Using plaster of Paris in lieu of concrete, the approach allowed the group to appreciate the chemical reaction that would occur (heat generation in the transformation from a fluid to a solid). The Co-designers each produced a 120mmx120mm relief tile.

**Workshop 4** was to be a live broadcast from the workshop in which the new sign would be poured from concrete into a mould in the same manner in which the group had made their relief tiles. Due to the onset of Covid-19, the Co-designers were not able to attend the BRC and so a decision was made to record the process to be shared at a later date (when Covid-19 restrictions allowed).

## 6.15 Gordon's Scanning service

The scanning service developed with a new collaborator who had heard of the work the Day-Opps group had been doing and asked for help to develop his idea. Initially, the approach was made by Anne Davies (Gordon's project champion) who had been working with Gordon for some time. Their shared desire was to do something innovative with a set of photographic acetate prints that he had been given as a memento of a work trip to Japan. The trip was of particular importance to Gordon and was a landmark event in his life. Working within the same Co-design principles as the group projects, the intention was to allow the work to develop from the instigation and through conversational direction of the collaborating partner or partners.

**Stage 1** Conversation and project scoping occurred within BRC, where Gordon explained that he had these images which were important to him and that he wanted to do something with them. Furthermore, he wanted them to be trigger objects for other

people that would encourage them to explore their photographic collections. He desired that these images turned into an artwork would be the starting point for a photographic collective based at BRC. During the session, a camera was set-up on a tripod in order to photographically digitise the slides. With support, Gordon operated the camera as he recorded the content and talked through what the pictures were. On completion of the discussion, which included Gordon's framework for the project, it was decided that the digitised works would be turned into a motion graphics piece that would be shared with other centre users. One request of the motion graphics work was that some of the black and white images might be re-coloured.

**Stage 2** Involved a re-digitisation of the slides through the use of a scanner, this was required as the photographically captured versions were not of sufficient quality. With the slides in a digital form they were adapted to form a motion graphics slideshow and two of the images were re-coloured. These tasks were undertaken by the researcher in accordance with the previous request and discussion of how this might look.

**Stage 3** Re-presentation meeting and public show of what had been developed around the images and the discussions. The re-showing of these to Gordon in the form of a short-animated artwork which included the recoloured images generated significant discussion between the members of the group involved in the project. Very quickly, Gordon decided that these were going to be shown and shared with other users within the BRC that day. He was adamant that this would help to trigger the following aspect of the projects which was to encourage other people to bring their images into a larger project. Within thirty minutes, he was presenting his piece. When he presented, his delivery was very lucid and fluid, stimulated by the collaboration and what he was showing. Stories, etc and behaviours from the trip were shared as were the experiences and memories of tastes and smells.



Figure 6.22 One of Gordon's retouched images which formed part of his artwork and presentation.

In later conversation of his presentation, Gordon expressed how his peers had valued his performance and what it meant to them:

*"The Japanese bit. I got told, when I started doing the Japanese one and talking to the members, down there, and somebody just told me that I was able to start talking about it and getting back into ma, that the brain was coming back in, and people had said to me and that's it, you're getting the bits and pieces coming up."*

Gordon

**Stage 4** Setting-up the scanning resource built upon Gordon's desire to make a project that would build a community of like-minded people bringing together photographs in order to share unbelievable moments from their own personal histories. In this, Gordon himself has been the creator of the project, shaping the intent and stimulating participation. Recognising Gordon as the true project champion, the decision was made to provide him and his wife with equipment that would allow them to run a Dementia scanning centre. An iMac and scanner were gifted for use during the project and a

printed set of instructions for using them was generated so that they could independently operate the system. The tools were run through with the pair where each of them took control and followed the directions for use. In testing the approach, it was clear that Gordon required the help of his wife to control the mouse. However, the other aspects he was more than capable of undertaking, from placing photos on the scanner through to naming and saving the work. From this Co-designer-led positioning, the project was undeniably Gordon's. Furthermore, the technical aspects of the equipment and process involved built upon Gordon's own professional history where he had been a technician with Sony. The intention of this was to re-invigorate personal esteem and to reinforce capabilities. Evidently, this was recognised by one resource staff member, Amanda Gillies, who stated "it's great but that's what you do, you put the power in their hands".

**Stage 5** Required no involvement or supervision from the researcher and incorporated an individually-led approach by Gordon where he organised other people living with Dementia. He developed times and dates for co-designers to bring photographs to his scanning resource and captured their images. In keeping with Gordon's belief that the objects were too precious for him to be responsible for, the other people living with Dementia sat with him whilst their photographs were scanned. During this time ,his wife helped to record details about what was being captured along with the stories that were being generated.

**Stage 6** Is still under development and was impacted by the onset of Covid-19. Gordon was continuing to run the service prior to lock-down and was collecting images from his own peer-based co-creative team. Gordon requested that he might retain the scanning tools for the foreseeable future in order to do other pop-ups at other resource centres with the help of Alzheimer Scotland. The intention is to generate a photo-casebook of the collected images and commentaries that represents the collective engagement of people living with Dementia.

The intention of Gordon and those people who help him to live with his Dementia is to achieve a collective goal - to find value in personally important lived experiences and to

do so through the medium of photography. Gordon has suggested that he has always been quite militant and that through this work, he intends to champion the capabilities of people living with Dementia to fight their collective cause and to remind people, "*There is still a life within the person that's got Alzheimer's*". Within this mindset, Gordon hopes to improve on the offering that BRC supplies to people living with Dementia when he declared, "The way I look at it in the café, the café is good for everybody but I think the café could be better". Through his user-focussed approach and project, Gordon hopes to inform and change the experiences of people living with Dementia: "Look everybody down here in the café today, we've all got Alzheimer's so let's try and say let's do something".

Gordon was also asked about the personal importance of what had been achieved by Anne Davies who queried, "*What did you get out of seeing your pictures, what are you getting out of this experience?*" to which Gordon responded, "*Me? My life. You know it's something I thought that I would never see it again*".

The series of interactions and discussions was recorded for the purposes of creating a broadcast for a Glasgow community radio station. This provided further evidence that given the relevant opportunities the Co-design approach with people living with early onset dementia can be a valuable in championing capabilities, esteem and influence.

The story of this chapter tells of the evolution required to achieve the final outcomes and lays the foundations for the Discussion Chapter.

The projects, throughout, focused upon the decisions and actions of the groups involved and have required researcher interaction - predominantly the expertise of a design interpreter and facilitator. The range of demonstrated decision making, thinking and actions have been highly independent and where required, collective. Fine motor skills have been regularly required and personal capabilities demonstrated in such ways that often contradicted the care supporters' perceptions. From handling of scissors to participation in drawing out patterns along with a number of smaller actions, all have

proven to produce surprising revelations in the carers' views. For example, hesitancy in allowing people to handle scissors led to highly watched behaviour but all cutting was completed without personal injury and with a greater degree of accuracy than was expected. In drawing out patterns, one carer explained that one of the co-designers would not normally be able to concentrate on the task of drawing out the required patterns and that it undertook considerable personal effort to do so. The participant achieved his goals and did so with demonstrated pride in his achievement. It was clear, however, that this had taken considerable energy. What appeared apparent was a degree of a bond with the researcher as the Co-designer wanted to achieve what had been asked and to demonstrate his achievements with pride. Here, the idea of social connectivity in presence played a key role (Greenfield, 2012).

## 6.16 Chapter Summary

Through the *Designed with Dementia* pop-up-shop at St Enoch Centre Glasgow and subsequent iterations in Bridgeton and Edinburgh, reflection suggests that all of the designed products and services have been generated by the workshop co-designers themselves. This has involved them creating artwork, making design decisions on scale, repeat patterns, material choices, and throughout, they have displayed assured creative decision-making and communication. These activities involve knowledge and skills that professional graphic and textile designers draw on in their day-to-day work. The *Designed with Dementia* pop up shops provide an inclusive and innovative platform to witness first-hand what people living with Dementia are capable of through the design work created, manufactured, exhibited, and disseminated. As such, the work shows how people living with Dementia can offer much to society. The platform has helped to change the thinking of the public who have interacted about what is possible after a diagnosis of Dementia and in other situations, visitors have been able to consider the situation presented to them and to add to the conversation through written commentaries.

The results of this work, their analysis and discussion continues in the next chapter.

## **Chapter 7: Results, Analysis and Discussion:**

In this chapter, a review of how the results of fifteen projects produced impact for the many stakeholders involved and in particular, people living with early-to-moderate stages of early onset dementia. This chapter proposes that the designed outcomes and the recorded actions of the co-designers have provided evidence of free thinking and self-belief, helped to develop collaboration and a sense of belonging, underpinned independence and have been anchored by independent personal narratives. The results of the design process in the form of products, proposals, systems, exhibition and sales provides evidence that has been reviewed and analysed to explore how the co-designers have been empowered within the approach.

The results of the research with people living with dementia has required analysis based upon observed, recorded and displayed participation in the design process. The analysis also looks at the results and project commentaries by a number of stakeholders through mixed mapping methods which includes thematic analysis of key insights and commentaries, and alignment to historic and new frameworks.

This chapter concludes with numerous insights and discussions that have been developed as a result of undertaking and reviewing the research.

### **Covid-19 Impact on Results and Analysis**

The following results and analysis have been severely disrupted by the Covid-19 pandemic. Relationships with, and access to, the co-designers, their primary carers and loved ones, and the professional support staff have been virtually disbanded. Many of the professional care staff have been furloughed and those who are left have been fighting to maintain a service for their clients. The funding/time restrictions on submitting this work has meant that certain interviews and reviews could not occur and with more than a year-long hiatus it would not be possible to gain the insights of participants in the same way.

As such, much of the review in section, '7.6 Commentaries', is not to the fullest extents of what was hoped for. However, this section still contains highly rich insights which are valuable to the discussion and which give a sound sense of the collaboration, commitment and value felt within this work by all the parties involved.

## 7.1 Results

The co-design projects in this work have allowed for significant levels of collaboration to occur between people living with dementia in the generation of inspiring designs. These have included graphic imagery, pattern making, product designs and the design of services. The results of the efforts have been experienced by the public through opportunities to buy the final designs, by visiting exhibitions and by taking part in creative processes developed with and by PLWD. The projects also reveal what is possible as designed outputs by collaborating with PLWD, carers and service providers.

These results represent 15 projects where PLWD have been highly stimulated and exceptionally active co-designers. They have proven to be adept at contributing to the creation and collection of research materials. They have provided rich insights and discussion around concepts to work within expected parameters of a design process, *i.e.*, brief analysis and discussion, data collection and generation, appropriate response to design opportunities, collaboration and negotiation surrounding prototyping and decision making, selecting and refining detail designs and delivering solutions.

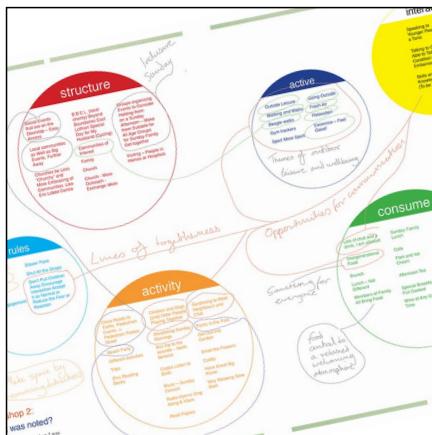
The participants have also shown distinct ability to challenge expectations and to appropriately change the remit of a project based upon their own creative endeavours. For example, not conforming to approaches as might have been expected but instead seeing opportunities, taking chances and doing things differently. These kinds of statements suggest that the co-designers are enthusiastic and engaged but also in the term of Rodgers and Tenant (2014), sometimes working within a kind of 'design disruption'.

The manner in which they have grasped tasks and opportunities, and even disrupted them, indicates the significant confidence, abilities and empowerment that the co-designers have demonstrated on a regular basis. In 7.2, a table of results of engagement in projects has been generated. This shares how engagements were mapped in terms of the actions of co-designers and the learning revealed through their participation. Their prowess in terms of control and direction or shaping the design stages through the co-design methods employed in fifteen projects are discussed.

### 7.1.1 Designed results

The following visual arrangement of outputs share the embodiment of the co-designers prowess. They are indications of commodifiable designs, service solutions and other design generated interpretations. The process of designing as detailed above is highly important in understanding the value of this six-year project but the tangible outcomes hold value worth conceiving and understanding. The following images represent the fifteen projects and outcomes in a chronological order from left to right.

Redesign Sundays



75BC Fabrics



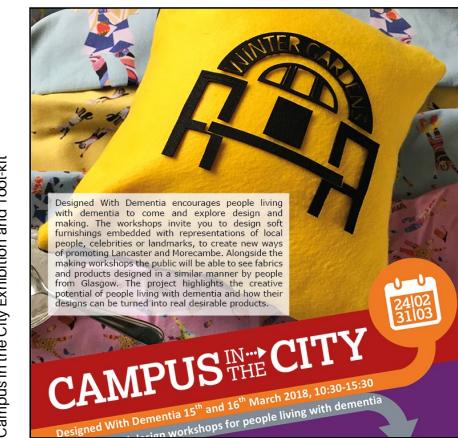
Travel Postcards



75BC Collection



Rabbie Burns Project



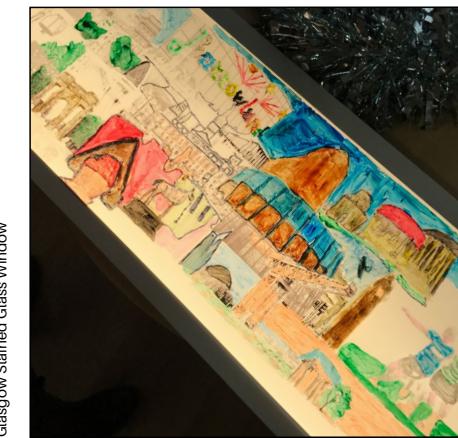
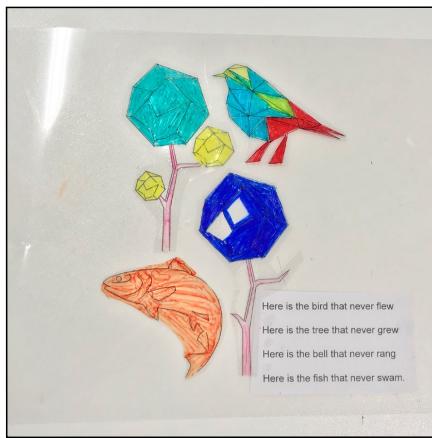
Campus in the City Exhibition and Tool-kit

75BC Cushions

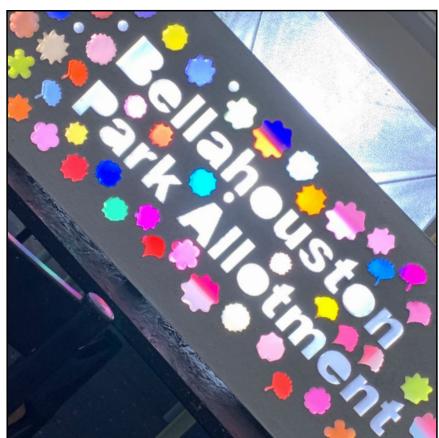
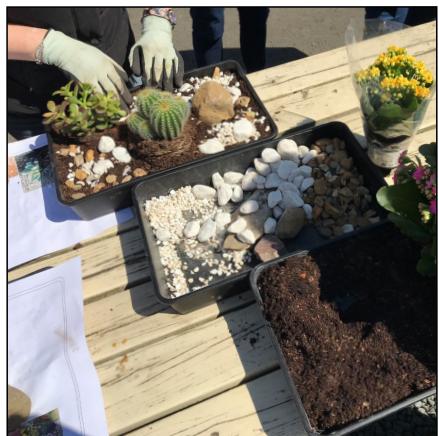


Mackintosh Inspired Light

Glasgow Coat of Arms



Glasgow Stained Glass Window



Figures 7.1 Single representations of project results

## 7.2 Project Summaries and Key Insights

The summaries of the projects contained within this thesis are presented below in chronological order. The projects were:

### 7.2.1 Redesign Sundays

The workshops were developed for an existing group who met semi-regularly. This ensured participation and exploration with PLWD and carers was achievable. The participation was effective and workshops were well received. However, participation in later events, outwith pre-scheduled group meetings proved unsuccessful. On the other hand, the workshops and participation in a <sup>1</sup>base-level co-design method were successful. The tasks and development of ideas proved rich and provided focus in the form of a brief to 'Redesign Sundays'. The rules and project scaffolding were those of the participants. The project formed the basis of a funding bid by the Eric Liddell Centre in Edinburgh who wished to work with the participant group to make it happen. Unfortunately, the bid failed and consequently the project did not achieve its ultimate aims. However, ELC's faith in seeking to pursue matters further did at least provided a sense of project validation.

Summary of findings/key insights from the project which informed future projects:

- Existing groups are the best to work with
- Working within validated services (existing centres, groups or networks) supported buy-in (participation in new stand-alone offerings is very difficult)
- More regular meetings (suggested minimum average of once a month) might better support continued engagement within the design process
- People living with early to moderate stages of dementia can achieve very interesting propositions if adequately supported
- Complicated thinking can be asked and should even be encouraged as long as this does not lead to any obvious distress.

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<sup>1</sup> Base-level pertaining to, containing tasks which allowed freedom of creative or more precisely design expression and input towards the setting of a projects goals and/or opportunities for further development.

- In the experience of running the *Redesign Sundays* workshops, far more was achieved when the primary care givers were not there.

### 7.2.2 75 BC Fabrics

The 75BC project involved significant levels of research and collaborative action. Working with people with early stages of early onset <sup>2</sup>dementia at the Alzheimer Scotland Bridgeton Resource Centre, new regular practices of co-design were developed. The projects formed collaborative relationships viewed as fun, beneficial and stimulating for the co-designers and BRC.

The initial project developed on activities already underway prior to the initial meeting and were shaped by discussions that flowed naturally as part of a new relationship. Perceived warmth offered by the collaborating group stimulated the development of the project. Responsive workshops reacted to co-design participants' discussions and their actions. They informed every process and aspect of planning. Their engagement and actions at each stage shaped co-design, resulting in a need to be highly responsive, dynamic and ready to eschew pre-conceived ideas and plans.

The all-inclusive, informed collaboration of the co-designers led to results and steps within the process which were theirs, were shaped and informed, progressive and iterative but accomplished in a systematic design process<sup>3</sup>.

Summary of findings/key insights from the project which informed future projects:

- Working within existing groups in their spaces creates a greater equality in power, where they choose how to engage.
- Regular connection and collaboration stimulate highly collaborative practices

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<sup>2</sup> Early on-set dementia co-design participants were all under the age of 65years.

<sup>3</sup> Systematic design process acknowledges a step-by-step sequence and a common flow of these sequences within the overall process that results in a final design outcome.

- Direction setting can be set by PLWD as long as you listen intently and develop rich auditory and creative conversations – listen to what is being said and see what they are showing you
- Adaptive and responsive approaches must respond to the co-designers
- Steps within a prescribed design process supports direction and project flow but these must also be flexible enough to be applied or adapted in response to the actions of the co-designers

### 7.2.3 Travel Postcards

The postcards were developed in advance of a forthcoming trip to the Riverside Museum. Results were personally narrated collages of favourite, memorable or desired trips. The project was a short interlude which had some very rich detail dictated by the co-designers. Information coded and contained within the final outcomes was very biographical of each co-designer but the project didn't stimulate the same kind of ownership as the 75BC fabrics.

Summary of findings/key insights from the project which informed future projects:

- The project responded to an upcoming visit and less so to the direction of the group resulting in a less engaging process requiring specialist skills.
- Rich material which was highly personal and biographical formed part of the process and as such created a valued experience despite being short.

### 7.2.4 75BC Collection

Holding the fabrics and exploring the colour and texture of their designs (75BC textiles) project greatly aided discussion about how and where it might be used, the results of which informed the shaping of a collection of furniture, soft furnishings and lighting that the group would explore. The material acted as a reference point and allowed the co-designers to think about real-world applications. Combining laser cut overlays (jigsaw-like

pieces) and acetate outlines, special projects tools became adaptable platforms that the co-designers could arrange and alter to create iterative designs. Their designs led to the development of an agreed, cumulative collection. These were prototyped for them in order to accomplish further real-world design outcomes.

Summary of findings/key insights from the project which informed future projects:

- Having something tangible as a real result of the first project encouraged direction, participation and exploration in the next phase.
- Facilitation of workshops of non-trained designers requires considerable thought and design actions in order to open up processes that might normally be closed to them.
- Give co-designers resource that they can interact with and shape results within, and they will provide outcomes that respond to the constraints in creative and adaptive manners.
- Co-design participation can act as a great way of welcoming new group members into a well-established situation. Here, activity and guidance of the other co-design participants supported the idea that design can be highly sociable and inclusive.

### 7.2.5 Rabbie Burns Project

The Rabbie Burns project aimed to explore Scotland's national day dedicated to the bard. Combining group, discussions, reading of his poetry and singing of songs informed responsive design-led practices. Incorporating stamp-based printing was tools for creating repeat patterns linked to the 75BC Fabrics. The group liked the idea of more direct and immediate print methods and it was decided collectively that this might be good for exploring a public engagement approach that could work at CITC. The results were contemplation of what worked and what didn't in the resultant Rabbie Burns stamp kit and the adaptions required for the CITC solution.

Summary of findings/key insights from the project which informed future projects:

- The group were adept at considering design solutions for other users where usability was key including advising on material properties and handling
- They also became active in the co-design of processes, including such things as how to apply inks/paints
- The considerations of other people's usability and needs supported a greater sense of service design first evident in the Redesign Sundays project (where this group were not involved)

### 7.2.6 Campus in the City Toolkit

The Campus in the City event represented an invitation to share the accomplishments of the co-designers with a particular focus on their 75BC work. The project allowed the co-designers to think about other users and service design which manifested in approaches to stamp-based printing for the public to engage with. The approaches that they helped shape and refine supported over 100 participants to make stuff whilst visiting the exhibition of the co-design group's work.

Summary of findings/key insights from the project which informed future projects:

- That the public presentation of their work had real interest to people in attendance and that people had travelled to see their work
- That the co-designers were capable of making telling contributions to a form of service design engaged by over 100 people
- That some projects might only serve to deliver outcomes such as these

### 7.2.7 75BC Cushions

The 75BC cushions conceived with the participants allowed for the transformation of the cushion designs from the '75BC Collection' to be translated into tangible prototypes that were predominantly made by the co-designers for their own meeting space at the BRC.

The co-design group took great ownership and control of the project thanks to lifetimes of experience in dress, curtain and even cushion making. The process supported by specific tools and templates became hugely hands-on and collaborative, the designs of which overcame participants physical restrictions. The group was so confident that members even altered the templates to fit their own knowledge and experiences. In practice, the co-designers tended to help each other in assembling the final designs and pinning the components ready to be stitched. Processes such as use of scissors and pinning tended to go against perceived wisdom of keeping such things away from people living with dementia.

The results were the set of cushions which were kept BRC. As one care provider noted, the result meant that other people saw and could use the work of the co-design group. Also noted was that each co-designer would gather his or her own cushion to wherever they were sitting when they were in the space. The group, through actions and communication, expressed how proud they all were of their own designs.

Summary of findings/key insights from the project which informed future projects:

- Value in existing knowledge and skills.
- Evaluating individual capabilities, including ability to work with small detailed pieces or potentially hazardous objects such as pins or scissors and finding ways to allow such actions to continue with adequate supervision.
- That the sense of ownership and pride in achievements is evident in actions, behaviours and verbal commentary.

### 7.2.8 Mackintosh Light

The Charles Rennie Mackintosh inspired light formed an introduction, to the co-design ways of working that had been undertaken in previous projects, to a largely new group. Only one person remained from the previous co-design group. The project leaned on a

visit to the Mackintosh designed Scotland Street Museum and was also influenced through discussions of the second Glasgow School of Art fire that had just occurred. The result was a light developed using templates, lighting gels and a physical framework that required every aspect to come together. When each component, individually crafted by a PLWD, was arranged together, the resultant light could be appreciated by all of the co-designers.

Initially, some co-designers appeared cynical or sceptical, almost aloof to the facilitator and some of the other participants. However, the final reveal (switch on) of the design was well received by all involved and by other users of the facility as they passed by.

On later review of the projects, it was encouraging to note that the co-designers had bonded, building their own community. It was also surprising to find that this had been an important project in the overall process, remembered fondly a year after it was completed.

Summary of findings/key insights from the project which informed future projects:

- New group dynamics have to be learned and developed through collaboration for both facilitators and peers - this takes time.
- Equal trust is important.
- Final project reveals can be great for bringing people together and to disperse negative overtones.
- That lasting value can be placed in projects by the co-designers.

### 7.2.9 Stained-Glass Glasgow Coat of Arms

The Glasgow Coat of arms was noted at the visit to St Mungo's Museum of Religious Art. Symbolic representations could be seen in the lampposts surrounding the museum. The co-design group explained the meaning of these and this led to their next project: to develop a stained-glass interpretation of the poem referencing the coat of arms.

The project was limited in its scope and purpose and became more of a developmental process. Interesting graphic elements emerged and there were some lovely and thoughtful deliveries of these small-scale graphics. Particularly evident was that each co-design participant was starting to show individual tastes. The growing camaraderie amongst the group members brought a shared project cohesion, confidence in tasks and thinking about creative decisions.

Summary of findings/key insights from the project which informed future projects:

- Creative confidence grew within the project and seemed to be embedded in a sense of trust or social cohesion.
- Confidence appeared to support quicker actions and greater discussion or even interest in other people's work.
- This project was more of a stepping stone than something that might manifest a meaningful usable design outcome.
- The co-designers again dipped into their own knowledge to shape the project showing satisfaction in discussing the coat of arms (with the researcher who knew nothing of its symbolism and meaning).

### 7.2.10 Stained-Glass Window for Glasgow

Using local knowledge whilst tying into the visits to museums and galleries across the city, an approach to representing Glasgow in stained-glass was developed. Co-designer-led arrangements of iconic buildings and landmarks were presented as a shared view. The project supported a degree of competition between small group teams. However, co-operation was also observed, for example, when one participant aligned both pieces across the backlighting panel that had been supplied to them and a shared result emerged. Through their actions, they developed a fun, creative competition. The project helped to develop creative confidence, which was evident in the paint explorations and experimentation with the available materials.

Surprisingly, this project unearthed hidden personal narratives and specialist contributions from one individual who had been a book binder and who was used to marking up and arranging documents. To him, the process of taping the imagery together resonated. The project linked ongoing visits and creative endeavours without resulting in any significant final result. The regular visits to museums and galleries supported a sense of continuation and new opportunity but also provided a sense of pressure to keep pace and project and relevance.

Summary of findings/key insights from the project which informed future projects:

- Some projects exist to move creative collaborations forward and may not result in a final design *per se*.
- Acceptance that a project has run its course is important and reflection on what has been achieved might prove the most important thing.
- That developing new projects regularly can be challenging but different reactions to visits and emerging opportunities must be found to nourish the creative relationship.
- Keeping enthusiasm and sense of purpose for the facilitator/researcher can also be a challenge.
- This project continued the sense collective collaborative action which kept the group creatively active together even if results were not directly forthcoming.
- Even in projects that might not feel as purposeful or focussed as others, something might have significant importance to somebody.

### 7.2.11 Floating Heads Plates

The co-designers acted in strong, confident ways during this project which made them disrupt any expected flow and created a completely new project focus. Taking greater interest in an artwork elsewhere in the Kelvingrove Museum, the group discarded the original focus. The group members themselves dictated that the Floating Heads should become the focus for the follow-up workshop.

The next session, as tools and materials were being brought out for the first task, one participant grabbed things she found interesting and created her interpretation of the Floating Heads. Drafting directly on to ceramic plates, editing templates and applying ceramic pens, she quickly developed a process that the other co-designers bought into. The other, previously programmed tasks were set aside. Their raw actions made for a highly charged creative environment where each co-designer was feeding off one another

Summary of findings/key insights from the project which informed future projects:

- Discarding ideas when better energy and actions are happening should be accepted.
- The co-designers created a project that was completely conceived by them.
- The co-designers felt confident and enabled to act without concern they might be doing something wrong.

### **7.2.12 Table-top Gardens**

The table-top gardens project was informed by a series of visits to gardens near the BRC. The visits again were photographed by the co-designers and during the time of the visits it was suggested to them that they might develop table-top gardens. These would be their own miniature experimental environments.

Taking shots of garden spaces that they found interesting - an allotment, a historic garden and a modern garden space - provided diverse content and ideas developed around the project brief. Gardening was explored, including sharing life-long experience, whilst reflections on their photos and conversations provided personally rich results. Their collaged plans formed the basis of a project shopping list allowing content to be purchased in an affordable manner. By creating the content rich plans, the next workshop became highly focused on construction and mutual support such that, where even when a

certain co-design member could not attend the workshop, her peers could complete the project for her.

The group had suggested that the potential in each of their table-top garden designs to become kits to be sold at the upcoming '*designed with deMEntia*' shop. In the event, this did not happen but did bring out the idea that the activity was considered by the group as something other people might like to do.

Summary of findings/key insights from the project which informed future projects:

- Peer groups become empowered to act on other people's behalf when they have the tools to do so.
- Co-designer planning results led to cost effective workshop developments.
- Perceived value in processes was seen as transferrable to other people.

#### **7.2.13 *designed with deMEntia* shop**

The presentation of 73 unique designs all created by people living with dementia through co-design projects through the *designed with dementia* shop was transformative. It moved their designs from theoretical endeavours into consumer culture and opened the designs to critique or praise. Ultimately, through commentaries of the participants and the people who visited and purchased the designs, this aspect was highly significant. In particular, it addressed a view that the projects had value beyond the resource centre that was evidenced in the generation of a combined income to the sum of £632.00 (after costs). In further iterations, the shop became smaller concession stands at an Alzheimer Scotland Market and at Edinburgh Napier University where again large numbers of people were able to learn about the projects and the designs which they could buy.

The funds that their designs generated was shared back with the Friday Opportunities Group at Bridgeton to support further design-led investigations and visits and to encourage new exploration. This meant that the groups had acted as pioneers and that

they, through their co-design, had provided a legacy that new members would have the opportunity to engage with and enjoy.

Summary of findings/key insights from the project which informed future projects:

- That the public bought the goods on sale thanks to their thoughtful designs and quality of production.
- The public had rich experience of dementia and were genuinely interested in seeing work that was unexpected or things could be done differently.
- People living with dementia surprised themselves and gained much satisfaction in doing so.
- Co-designers from all parts of the projects came in to have a look and brought their loved ones - sharing pride in what had been achieved.
- Given the opportunity, people living with dementia can do things that are extremely positive.

### 7.2.14 Bellahouston Allotment Sign

The project was conceived by the co-designers and started as a design challenge and brief set for the design researcher. Flipping the workshop scenario, the group demanded that a sign be conceived for the Alzheimer Scotland's Bellahouston Allotment Sign. Here, the challenge became one for the design researcher to come up with an idea that the co-designers could get involved with but which had to meet their criteria. This taking of control of the project reinforced their cohesion as a group and their creative sensitivities concerning, site, environmental concerns and aesthetic desires. The design concept had to draw influence from the stained-glass, lighting and gardens projects that they had explored and to demonstrate that they *could* have the ability to drive projects from concept to completion.

In the stage of setting the brief, the group reflected on previous visits and used their own individual primary research outcomes (in the form of photographs from those visits), to

help set the parameters of the project, the manner in which they defined an opportunity, decided on how that might be fulfilled and set the challenge for the design researcher. This developed a solution that facilitated their continued involvement as co-designers, was evident of high levels of understanding and demonstrated an empowered position. The project, therefore, expressed a significant capability to think and act within the creation of more industrial design practices including material explorations, mould making and combining technologies. The result was that they had a specialist manufacturer, using the same processes they had explored, make their bespoke sign to their designs.

Summary of findings/key insights from the project which informed future projects:

- That aspects of each design project had the ability to resonate for prolonged periods of time in some cases as much as 6-18 months (early stained-glass work influenced the final design thinking and planning of the co-designers).
- The co-designers could conceive of a design opportunity and set a brief with minimum input from external sources.
- They could shape the project from beginning to end.
- That more industrial processes and material investigations, new to them, were enthusiastically undertaken.
- Their choices were underpinned by collective and individual confidence.

### 7.2.15 Gordon's Scanning Lab

The Scanning Lab was a stand-alone project conceived by the co-designer and supported through technological capabilities of the design researcher. The PLWD request for collaboration centred around photographs owned by the co-designer and his desire to make them into an artwork and to stimulate other people to be involved in extension of the project. On completion of the artwork, the co-designer delivered a semi-public presentation of the piece and expressed how he aimed to help other people living with dementia to explore their most treasured photographs.

To fulfil this aim, the co-designer and his carer were supplied with the kit to form a scanning lab. Working together, a manual for operation was developed. From this stage, the gathering of images and stories became the responsibility of the co-designer and his primary carer (wife). The result was a new service housed within the BRC. The project started to provide a valued service with the intention that further design collaboration could follow but unfortunately, this was impacted and shut-down by the onset of Covid-19 restrictions. Of course, there remains the hope that it could be reincarnated.

This project was highly impressive and provided great evidence of how somebody living with dementia can be determined, effective and driven to make changes that impact the lives of his peers. A radio programme was made about the project and broadcast on a local Glasgow station.

Summary of findings/key insights from the project which informed future projects:

- People with dementia can have idealistic viewpoints that have been highly important throughout their lives and that can support actions and intentions in the creation of new design services.
- People with dementia can provide powerful direction and can facilitate other people's engagement in projects.
- Providing tools, guidance and support, people living with dementia can set and achieve their own goals
- Projects such as this one can be deeply meaningful and enriching for the individuals and the people who support them.
- Using design as a support tool allowed the co-designer to speak expressively and with fluidity for a long period of time.

### 7.3 Analysis

*"In practice-based research in Art and Design, there is no 'right way' to analyse research findings. Coffey and Atkinson urge us to be 'artful' and 'imaginative' but also 'rigorous. Qualitative analysis is intellectual*

*craftsmanship - playful but methodical... Imagination, crafted construction and artful persuasion are things to which we can relate. Integrate these with critical thinking and response - essential intellectual elements of the creative process - and we have a sound basis for analysis."*

(Gray and Malins, 2004; p132)

Analysis of how these projects occurred, how relationships shaped outcomes and how co-designer actions mapped to different ideas of what co-design is, and whether co-design has been a valuable form of care/support follows. In addition, what insights and occurrences might provide lessons to be learned from when working in a co-design approach along with evidence of how design has supported personhood and the empowerment of PLWD through the projects undertaken will be discussed.

Actions happening within the projects have been looked at as learning opportunities that have shaped the next stage in the design process. This is because within the workshopping design process, constant reflection and analysis occurs. Each decision and justification is considered and evaluation is undertaken in order to drive the project on. As such, many of the project stages have been developed within designer-oriented ways of thinking and doing, shaped by actions, decision making, rule breaking, proposition making and testing. These have been explained in the previous chapter (chapter 6) as ongoing in the collaborative process. In the research methodology chapter (chapter 4), it was also explained that this was to be expected and as such, the workshops would reflect upon, and respond to, what occurred in the preceding workshop, visit or conversation. The following diagram (Figure 7.2) explains how the in-project and final results analysis has developed showing that the analysis was occurring within workshops before the complete post research analysis was undertaken. What follows in this chapter is largely focussed upon the results from the workshops, visits and co-design in action including how multiple parties was reacted to by.

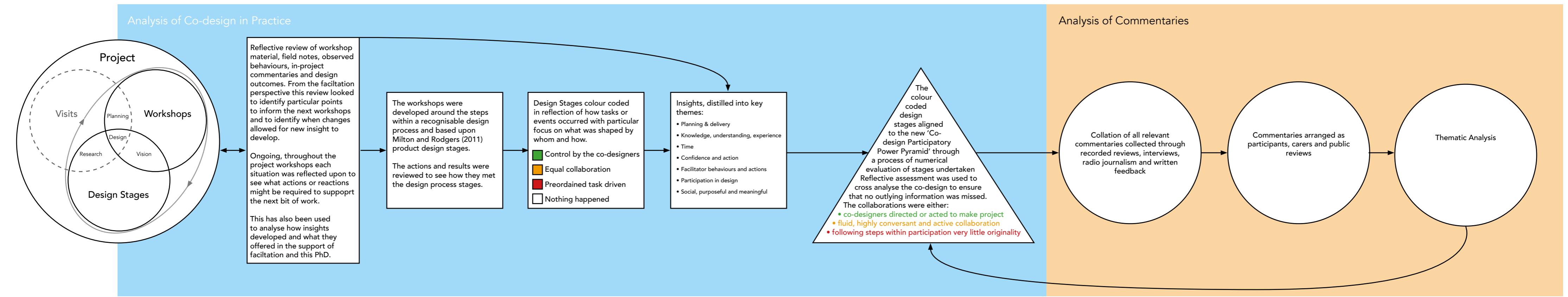


Figure 7.2 Review of workshops actions and results from field notes, observed behaviours, in-project commentaries and design outcomes.

### 7.3.1 Thematic Analysis of the Co-design Project Key Insights

The key findings from each project were developed as themes to more precisely identify what could be learned from the process and to provide meaning for anybody intending to undertake long-term design collaborations with people living with dementia. By distilling these insights under key themes (Figure 7.3), emerging patterns became more evident what the workshops revealed, behaviours that they supported and changed, whilst also identifying insight around the project challenges. What becomes clear is that the process of co-design will have plateaus where not much seems to be happening, but that in these spaces, more might be happening in terms of team building, sharing, personal insights and peer support. These things might become more evident to the researcher on reflection rather than when in the midst of a project.

The themes representing core concerns of undertaking co-design with people living with dementia are:

- **Planning and delivery** - pertaining to the process of doing co-design
- **Knowledge, understanding and experience** – pertaining to capabilities and personhood of people living with dementia
- **Time** - a consideration of the importance of time throughout of the individual and collective projects and actions involved in doing co-design for all parties involved
- **Confidence and action** - Pertaining to individual and collective ability to contribute to, drive or even disrupt the projects
- **Facilitator behaviours and actions** - pertaining to the behavioural and action-based adjustments the design researcher had to be aware of
- **Participation in design** - pertaining to design requiring structure, replicable methods, expectations and revelations that identify the process as being rigorous yet potentially unexpected for all parties
- **Social, purposeful and meaningful** - identifies the social quality of designing which encourages collaboration and that might lead to deeply felt value which tangible outcomes might not explain or share.

Planning and delivery	7.3.1	Existing groups are the best to work with Working within validated services supports buy-in	Time Confidence and action Facilitator behaviours and actions	7.3.1	That regular meetings (suggested minimum average of once a month) supported might better support continued engagement within the design process	Participation in design Social, purposeful and meaningful	7.3.2	The steps within the design process directs project flow, these must also be flexible enough to be applied or adapted to in a reactive manner
	7.3.2	Working within existing groups in their spaces creates a greater equality in power. Adaptive and responsive approaches must react to the actions of the co-designers Steps within the design process supports direction and project flow but these must also be flexible enough to be applied or adhered to in relation to the actions of the co-designers		7.3.2	Regular connection and collaboration stimulate highly collaborative practices		7.3.4	Having something tangible as a real result of the first project encouraged direction, participation and exploration in the next phase
	7.3.3	Responding to an upcoming visit and less so to the direction of the group results in a less engaging process and one that was not taken any further		7.3.8	New group dynamics have to be learned and developed through collaboration for both facilitators and peers – this takes time.		7.3.8	Final project reveals can be great for bringing people together and to disperse negative overtones
	7.3.6	That some projects might only serve to deliver outcomes such that provide services or public engagement		7.3.14	That aspects of each design project had the ability to resonate for prolonged periods of time in some cases as much as 6-18 months		7.3.10	Some projects exist to move creative collaborations forward and may not result in a final design per se
	7.3.8	Equal trust is important		7.3.1	People living with early to moderate stages of dementia can achieve very interesting propositions if adequately supported  In the experience of running the Redesign Sundays workshops, far more was achieved when the primary care givers were not there.		7.3.14	The co-designers could conceive of a design opportunity and set a brief with minimum input from external sources  They could shape the project from beginning to end
	7.3.9	This project was more of a stepping stone than something that might manifest a meaningful usable design outcome		7.3.4	Give co-designers resource that they can interact with and shape results within, and they will provide outcomes that respond to the constraints in creative and adaptive manners		7.3.4	Co-design participation can act as a great way of welcoming new group members into a well-established situation. Here activity and guidance of the other co-design participants supported the idea that design can be highly sociable and inclusive.
	7.3.10	Acceptance that a project has run its course is important and reflection on what has been achieved might prove the most important thing  That developing new projects regularly can be challenging but different reactions to visits and emerging opportunities must be found to nourish the creative relationship		7.3.5	They also became active in the co-design of processes including such things as how to apply inks/paints		7.3.6	That the public presentation of their work had real interest to people in attendance, and that people had travelled to see their work  That some projects might only serve to deliver outcomes that provide services or public engagement
	7.3.15	Providing tools, guidance and support to people living with dementia can set and achieve their own goals		7.3.7	That the sense of ownership and pride in achievements is evident in actions, behaviours and verbal commentary		7.3.8	Lasting value can be placed in projects by the co-designers
	7.3.1	Complicated thinking can be asked and should even be encouraged as long as this does not lead to any obvious distress.		7.3.9	Confidence appeared to support quicker actions and greater discussion or even interest in other people's work		7.3.9	Creative confidence grew within the project and seemed to be embedded in a sense of trust or social cohesion
	7.3.2	Direction setting can be undertaken by people living with dementia as long as you listen intently and develop rich auditory and creative conversations – listen to what is being said and see what they are showing you		7.3.11	The co-designers felt confident and enabled to act without concern of doing something wrong		7.3.10	Even in projects that might not feel as purposeful or focussed as others something might have significant importance to somebody  This project continued the sense collective collaborative action which kept the group creatively active together even if results were not directly forthcoming
	7.3.3	Rich material which was highly personal and biographical formed part of the process and as such created a valued experience despite being shot and taken no further		7.3.13	Given the opportunity people living with dementia can do things that are extremely positive  People living with dementia surprised themselves and felt great in doing so		7.3.13	That the public bought the goods on sale thanks to their thoughtful designs and quality of production  The public had rich experience of dementia and were genuinely interested in seeing work that was unexpected or doing things differently  Co-designers from all parts of the projects came in to have a look and brought their loved ones – sharing pride in what had been achieved
	7.3.5	The group were adept at considering design solutions for other users where usability was key including advising on material properties and handling  The considerations of other people's user needs supported a greater sense of service design first evident in the Redesign Sundays project (where this group were not involved)		7.3.2	Adaptive and responsive approaches must react to co-designers' actions  Steps within the design process supports direction and project flow but these must also be flexible enough to be applied or adhered to in relation to the actions of the co-designers		7.3.15	People with dementia can provide powerful direction and can facilitate other people's engagement in projects  Projects such as this one can be deeply meaningful and enriching for the individual and the people who support them
	7.3.6	That the co-designers were capable of making telling contributions to a form of service design engaged by over 100 people		7.3.4	Facilitation of workshops of non-trained designers requires considerable thought and design actions in order to open up processes that might normally be a closed to them			
	7.3.9	The co-designers dipped into their own knowledge to shape the project showing satisfaction in discussing the coat of arms (with the researcher who knew nothing of its symbolism and meaning)		7.3.7	Evaluating individual capabilities, including ability to work with small detailed pieces or potentially hazardous objects such as pins or scissors and finding ways to allow such actions to continue with adequate supervision			
	7.3.11	The co-designers created a project that was completely by them		7.3.10	Keeping enthusiasm and sense of purpose for the facilitator/researcher can also be a challenge			
	7.3.15	People with dementia can have idealistic viewpoints that have been highly important throughout their lives and that can support actions and intentions in the creation of new design services		7.3.11	Discarding ideas when better energy and actions are happening should be accepted			
				7.3.15	Using co-designed outcomes as a support tool allowed the co-designer to speak expressively and with fluidity for a long period of time			

Table 7.1 Themed relationships developed from the project reflections and their key insights

Many of the statements aligned to these themes could also fall under other themes. They have been distributed through a process that included reflection on the projects in order to classify their appropriateness and meaning.

### **7.3.2 Project Analysis and Mapping: Table of Co-design Engagement of People Living with Dementia and the Method of Representing Levels of Engagement**

The analysis starts with a review and mapping of the projects in relation to stages of the Milton and Rodgers (2011) product design process analysis of the results helping to explain to what extent each project was 'to', 'for', 'with' or 'by' in terms of collaboration. This presents an aspirational co-design where collaborators are engaged in multiple stages of a recognised design process and where they must have achieved a minimum of 50% of the stages undertaken to be seen as 'with'.

The table below provides detail of where and how the co-designers engaged within and directed projects. The statements dedicated to each stage of the design process provides an overview of where and how they were involved in developing each project and ensuring it had consistent momentum. The projects might last for only one or two sessions or indeed, over months and even years. To identify the balance of power and their prowess as co-designers, a red, amber and green colour coding of activities has occurred:

<b>Red</b>	Indicates little involvement in a specific task or process - this might be a natural omission of the co-designer (e.g. production by external specialist), or identify positions where the co-designers were not or could not be involved (e.g., running the <i>designed with dementia</i> shop)
<b>Amber</b>	Indicative of engagement in a process which is pre-ordained and largely prescriptive but is likely to have adapted to the actions of the co-designers and will shape the next step in the design process.

Green	High level of control, direction setting, ownership and influence in development of a stage or set of stages within the project
Blank	If a cell is blank that stage or process was not evidenced as being engaged with or relevant to the development of the project

The following table (Table 7.1) expresses how the projects delivered co-design.

Overview of Co-design Participation by People Living With Dementia Throughout Design Process

Projects in Chronological Order	1. Proposal	2. Research Phase	3. Concept Design	4. Evaluation	5. Design Development	6. Detail Design	7. Testing and Production	Learning	Project Visits	Project Co-design Workshops														
Redesign Sundays	Subject proposed by group members	Initial concepts developed through conversations around postcard prompts asking questions about improving situations, fixing problems, bringing back something...	Through workshops discussions	Generation of ideas	Visual communication	Verbal communication	Selection	Refinement	Defining	Technical visualisation	Prototypes	Material explorations	Manufacturing Techniques	Specialist Maker	Exhibition	Commercialisation	Service Delivery	Personal display	What was learned by running the co-design group activities	What was a success	What were failings in the process			
				Mapping of ideas and possibilities, rules, inclusions and exclusions during the early workshops where table tops became shared canvases to be drawn, collaged and written upon.	Visual form giving through college workshop	Verbalisation of views	Or core themes through group conversation and voting	Through workshop setting where parameters were set into rules and guidance formed by participants										Work within existing groups. Be sure that what appears to be complicated tasks can be very powerful and addressed well by people living with early to moderate stages of dementia. Appropriate support such as somebody acting as a scribe might be required but complex answers to open question methods can be very powerful.	Shaping the project intent and direction, proposing rules, guidelines and content	Sudden end due to lack of interest in independent workshops and the infeasibility to continue to work within the existing quarterly meetings.	0	3 x 2-2.5hrs		
75 BC Fabrics	Subject of Billy Connolly proposed by group members based upon a previous walking tour	Initial walking tour taken as independent group and reflections on the Billy Connolly mural that they saw	Photographic investigations (informed by one participant's desire to use a camera) and museum/gallery craft making session	Three Site Visit, Street Tour, Gallery and Exhibition - Group Discussions	Discussion Informed Workshop of Participatory Making - Response to task	Visual form giving through college workshop where unexpected results occurred including the basic patterns and arrangements of multiple figures	Verbalisation of views intention and personal narrative, during activity, with fellow co-designers or with design researcher	Reviewing and selecting patterns formed from the collaging workshop results. Selecting 4 instead of the suggested 3 patterns	Identifying scales of patterns for reproduction.			Choosing base fabrics to be used in production	Digital printed textiles produced to chosen specifications concerning materials	The final product making was shared with the group through filming processes.	At Campus in the City Through accessories in the Resource Centre. At the designed with deMentia pop-up shop.	Featured as the basis of many projects on sale in the designed with deMentia pop-up shop			Working with a group that can be met with regularly and in their own settings, where no new group management and facilitation is required or environment organised supports a situation that everts power dynamics. It is their space and their meetings including collage based prototypes supported an inclusive involvement of the co-designers in the planning and the impending visit than to the content direction of the co-designers. The project was therefore collaborative at stages but done for them at other points. It was enjoyed but evidently not destined to be used as a tool for dementia.	The completion of a highly co-design project easily in own settings, where no new group management and facilitation is required or environment organised supports a situation that everts power dynamics. It is their space and their meetings including collage based prototypes supported an inclusive involvement of the co-designers in the planning and the impending visit than to the content direction of the co-designers. The project was therefore collaborative at stages but done for them at other points. It was enjoyed but evidently not destined to be used as a tool for dementia.	Minimal failings were experienced though it became clear that highly responsive design workshop facilitation was needed which shaped fluid expectations (of the researcher) led to unexpected outcomes and results.	3 x 1.5-2hrs	5 x 1-1.5hrs	
Travel Postcards	In preparation for a visit to the transport museum where a discussion and exploration of travel was led by the museum's outreach team	Discussion of travel and favourite holidays or trips			Discussion Informed Workshop of Participatory Making - Response to task	Visual form giving through collage	Verbalisation of views intention and personal narratives which were embedded in final postcard designs	Personal narrated content selection	Transformation of collaged designs into final graphic outcomes.			Sign-off of final postcard designs.	Digital printed personal prototype.			Digital printed postcards from online supplier			This short project was an intense piece of work achieved over two weeks but limited in terms of the influence, shaping and direction of the initial proposal by the co-designers. Their involvement through creative and verbalised communication including collage based prototypes supported an inclusive involvement of the co-designers in the planning and the impending visit than to the content direction of the co-designers. The project was therefore collaborative at stages but done for them at other points. It was enjoyed but evidently not destined to be used as a tool for dementia.	The embodiment of highly personal narratives in a graphic design outcome e.g. the bus that one participant had worked on in 1967 including its company serial number formed a significant link to the journey he identified as being meaningful and the reason it was.	Limited opportunity to engage in highly technical delivery of final design and a pre-planned method of co-design which afforded limited creative direction from the co-designers.	2 x 1-1.5hrs		
75BC Collection	From group discussion of how textiles are used and what to do with 75BC textiles		Picking kinds of uses through search engine selection on iPad		Discussion Informed Workshop of Participatory Making - Response to task	Template tools created for workshop where textiles where areas where they would use the forms previously selected	Concerning personal tastes and areas where they would use the designs they were creating	Reviewing and selecting from the combined contributions of the co-designers within the group	Personal reviews of designs during the creative process where proposals were made, revised and added to	How patterned fabric might be used through exploration of test print fabrics and conversation	Utilisation of technical illustrative templates filled through personal actions and selection	Generated by facilitator as direct representations of the 2d technical illustrations			At Campus in the City and at the designed with deMentia pop-up shop.	Display of Lighting at the designed with deMentia pop-up shop			The group were thoroughly engaged in discussing how the fabric was to be used. Having the digital textiles allowed them to conceive of the project being more real and allowed them to have a tacit connection to their creative endeavours. By touch and feel they were able to make connections to the fabric connections that they should be used. This material connection was highly valuable and stimulated rich conversation and creative direction. Creative planning that the co-designers could use was also relatively adaptable and did not require technical expertise to use. It was also relatively adaptable and did not require technical expertise to use time and thinking from the facilitator and their technical expertise but this is to support the next actions of the co-designers to find the right project for them.	Defining the uses of the material which they were able to see and hold. Defining on furniture, soft furnishings and fittings that they hoped to apply the fabrics to. Using templates to achieve their goals but also generating iterations within the design visualisation. The digital tools used were also very easy to use that did were intuitive adaptable and did not require technical expertise. Their result would inform the next 75BC project.		2 x 1-1.5hrs		
Rabbie Burns Project	Group interest in Burns' Night	Discussion of Burns' Night leading to request for themed workshop			Print making session					Usage and processes of paint medium application			Different textiles, stamp tools and paint mediums					The printed outcome allowed for very direct approaches that broadened the suite of tools used within project approach and shaped the tools to be used for Campus in the City (the next project) This was a short project with limited opportunity for the expansion of the group's design activity but it did allow for them to be more open to the public.	This was a short project with limited opportunity for the expansion of the group's design activity.		2 x 1-1.5hrs			
Campus in the City Toolkit	The project was proposed by the design researcher and opened for discussion in an open session considering the Rabbie Burns project	Public engagement toolkit based on informed and altered as a result of discussion within the Burns workshop		Informed by the co-designers but content was selected by the facilitator with support of people with local knowledge of the Lancaster area.		Response to workshop task and using tools created for them				Usage and processes of paint medium application								The printed approach was directly informed from the Rabbie Burns project and supported by the group that had undertaken. This represented the ability to affect real-world experiences that were engaged by over 100 people within the co-design group. Here they started to design for other people with them in mind.	The inability to have any of the co-designers engage directly on a one-to-one basis with the public.		1 x 1.5hrs			
75 BC Cushions	How to use the fabrics in their own environment (resource centre)	Method of cushion cover making adapted and changed initial proposal based upon their own knowledge and experience		How to make cushion covers		Knowledge of individuals within the group of making cushion covers	Individual selection of materials (backings and fronts) consisting of 75BC textiles and complementary colour	In pattern cutting and preparation of pinned components		Stitch ready production through collaboration with group members and facilitator including, chalking out patterns and component assembly	Co-designers' defined approach - Stitching was undertaken by design researcher		In Alzheimer Scotland resource centre	Sold at designed with deMentia pop-up shop			Many participants bought their own designs to display them in their own homes. In particular co-designer and their carer contacted to get more info to get more info and the event.	The key aspect learned within this for the design researcher/facilitator process was to make use of the knowledge and expertise of the co-designers and to recognise that their lived experiences will feed into projects in a manner that supports their estimation and vision. The value of the positive way in which co-designers show and share patterns in their designs and the way in which they can be used and that with suitable support and guidance tasks that are familiar can be undertaken even if they contain medium risks such as cutting and pinning.	The cushions became symbols of ownership of the project and the spaces in which it occurred. At the same time became markers of capability within the resource centre asserting a sense of achievement and providing a talking point between different groups.		2 x 1-1.5hrs			
Macintosh Inspired Stained Glass Light	Proposed co-designer project for new group responding to conversations and site visit	Discussion based upon second School of Air Fire and visit to Scotland Street Museum (Charles Rennie Mackintosh buildings)	In museum craft making session	Visit to Scotland Street Museum	Response to initial design workshop task	Exploration and application of lighting gels in the development of personal designs			Testing with light allowed to see overlaps and new colour mixes		Utilisation of technical illustrative templates filled through personal actions and selection	Creation of light through collaborative making and application of lighting gels						Success in previous group activities did not ensure other groups would have the same enthusiasm. Merely because a previous group in the same setting have shared their knowledge and experience and made the next set of co-designers feel that past projects co-designed did not translate as an indication of their learning and that the group became aligned to the practices they explored.	Each participant engaged with the project in their own way. Some acted quickly and were quite vocal as they went about their business. Other were quiet and methodical testing different options in order to come to their own solution. When combining the panels and forming the lighting unit the co-designers shared their ideas and the group were able to work together. The final design on the design outcome was well received by all involved and other users of the facility as they passed-by.	Less of a failing but an observation was that initially some co-designers appeared cynical and sceptical, almost aloof to the facilitator and some of the other participants. This might have been due to a lack of clarity in communication or an uncertainty of the co-designers about it being their kind of thing.	1 x 1.5-2hrs	1 x 1.5hrs		
Glasgow Coat of Arms	Group discussion of Glasgow's Coat of Arms and the poem that explains it as identified through the lamprey at Glasgow Cathedral (present IS Museum)	Discussion based upon visit to the surrounding Cathedral Precinct	Photographic investigations and museum/gallery craft making session	Visit to Scotland Street Museum and Museum of Religious Art	Response to initial design workshop task	Visual form giving through collage workshop using transparent themed materials and stained-glass pens where co-designers selected and arranged content based on the theme			Testing with light allowed to see overlaps and new colour mixes								Some projects are vehicles to keep the conversation and collaboration going and to develop trust and confidence between co-design group members and the design researcher/facilitator. These are most likely to support longer-term developments and as such become smaller portions of a larger connected body of work.	Some projects are vehicles to keep the conversation and collaboration going and to develop trust and confidence between co-design group members and the design researcher/facilitator. These are most likely to support longer-term developments and as such become smaller portions of a larger connected body of work.	Developing a long-term purpose for the final coat of arms designs was difficult and as a result was closer to a task undertake as a form of art therapy.	1 x 2.5hrs	1 x 1.5hrs			
Stained Glass Window for Glasgow	Previous groups who attended the Friday opps group had created a stained glass pane	Cumination of visits to galleries and museums in Glasgow	Visit to Mitchell Library without researcher	Proposal by group of linking places of visits	Visual form giving through transparent themed materials and stained-glass pens where co-designers selected and arranged content based on the theme	Aspects of previous visits but also the new visit not attended by researcher.	Range of landmarks that must be included decided by co-designers	Scenes and arrangements of content	Final composition and overlay arrangements									That developing new projects regularly can be challenging but different reactions to visits and emerging opportunities must be found to nourish the creative relationship between the co-designers and the design researcher/facilitator. When projects start to feel that they have run their course be willing to move on. Keeping the pace flowing becomes more important as relevant ideas and taking actions. Through these actions the original research and follow-up workshops were altered in a positive way the researcher lost control of project directions.	Participants made links between the pieces they knew and enjoyed the direct action of painting or colouring the stained glass template that they had assembled.	Developing a long-term purpose for the final coat of arms designs was difficult and as a result a feel of finishing complete. The final purpose was not particularly evident even though the participants had enjoyment in the process.	1 x 2.5hrs	4 x 1-1.5hrs		
Floating Heads Plates	Project hijacked to participants to create own desired solutions	Specific exhibition visited at Kelvingrove Art Gallery and Museum	Photographic investigation	Visit to Kelvingrove Art Gallery and Museum	Diving into materials bag brought for workshop - this occurred during the set-up was occurring for the proposed workshop. Their diving in created a wholly new project	Disrupted and reconfigured workshop due to actions of co-designers and their own explorations of available content.	Between co-designers in regards to how they enjoyed the approach and how it linked to the motivation they had seen at Kelvingrove.	Through material investigations, creative confidence and actions	By repetition of process by group members and group generated templates	The simplification of the final designs to eschew facial outlines		Quick direct actions on plates using ceramic pens and personally conceived templates	Creation of templates, the use of ceramic pens and applying visual forms straight onto ceramics.			Sold at designed with deMentia pop-up shop			The confidence of the co-designers along with their very direct responses to stimulus became most evident in this project. They changed the focus of what was being explored because they wanted to testify exactly what the workshop had not been the primary focus of the co-designer. When they then took control of the follow-up workshop by diving into the collected materials brought for a different purpose. By this time they had become a collective group and were sharing ideas and taking actions. Through these actions the original research and follow-up workshops were altered in a positive way the researcher lost control of project directions.	Their designs, created from their identification of stimulus during their visit and their actions leading to designs that went straight into production for the designed with deMentia pop-up shop		1 x 2.5hrs	1 x 1.5hrs	
Table Top Gardens	From shared visits and discussions with co-designers regarding up-coming shop and gardening as an enjoyment or pastime of each co-designer	Photographic investigations	Visits to Trinity Hockerton, Pollok Park and Bellahouston Allotments (Glasgow)	Group discussion of how a simple table-top garden system (table-top garden) might be approached and delivered	Collaged visions of personal table-top garden designs - magazines supplied materials and pens were cut and stuck within a specific sized design space	Discussed throughout creation of the designs which encouraged sharing of images and materials between the co-designers. Each person presented their ideas and completed designs at the beginning and end of the session to the rest of the group.	The collaged content was reviewed with the design researcher so that they could formulate a shopping list	The supplied plants were used to complete the final designs but also to edit some of the ideas.									Designs intended to be sold as kits at the designed with deMentia pop-up shop but time and materials constraints did not allow this to occur. The design journey or prototyping process of making the gardens was shared in a project fair displayed in the shop window.	In personal spaces including where two participants discussed the fact they had made particular spaces for their designs in preparation of them coming home. One participant stated that she had intended to use it on her garden table as a centre piece for discussion.	The togetherness of the group and their enjoyment in a process where they could demonstrate existing skills and knowledge.	The inability to fulfil their desire to have kits available for sale within the designed with deMentia shop.	3 x 1.5-2.5hrs	2 x 1-1.5hrs		
Pop-up Shop	Discussed with group as a means to promote designs to the public.	Reviewing previous projects and potential future projects		The shop concept and design was largely created onto behalf of or "For" the co-designers. Through participation in and generation of designs detailed in the above projects the co-designers generated the content to be sold through the shop.													The shop delivered 73 unique designs all of which were designed with by group members using basic materials and pens. These were purchased by diverse demographic in terms of age and ethnicity. Children through to senior citizens visited, bought and angered within the store and the supporting exhibition. This showed a generally widespread appreciation of what had been done and bought the designs they liked. One visitor even returned with cash later in the day to buy stuff he had set aside.	Comments collected from the co-designers that visited the shop and the shop itself. The shop was a success and their achievements. Public visitors expressed significant appreciation of what had been done and bought the designs they liked. One visitor even returned with cash later in the day to buy stuff he had set aside.	It was hoped that the co-designers might have been able to work with the shop to create a shop and to demonstrate people reacting to it in real-time. This was not possible due to complex issues of permissions, care and support that would be required.					
Bellahouston Allotment Sign	Formulated by co-designers	Reviewing previous projects	Looking again at photography presented to the co-designers. Including the table-top garden, Macintosh Light and the many visits.	Combining influence from previous visits to Scotland Street Museum, St. Mungo's Museum of Religious Art, Kelvingrove Art Gallery and Museum, Trinity, Pollok Park and Bellahouston Allotments (Glasgow)	Discussion leading to a brief formulated by the co-designers to explain the design researcher. This was to design a light box sign for the Alzheimer Scotland Allotment. The sign should be colourful using stained-glass styled techniques, light-based and solar powered.	A proposal by the design-researcher was created to explain the design researcher in response to the brief. Here, the co-design team had to develop choices of arrangements of glass panels, light and lighting structures to develop the concept and to provide final form and design intent.							Through hands-on prototyping the group experimented with light and lighting cells and how they expressed how the designs were to be realised through material, colour and form.	The group were provided with instructions to share with the group and with hands-on and video relayed experiments of making processes including mould and laser cutting. These results shaped the final outcome and informed the manufacturer employed to undertake the final design and production. Co-designers defined approach	The final product making was shared with the group through filming processes.			The project supplied much evidence to what extent the co-design group had understood the brief. Through the development of the project they engaged in making testing and collaboration but the position of being the lead designer and the researcher had to be shared to help shape the final delivery through a continuous engagement in the process. The co-design group also engaged with learning about new technologies and techniques to inform the final production of the design.	The group set and shaped the project from beginning to end, they understood requirements and explore material manufacturing in order to support the final product producer.	COVID-19 stopped the project soon after the final product was created and has meant that it has not been installed any the point of writing-up.	6 x 1.5-2hrs Previous visits re-visited through photographic reviews and discussion	5 x 1-1.5hrs		
Gordon's Scanning Service	Invited to collaborate with a peer living with dementia whose proposal was to create some sort of photographic resource centre for his peers	Working with the design researcher, the co-designers were recruited around the photos and how they might be used to tell a story.	These were historical personal items that the co-designer had collected and wanted to tell a story.	Two audio recorded session allowed for the co-designer to develop his some digital manipulations and to use the design researcher to communicate how the project might develop	The co-designers were highly verbal discussing his views on quality and historical union connections which led to the co-designer to continue doing things that were for other people as well as himself.	On going demonstration and discussion of how the original photographs were touched and colourised the materials. The co-designer acted more as an art-director at this stage but held the project focus	Was achieved through collaboration but learned heavily on specialist abilities of the design researcher	Unexpectedly the prototype was not able to be used by his peers by the researcher using a flatbed scanner and an iPhone. This step guide was produced by the parties and allowed for the co-designer to resource to be established.	A scanning lab was developed between the co-designer, his wife and his wife's primary caregiver.	Initial designs/ artwork presented verbally to the group of 50 co-operating peers and caregivers. Further exploration	Scanning resource service delivered for Alzheimer Scotland Resource Centre. COVID-19 disrupted the intention to take the resource to other venues - the co-designer had started to investigate funding for further roll-out					That projects with great purpose and value can originate with the person living with dementia. That supports their interests and hobbies to help them engage in opportunities where they are the lead driver and partner of innovation central to their and achieving goals. That their historic design projects, opportunities and potential to engage with other people living with dementia and their carers. The designed artefacts also helped to prompt rich verbal delivery and deeply felt emotional responses.	The capacity for the co-designer to conceive of, develop and deliver his own scanning service.	COVID-19 stopped the project and therefore its service before the collection of images and stories as an artwork.	4 x 1-2.5hrs Workshops with the design researcher. 4 x 2hr workshops for the co-designer in his carer for other people living with dementia.					

### 7.3.3 Analysing Each Project Within the 'Co-design Participatory Power Pyramid'

The 'Co-design Participatory Power Pyramid' framework introduced in the literature review helps to elucidate how co-design commonly develops when working with people living with dementia. It was created to aid understanding of both co-design and more precisely, the use of co-design projects with PLWD. Common patterns revealed that co-design was proposed in many different ways and that often, the collaborative aspect was not much more than consulting with people living with dementia in order to provide for design solutions directed 'to' them or as projects styled as being 'for' them. Here, the designers either have ideas or even existing technologies they hope to apply to dealing with the problem of dementia or aim to gather some information before designing on their behalf. These kinds of practices (because of the difficult nature of undertaking collaborative design) nod towards more historic models of information gathering to influence a planned position or approach. It does not so much engage with participative opportunities. Instead, these approaches appear to accept the need to talk to all the stakeholders.

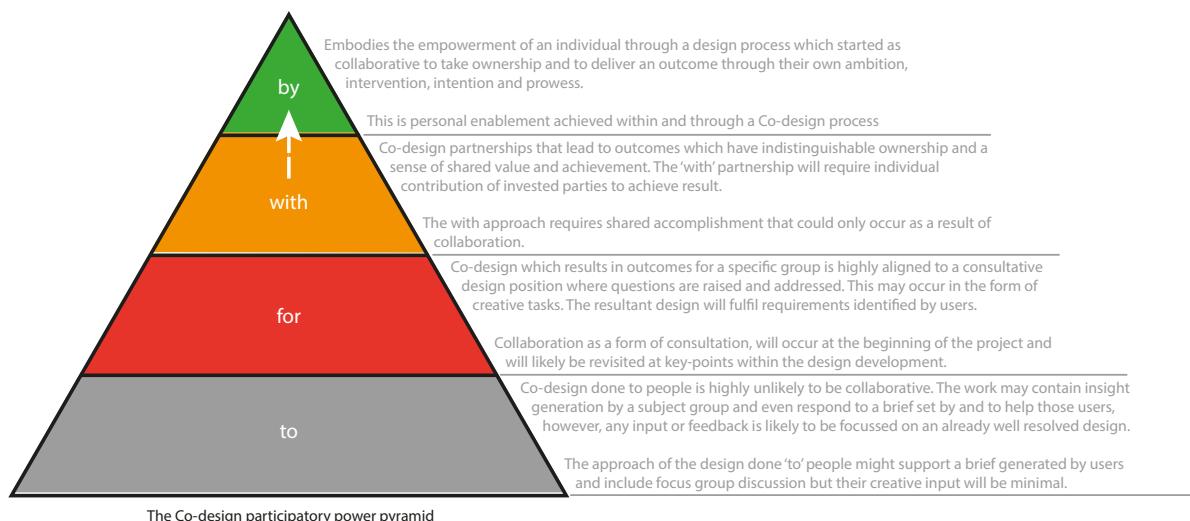


Figure 7.3 Co-design Participatory Power Pyramid devised to understand different approaches and associated behaviours connected to differing forms of participation.

To understand the application of the model to the 15 projects the coded table of the co-design projects (Table 7.2) was used to illucidate the efficacy of each project in regards to

the Co-design Participatory Power Pyramid (Figure. 7.3). This analysis mapping of the projects to the model has involved recognising actions within the co-design projects, interventions by the co-designers, the results of their designs and reflection on their engagement in the different stages of the design projects. Furthermore, it seeks to assess how many of the design stages were fulfilled and perceived to be either delivered 'for' them to engage with, developed 'with' them from conception and as part of ongoing actions and reactions, or directed 'by' them - controlled and delivered by their insightful investigations, daring actions and thoughtful delivery. In many cases, the mapping has developed an understanding of processes that moved between approaches e.g., 'with' and 'by' or 'for' and 'with'. Where the process is less evenly balanced, for example more significantly 'with' than 'by', an arrow is used to express the direction of transfer of significance, *i.e.*, the arrow is directed towards the 'with' state.

As a result of this research and the creation of the participatory power pyramid there is a hope that other researchers might evaluate their projects or plan their co-design processes with the pyramid in mind. The co-design participatory power pyramid should be used in conjunction with a design method that has key stages in a lasting process. The practice of which should engage collaboration as much as possible and will provide opportunity to evaluate the extent of that collaboration including the balance of power and responsibility of the parties. In particular this should recognise expectations and provide positional consideration of what is achieved along with the messy qualities that come to the fore when undertaking projects. The result should sit within a quantitative and qualitative review where participation is evaluated through evidenced justification. If the evidence poses that the collaboration has occurred across 50% or more of the intended stages within the complete process then the practices will be achieving a *with* position. As the ownership, direction and control of a project become more closely aligned to the actions of the collaborating participants questions pertaining to what degree of by the co-designers will arise. If the creative direction is shaped by the co-designers and their actions change expectations within the project and where they have been engaged and proactive in at least 70% of the stages of the design process then these start to align to the *by* conditions.

## The 15 projects mapped to co-design participatory power pyramid

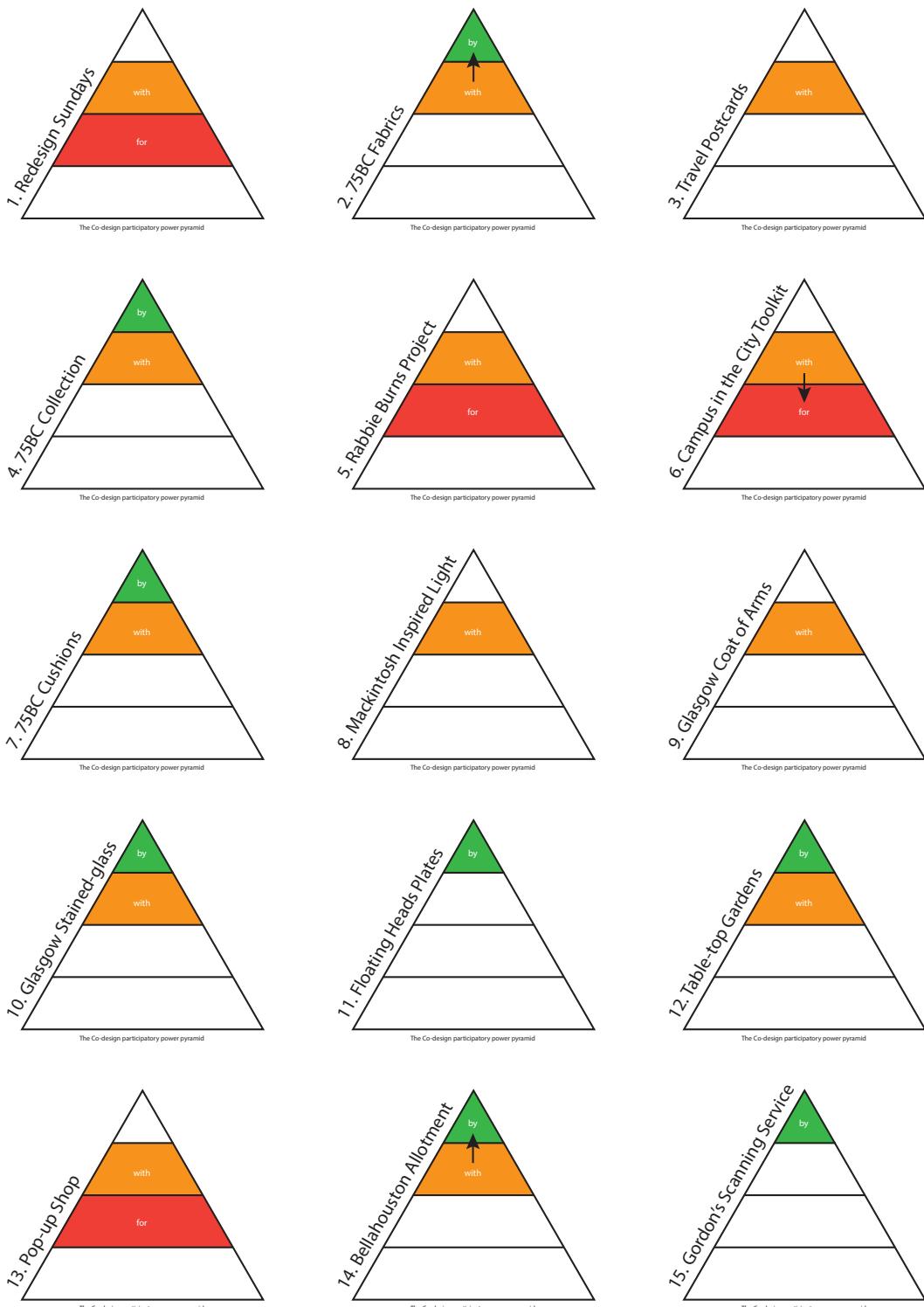


Figure 7.4 The fifteen co-design projects from this investigation analysed against the 'Co-design Participatory Power Pyramid'.

### 7.3.4 Key Insights from the 'Co-design Participatory Power Pyramid' Analysis

One project was deemed to be predominantly done 'for' the group (Figure 7.6, No.6) but still supported a valued amount of 'with'. This was a project where the participants had significant involvement but could not provide contributions in final delivery and acted largely as asked within the workshop setting. Their contributions were effectively closer to consultancy rather than participation within co-design. However, their actions and insight richly informed how the project would allow visitor participation.

Three projects were evaluated as being 'for' and 'with' (Figure 7.6, No's.1,5,13) crossing from an initial provision of an idea, service or project direction, that then gained creative traction and buy-in and where the co-designers started to give significant creative input. Three projects were adjudged to be significantly 'with' (Figure 7.6, No's.3,8,9) demonstrating cohesion within the groups and providing rich evidence of their ability to inform and shape the design process. Here, the design researcher played an equally significant role in connecting content and providing opportunities but the creative conversations provided a highly equal and inclusive design process for all parties involved.

Four of the projects were significantly 'with' and 'by' (Figure 7.6, No's.4,7,10,12) meaning that ownership, origination, development and results were significantly moving towards a position of being based in rich positive and capable actions by the co-designers. Here they took opportunities and made them their own. The results were projects that required some workshop tasks designed around their wants and desires but that showed real independence and collective cohesion *en route* to delivering designed outcomes.

Projects that were shown to cross into the higher levels of 'by' and 'with' (indicated with an upwards arrow) show particularly strong design actions and independence where the facilitator saw unexpected outcomes develop and where the results could only have been achieved thanks to the way the co-designers engaged in the process. Here, they changed any kind of expectations and directed longer-term goals or project objectives, purpose

and applications. Although these projects were close to being termed 'by', there was still important support provided by the design researcher (Figure 7.6, No's.2,14).

Only two projects could be described as fully 'by' the co-designers (Figure 7.6, No's.2,11). By changing the project focus, setting a workshop brief and disrupting project plans, the co-designers took control of the project from beginning to end. In the first example, the design researcher was able to sit back and observe. The co-designers fed on one another's creativity, energy and excitement in the process that they had developed. They then refined the process and the prototypes before creating a system for producing multiples of their designs. By taking control, the group provided evidence of its belief in its ability to act, empowerment to make and do things whilst testing their own, individual creative ideas.

The second of these projects was far more akin to design direction by a highly impassioned and driven co-designer. The project differed somewhat from the other group-focussed projects in that it was driven by one person, and aided by his primary carer. The scanning-lab service that became the ultimate result of this project was run by the project driver and his primary carer resulting in a design research project of his own, run by him for the benefit of other people living with dementia. The project ultimately resulted in a radio programme being made about the project and this remarkable man. The original commission of the project was also based within his own interest in how images (in particular, ones from a historic visit to Japan) could resonate and unlock deep memories and conversations about powerful and rich autobiographical accounts. His approach resulted in the design researcher working with him to achieve his goals and to put the power in his hands to advance his own agenda.

Although vastly different from the other projects, the empowering of the individual, given the opportunity to fulfill his own creative desires, proved to be deeply meaningful. Although some technical delivery of this project was undertaken by the design researcher as a specialist technician, the concept belonged to the co-designer. The presentation of the project was undertaken by him to a large audience. He then developed the idea of a service based on his presentation and invited people to make use of his scanning-lab.

Here, he collected stories and images from his peers and created a library of content to be explored further. Unfortunately, the Covid-19 restrictions halted the project but it may still resume.

In mapping the co-design projects, it was possible to correlate where changes had occurred in the group structure and therefore dynamic. The new group formed at the time of the Mackintosh Light project created a period of time where the projects were very much 'with' the researcher. The group dynamic at this stage is discussed in both 7.2.8 the 'Mackintosh Light' project description and 7.8.3 ('Social inclusion and camaraderie').

As this group developed, greater engagement between one another, with the various visits and the new projects, **led to** their cohesion as a group and their capabilities as co-designers developed with genuine prowess. The group became so effective that by the end it set a comprehensive brief for the design researcher to undertake a project on its behalf. This aspect had significant links to Arnstein's 'Citizen Power' where the group asserted control and delegated. The delegation was not so much in the form of power as Arnstein had identified but tasks to then develop with the group. Unlike other examples achieved through creative conversations in other projects, this process involved the co-designers dictating what was to be done and how it was to occur, including setting design restrictions.

Throughout the mapping of the project and the analysis of the method, projects and processes, it has been possible to extract key themes and to form packages of insights within these themes which the following section discusses.

## 7.4 Commentaries

What follows are a number of commentaries collected in the presentation and review of the projects involved in this body of work. They represent viewpoints of the co-designers, carers, and public audiences. They have been analysed to generate thematic

understanding of what they communicate and how they do so. The collection of this data was significantly impacted by the Covid-19 pandemic and as such, does not fulfil as broad a set of insights as might have been expected.

The collection of this data represents content from field notes, a semi-structured group interview with co-designers, an individual interview with one stand-alone co-designer and his primary carer and written commentaries collected at the '*designed with deMEntia*' shops and the *Campus in the City 75BC Exhibition*.

The content of these commentaries is therefore not fully representative of the significant numbers of people that the projects have been able to engage with. However, they still provide highly insightful and valued qualitative data.

The analysis of the data is presented as:

- 7.4.1 from a co-design group
- 7.4.2 from the singular co-designer and his wife
- 7.4.2 from carers
- 7.4.3 from the public
- 7.4.4 further thematic analysis of the feedback
- 7.4.5 final distillation of themes

#### **7.4.1 Bridgeton Day-Opps Group**

The interview that has been analysed in the following section involved four co-designers and two care support team members. The care providers rarely interjected in the conversation but if they did, they were omitted from the following interview extracts and analysis. The semi-structured approach supported the development of naturally evolving conversations and acted as prompts for discussion. The openness was required in order

to let the individuals respond and for their peers to join in. The interview occurred over a 45 minute session in the Bridgeton Resource Centre in Glasgow.

The responses gathered through the recorded interview have been split into naturally occurring periods of discussion that correspond to a question or prompt. They have then been analysed to see what is being shared or where common patterns have occurred in order to generate themes.

Where direct quotes are used colouring has been used to identify different voices recorded as the conversation flowed. This has been done to understand how the participants fed off one another in a conversational manner and to elucidate the shared views. Any quotations in black are the design researcher's voice. The key themes extracted from the data were:

**Enduring memories** - of projects, processes and design practices was evident during the conversation where most of the projects were discussed. The details of their memories were suggestive of significant importance to the co-designers as they discussed them.

**Camaraderie** - Discussion of how the co-designers created things or engaged with one another was important and showed acceptance, understanding and togetherness. Included in this discussion was that the group could share ideas and feed off one another:

*"We got a laugh n things like that."*

*"We were yeah cos we all got on well. We all had our own bits to and whoever was doing that bit we just moved on so it wasn't a problem. It was just thoroughly enjoyable."*

*"Aye the groups ok init."*

The ability to negotiate roles, support one another and to do it with good humour provided a real sense of building their own support network with no individual member being excluded or lacking value within tasks.

**Enjoyment** - the commentaries repeatedly presented terms such as enjoyed, fascinating, smashing, liked, loved, good and enjoyable, to explain how the projects were engaged with. A sentiment echoed in the conversation of two participants:

*"Well done you... its been thoroughly enjoyable."*

*"And a pleasure."*

*"Really interesting and learning how to do all the different things as well."*

The endeavors therefore presented an ongoing sense of purposeful fun where their emotional intelligence supported real lasting engagement.

**Capabilities** - The way in which the projects developed and didn't require particular skills e.g., drawing, was important and allowed enjoyment of the design process, the suggestion being that everybody was capable of taking part and expressing themselves. The use of photography further supported these actions and was seen to be important for collecting details:

*"Its good to have a camera you know for something like that, because, you see, pick out different things you know."*

The ability to participate was not restricted and the evidence suggested that this had worked well, allowing the co-designers to feel completion in the work they undertook:

*"I liked how whatever was done how kind of, you know, it was, obviously I canna draw, but I loved seeing something coming, the finished article."*

*"The finished thing."*

*"But there wasn't a need to draw though was there?"*

*"No that's why I thoroughly enjoyed it."*

By unlocking creative potential through accessible models and by removing normative barriers, i.e., perceptions of own ability to draw, the capabilities of the group in its own words talks of "finishing" projects. Meaning that they had got involved and made things happen thanks to what they could do.

Most telling of all was how the perceptions of capabilities were railed against and how the participants were acting defiantly towards poor public understanding through doing the projects:

*"A lot of people come in think we just sit here we don't do anything. People with dementia can do great things."*

*"Ah know a lot of people think that dementia people can't do a thing."*

*"We don't know anything."*

*"No we don't know nothing."*

The take-away message is that through the projects, they have proven people wrong and that this shows individual and collective empowerment and esteem.

**Knowledge and Understanding** - being asked to think and to use their own knowledge or understanding was of high importance in the *Re:design Sundays* (Chapter 5) project. One participant stated: *"You made us think more than we are usually asked to do and it is good for us to have to think"*, which was a very similar statement to one made by one of the Bridgeton group members when she stated:

*"You know, it was good as well to have the different, it was like questions you had to put in, put a point forward, questions. Get the grey matter going."*

These statements re-enforced the importance of asking for opinions and views through the projects and particularly of asking participants to think about things. This builds on the very essence of personhood and the person's need to be valued for what he or she can contribute.

**Pride and Esteem** - In talking of the power of their work and by osmosis themselves, the co-designers have talked about ability to develop projects and of a sense of completion. To be involved through tasks and approaches that they have achieved, using their brains and thinking, they have often talked of their own historic experiences that have frequently played an important role in shaping, informing or driving projects. These have helped to develop personal efficacy and esteem. However, their responses to the shop was probably the most powerful communication of the effects the projects had:

*"I thought that was absolutely brilliant."*

*"It was, it really was...I didnae think, I thoroughly enjoyed making whatever, but I still didn't think it was good enough to sell kinda thing"*

*"And it was."*

*"It definitely was."*

*"It certainly made you feel quite good (laughs)."*

*"It's good for your morale and good for your confidence."*

*"Thats the thing about it is what you value you canna buy."*

Not recorded in this interview but written as a commentary at the *designed with dementia* shop by one of the participants when visiting was the statement:

*"Brilliant never thought dementia people could do this. I did and I've got dementia."*

The sentiment in this particular statement has been discussed previously for how it is suggestive of changing perceptions, including those of people who are living with dementia. However, it also represents a great sense of pride in being involved in the projects and the personal esteem that has been provided.

#### 7.4.2 Gordon and his wife

Gordon and his wife (and primary carer) have provided the focus of the following review and analysis. Gordon's Scanning Lab was a service that grew out of an initial project where co-design supported the creation of a digital art piece based on his own historic images of Japan. The approach to work with Gordon was very much focussed on achieving his goals and desires. In the development of the original artwork, he developed the idea of creating a service to support his peers who were using the Bridgeton Resource Centre.

The result was the creation of a scanning service run by him and his wife. Over the course of this project, many interviews occurred. These resulted in a radio programme being made about the project. The recorded interviews have been provided as a resource for this PhD and the content reviewed here focusses on the last of those interviews. It is a reflective piece that looks at what has been achieved and what the process has delivered.

The answers have again been thematically arranged to understand what was being said, how and why. In this process, two key perspectives come into consideration - that of an individual co-designer living with dementia and that of his wife (carer) who became an inadvertent co-design participant. The focus of the work lies within how Gordon has

driven the project and delivered a valued service to other people living with dementia but it also notes the significant contribution his wife made through her facilitation and support.

The key themes that were extracted are:

**Memory, thinking and communication** - played a significant role in the stimulation of the audience for the scanning lab. Thanks to his Japanese picture artwork, Gordon was able to present his work to an audience. In particular, key to this was a renewed confidence and a clarity of both memory and thought. As his wife stated: *"Initially, when we said he was going to have to stand up and talk, he was reluctant and said he didn't want to do it, you are going to have to do it for me [referring to the facilitator] and I said I don't want to do it,"* she continued, *"but when you got up, it just started and it just came out".*

The process of public speaking was not new to Gordon but it had been so long since he had done anything of note. However, the effectiveness of the artwork/design as a tool for triggering thought processes was appreciated by his peers as Gordon explains: *"That's what somebody said to me, the group were in the seats and I started talking about kobi beef and bits and pieces, and somebody said to me, you have actually been able to speak and let it come out without..."* 'fighting for it', was the prompt which followed and he emphatically responded, *"I wasn't, no!"*.

The noticeable change in Gordon's ability to communicate along with the confidence in which he did so, as discussed by Gordon his wife and peers, expressed a perceived value of the collaborative process and what that had achieved.

**People, presence and hope** - Throughout the discussion, the overarching theme of people and service for his peers was evidently important to Gordon. This resonated with his historical position as a trade union activist, it also continued as a theme in his aim to provide something that would be beneficial to other people living with dementia. His rewarding statements included,

*"You have got Alzheimer's, but you can still be here and things can happen"; "There is still a life within the person who has Alzheimer's, that's way that I see it" and "Because I've got Alzheimer's I tend to chatter too much but it's to try and help people, it's to say you can still have a life with it and with good people, you know".*

In these statements, when aligned with the work that he undertook, it became highly evident that being present, participating, having purpose and sharing in activities, people living with dementia can live rewarding experiences together.

**Capability (providing a service)** - Throughout this co-design project, the designed solutions have unlocked potential in people and their practices. The initial artwork allowed Gordon to regain his lost images but also to talk openly to a roomful of peers and to organise them into action. That action informed his scanning service and the results were a service design that as Gordon stated, *"If you have lost your photograph what we have done is we will get you back, we will get it back for you as best as we can"*. The interpretation of this is that the photographic image might be interchangeable with treasured memories.

Gordon was an ever-present force in making things happen as he explains, *"When we got it, that [scanning] kit was there and then... the end of the day people came up with photographs that they had lost and some of them were colleagues in the café and I said to them come on. Most of the people were good as we got pictures from everyone that wanted to"*. His participation in this instance was not restricted to being the voice of the project but he also became the active driver of it, with a little help from his wife, as she explained: *"The scanning was alright, once we figured it out properly, it was alright, it was just getting the photographs in the right position or the right way round, it was alright."* Her further involvement explained how the two worked together further, *"I helped Gordon move the mouse and things like that"*. This might seem simple enough but by having somebody support simple actions based on request was liberating. Gordon appeared to have developed renewed purpose and a sense of capability because he could enact his wants and desires. He could provide a service and act for people, something that as a

shop steward, he had done throughout his life. The lab therefore acted as an embodiment of his self-worth, personal position and prowess.

It also strengthened a sense of value for Gordon's wife who explained: "*It's been a right good experience and talking to people, because I am myself quite shy but it's been great getting to meet people and it's been really interesting being able to talk to different people and to learn about their different experiences and be like, WOW, you have been here and you have done this, it's really been a good exercise for me as well and I have enjoyed it*".

Working together, the pair were able to gather highly detailed, valuable content and to build supportive relationships with other resource users

**Informing situations and shaping possibilities** - The project focussed on Gordon's idea that other people could be better supported, that services could serve their users in better ways and that encouraging people to act together might overcome complacency or acceptance of the situation. Much of this has been expressed under 'People, presence and hope'. However, the creation of the scanning lab and the recurring theme that Gordon provides: "*The way I look at it in the café, the café is good for everybody but I think the café could be better*," reinforces the message. In a way, Gordon was always likely to fight for change in services and approaches but through his scanning lab he has been able to take control, make things happen and shape possibilities.

**Friendship** - In the previous analysis of the co-design group working practices (7.4.1), camaraderie was discussed as an essential part of the group working practices. In Gordon's service driven narrative, this is viewed more akin to a friendship, the difference being that camaraderie is associated with friendships developed in strong working relationships. In this work, friendship was aligned to support, openness, interest and a welcoming consideration. Gordon explains, "*Let's look at something that says Alzheimer's [people] don't have to be frightened, you know but be friendly with everybody*". This, as a part of the service, was essential in getting people to do something that Gordon could

respond to and build upon. Differing ways of working, therefore, provide different kinds of relationships but in this dementia setting those relationships are very important.

**Meaningful and purposeful** - The co-design projects contained within this research have hoped to provide meaning and purpose for the people involved. The following statements have been provided to explain, in Gordon and his wife's words, how that has happened through this collaboration:

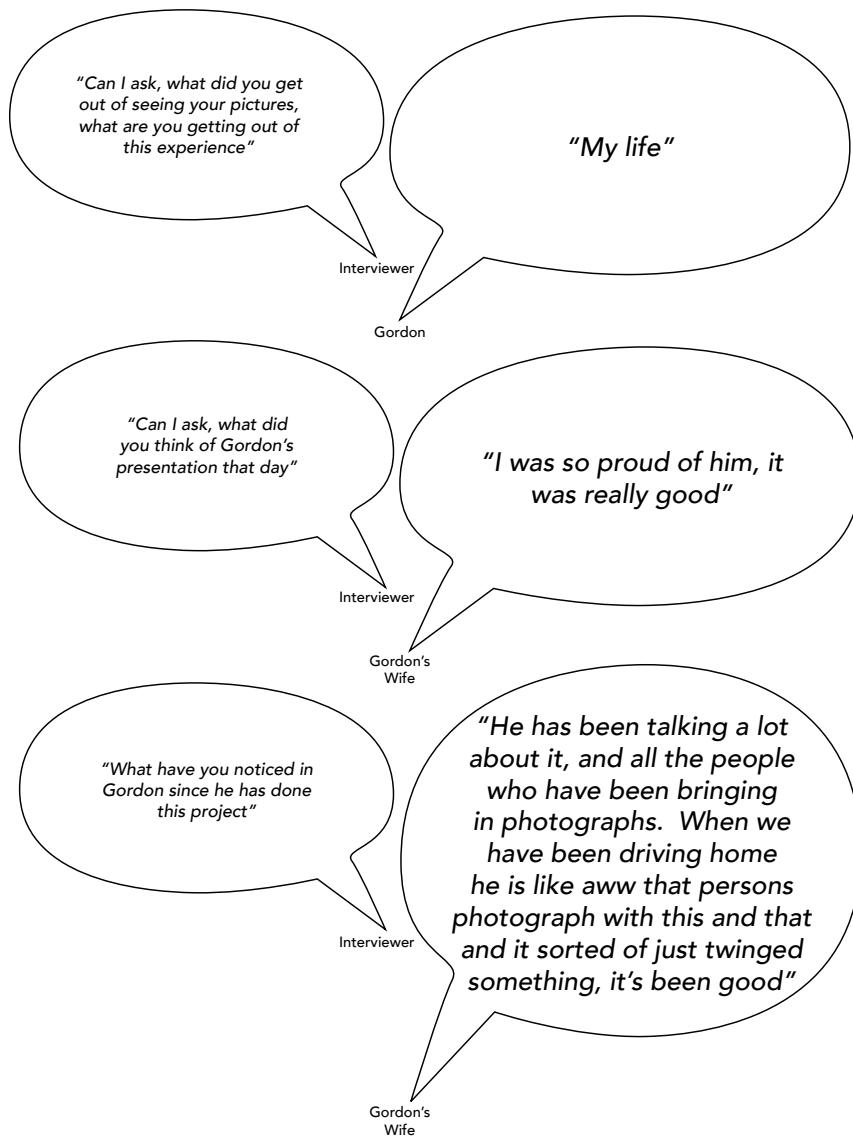


Figure 7.5 Gordon and his wife explaining the importance of the scanning lab project.

Another aspect contained within this interview is that Gordon has also hoped that the project has the meaningful and purposeful quality for his peers as he explains, "You want to try and look to say look everybody down here in the café we all have Alzheimer's, let's do something and whether it can be a bit funny, brain and happy".

In this discussion of the commentaries made by Gordon and his wife, it is evident that the process has given purpose and meaning to Gordon and his created endeavours that have been valued by other people.

#### 7.4.3 Carer feedback

Unfortunately, the carer feedback was considerably limited due to the lack of ability to conduct interviews throughout the Covid-19 Pandemic. This was also as a result of many of the staff being furloughed and as such, not being able to respond to contact.

The value as perceived by the care staff is therefore restricted to field notes, limited participation in interviews and passing commentaries. Much of the discussion has been about how it was seen as positive and that people had enjoyed being involved in the projects. Many of the comments also appeared to affirm that the way facilitation had occurred was significantly important.

*"That's what you do Euan. Put the power into people's hands"*

(Amanda Gillies, Alzheimer Scotland, 2019)<sup>4</sup>

Many primary carers were likely to have shared their opinions when they visited outcome driven events, in particular, the *design with deMENTia* shop. During the event, conversations occurred with loved ones whom they had brought in to let them see their work. 'Brilliant' was common parlance to explain the views that the loved ones and primary carers had. One particular couple came into see the cushions and lighting created by that particular co-designer. His wife explained how excited he had been at

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<sup>4</sup> Field note from conversation with the Bridgeton Resource Centre director December, 2019)

showing her his designs and that he had missed not being part of the group. Unfortunately, his care needs had developed such that he could no longer play a part. However, she explained that it had been really important for him and that he wanted to buy a version of his cushion. She purchased a couple of them and the following week made contact through the resource centre to order some more.

The importance of the work and how it was valued by the Alzheimer Scotland professional care providers was demonstrated when the work was unexpectedly shared as an exemplar of great new projects and practices during the Alzheimer Scotland National Dementia Conference 19<sup>th</sup> October 2018, when Chief Executive Henry Simmons included it in his keynote speech.

Common perspectives shared by the professional carers was that the groups enjoyed the processes, found value in them, that they could use them elsewhere. The most significant commentary involved collective empowerment where the discussion was focussed upon making use of people's thoughts in connected meaningful ways: *"It's like brain storming isn't it. You take everybody's ideas and develop it"* Elizabeth (Alzheimer Scotland care provider)

Themes extracted from the limited discussions and collected comments were:

- Inclusion
- Empowerment
- Meaningfulness
- Value
- Purpose

#### 7.4.4 Public Commentaries

The handwritten commentaries collected at the '*designed with deMEntia*' shops (Glasgow and Edinburgh) and the *Campus in the City* event (Lancaster) were collected through an invitational approach where pens and tools for feedback were collected under statements which asked:

- What are your thoughts on the designs by people living with dementia?
- Has what you've seen changed or challenged what you think about people living with dementia?
- What does dementia mean to you?

Capability	<p>It's great to use people with dementia using their creative skills and talent!</p> <p>It's wonderful what you can do</p> <p>People living with dementia inspire me every time.</p> <p>Amazing! So positive!</p> <p>I've worked a lot with dementia so I know not too assume the worst or to write people off... fuck ableism and ageism!</p> <p>People should not purely be defined by their dementia they are more than that!</p> <p>Challenge is fun!</p>	Knowledge of dementia	<p>I work with people who have dementia</p> <p>My son in law has dementia</p> <p>My wife's dad had dementia and mum might do too</p> <p>Everyone knows someone with dementia or related diseases. It is becoming the norm in people's lives (grumpy face)</p> <p>There is definitely not enough information out there about the effects it has on people. I definitely didn't a couple of years ago.</p> <p>My granny had Alzheimer's disease</p> <p>People living with dementia inspire me every time.</p> <p>Often some of the happiest people I have ever met.</p> <p>It's so hard we are just getting used to it things amenity what they used to be</p>
Empowerment	<p>The project gives and gives back empowering many people who may be seen as non-productive (curses)</p> <p>I like to see the positivity around the diagnosis of dementia</p> <p>Inspiring the mind to think differently, to expand and to empower each individual, life goes on, be positive with every situation</p> <p>This shows people living with dementia can contribute greatly to society, in a very beautiful way!</p> <p>A very inspiring project, It puts the person first rather than their dementia</p> <p>Empowerment through design! Really awesome giving back to people.</p>	Changing Perceptions	<p>My gran had Alzheimer's disease</p> <p>My uncle has the onset of dementia</p> <p>A dramatic change day to day without my carer I would be so depressed</p> <p>Life changing but not necessarily the end...</p> <p>My gran has vascular dementia.</p>
Social inclusion	<p>The main thing I think about is how sufferers can get separated from life and it makes me sad. In this project I see a very positive effort around reversing that, and the promotion of an inclusive attitude and I am thankful for that.</p> <p>Different local people making things together</p> <p>Talking to people and being happy</p> <p>The social aspect of this is a really important thing a lot of older people lose.</p> <p>Inclusive design is important to ensure all communities are included and benefit from positive input.</p> <p>The work/exhibition is testimony to the achievements of all involved and the change in behavioural attitudes in people who suffer from this condition. A wonderful exemplar.</p> <p>It's really great that this is the outcome and that it is all really different, getting fun results.</p> <p>Great to see such contemporary stylish art with such a strong community ethos behind it!</p>	Designs reviews	<p>I'd never have thought people living with dementia would be capable of this</p> <p>It's amazing how much things have progressed in 20 years since my dad. Good to know things other than medical care are being looked at. It's about the person</p> <p>Insightful, educational, inspiring, very positive and we need to talk about key issues more</p> <p>Brilliant never thought dementia people could do this. I did and I've got dementia</p>
Support	<p>This project has been very good. Staff and service workers should continue to work with the service</p> <p>I've been working with people with dementia for over 10 years and I treasure every minute of it.</p> <p>Some challenges however lots of love and support... not forgetting fun! (smiley face)</p> <p>My mum has dementia but won't get into anything so I'm getting some ideas here.</p>	Participation	<p>They are brilliant</p> <p>The designs are so thoughtful and individually made</p> <p>Art is a universal language and this speaks all of the words that sometimes others can't. Beautiful work.</p> <p>Just like walking into habitat!</p> <p>It's lovely it really is</p> <p>A great selection of artworks. A really important project. Good Luck</p> <p>Very interesting and thought-provoking ideas X</p> <p>I'm loving the fact that people with dementia helped with the design of the products.</p> <p>(Smiley face) Love the repeated patterns as each item adds a bit of personality to each of them</p> <p>There's some really nice stuff</p> <p>I love the mini sculptures of machines and people.</p> <p>Fabulous concept everyone should see this amazing work. X</p> <p>I'm impressed as a designer myself I think these designs should be on the high street!</p> <p>Love the designs and stories that created them</p> <p>They are amazing (love heart)</p>
			<p>It was wonderful to learn about the project and get involved!</p> <p>We really liked making a castle cushion and talking to the friendly people!</p>

Table 7.3 Public commentaries grouped within emergent themes

#### 7.4.5 further thematic analysis of the feedback

The following table (Table 7.4) groups the themes resulting from the analysis into family sets, following which, outlying themes are explained. In section 7.6.6, the thematic families are distilled into final themes which support recommendations and guidance for design researchers planning to undertake co-design projects such as this.

Themes arising from projects	Themes arising from co-designers	Themes arising from Gordon and his Wife	Themes from Carers	Themes from the Public
	Enjoyment	People, presence and hope	Value	Designs reviews
	Capabilities	Capability (providing a service)	Purpose	Capability
Confidence and action	Pride and Esteem	Informing situations and shaping possibilities	Empowerment	Empowerment
Social, purposeful and meaningful	Enduring memories	Meaningful and purposeful	Meaningfulness	Changing Perceptions
	Camaraderie	Friendship	Inclusion	Social inclusion Participation
Knowledge, understanding and experience	Knowledge and understanding	Memory, thinking and communication		
Planning and delivery				
Time				
				Support
Facilitator behaviours and actions				
				Knowledge of dementia

Table 7.4 Thematic review looking at the relationships emerging between all of the interested parties.

Through analysing the projects and what people said about them, various linked themes (and perspectives) became apparent where some were noted for how much they stood out as being particularly relevant. For example:

- **Time:** which was notably important within the technicalities of undertaking and delivering projects but did not appear as a consideration for co-designers, their carers and public audiences
- **Facilitator behaviours and actions:** again, were significant in understanding how to undertake these kinds of projects and as to how the projects developed but was not evident for the co-designers, their carers and public audiences, apart from a couple statements which stated how those behaviours were evidenced, such as Amanda Gillies' statement about empowerment (above) and the co-designers' "well done you" statements.
- **Planning and delivery** were closely associated themes to the facilitation set above and again, were involved in the key overview that these were of significance as noted by the researcher but less so than the other people involved. This was largely due to these tasks being a requirement within the processes of doing co-design and project production but were not seen or undertaken by the co-designers or carers. The understanding here is that co-design has provided significant opportunity for collaboration, which could only occur because of the organisation and arrangement of all the associated administration, *i.e.*, facilities organisation, equipment purchasing, project planning tec. These aspects are essential.
- The public realisation of this being a form of **support** (or care) was largely limited to the review of the work through the '*designed with deMEntia*' shop and '*Campus in the City*' exhibition. This suggests that the work could be seen as such to outsiders looking in but to those more closely involved, it was a more natural process of working together, perhaps not seen as care or support. This indicates a stronger sense of design 'with', which is underlined by narratives of inclusion, friendship and camaraderie.
- **Knowledge of dementia:** was a statement asked for in the questioning of the public and, as an investigating statement, was an outlier. This was less significant to the activities of the study and more closely linked to the prevalence and experience of dementia in society. The question, though largely disconnected

from the acts of co-design and the main purpose of the investigation, allowed audiences to understand the work from a more personally informed perspective. It also underlined information provided in the background setting of this study (Chapters 1 and 2) as to the wide societal knowledge and experience of dementia.

#### 7.4.6 Distillation of themes

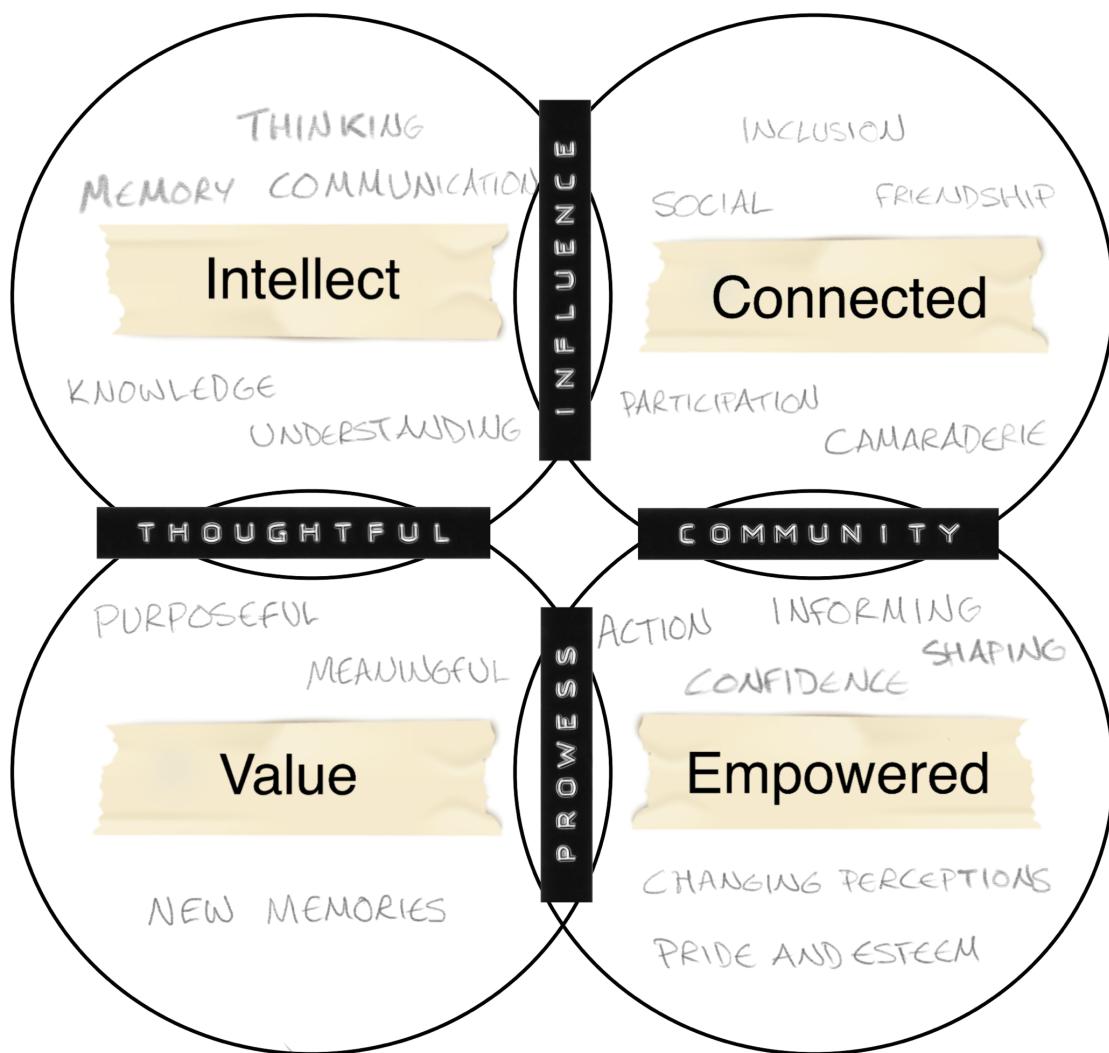


Figure 7.7 Distillation of themes originating in headings and intersection labels of thoughtful, influence, community and prowess where the co-designers created connected meaning through actions.

In the above diagram, the occurring themes have been distilled into:

- **Intellect** - where the person living with dementia has been asked to think about scenarios, to use his or her own knowledge and insights, to discover new

knowledge and to develop understanding. In the diagram, the application of intellect has supported the other three themes, creating interlinking significance between each aspect.

- **Connected** - is about how the co-designers developed their own collaborative ventures, networks of support and sense of belonging. The connected aspect relates to the importance of being part of socially driven practices and retaining multiple connections. These might be between individuals or into the wider community or society.
- **Value** - identifies the methods of working together as being, and leading towards, purposeful and meaningful endeavours. Here, their intellect and their sense of place in groups or society are reinforced by the designs and interventions they have made. Included in this is the self-affecting value found by the co-designers during the projects and from their results.
- **Empowered** - identifies the combined personal and collective positions the co-designers were able to control and shape, to influence, to inform and to provide evidence of capability within. It suggests the groups and individuals involved have been enabled to follow ideas and to provide thinking that is valued by other people, services that other people could engage with and products that people could buy. The empowerment is the culmination of all the other themes and interlinking relationships.

In reviewing the central themes subsets were identified at the intersections these were:

- **Thoughtful** - evidence of thinking aligned with valuable contributions in and throughout projects but also in the outcomes that they shaped.
- **Influence** - evidence-based understanding that their intellectual endeavours informed and contributed richly to social groups and society whilst reinforcing themes of capability.
- **Community** - rich evidence that the co-designers developed their own support networks and formed both working and social togetherness.

- **Prowess** – evidence of capabilities in tasks that led to feeling greater self-esteem and personal-belief whilst also allowing for personal development and new learning to occur.

The distilled themes have helped to programme the guidance for undertaking medium-to-long term co-design with people living with dementia. These also form a significant value-led understanding as to why co-design can be so important as a method for working with people living with dementia.

The work has also allowed for a belief in capability to develop within the co-designers, provided there is an additional long-term form of care support that can be beneficial to the co-designers, their carers and the resource centres they use.

## 7.5 Discussion

So far, the analysis and discussion of the projects and activities of people living with dementia explore throughout this thesis have focussed on how co-design has proved to provide empowering, inclusive, meaningful and valued experiences. The work has looked at the long-term effectiveness of the approach as a form of care provision and has shown that people with dementia are capable of delivering great things. The evidence emerges through projects and outcomes, the views of co-designers, carers and public audiences which communicate these perspectives. The work has provided many ways to look at co-design and its efficacy in enriching lived experiences of people living with dementia whilst building upon themes of personhood such as esteem, capability, personal and collective empowerment.

Throughout the multitude of case studies represented in Chapters 5 and 6 which are analysed in this chapter, it is clear that the projects have supplied highly enriching and valued experiences for many people, including; professional caregivers, primary carers, the design researcher, the public (attendees at various events generated with the co-designers) as well as the co-designers themselves (people living with dementia).

The project has also helped to identify a number of insights, influences and issues that should be considered when undertaking co-design projects. These have helped to shape the guidance in the final chapter (Chapter 8, 'Conclusions and Recommendations').

The work has helped to inform audiences through public presentations, events, exhibitions and shops. It has been presented at the House of Lords and has formed five papers and three book chapters. A short film of the work has also been produced by the AHRC so that the endeavours could be shared as an exemplar of design with dementia. The volume of outputs further enhances a view that the work has provided valuable experiences for people living with dementia and much wider audiences where the co-design relationship has been the driving force.

For anybody intending to undertake co-design in the field of design with dementia, this thesis seeks to provide valuable insight as to how to do so.

Most importantly, it supports a view that people living with dementia can make telling and valued contributions to society when provided with the appropriate tools, opportunities and support. Contained within the overall review of the projects, much of the discussion reflects on capability and how that informs action through thought. This arguably demonstrates achievement, evidenced affirmations of personhood and displays of collective and individual empowerment of people living with dementia.

What follows are further reviews and additional, extracted understandings that have emerged from the study and undertaking the various projects contained in the research.

### 7.5.1 Co-design and working with people living with dementia

The projects provided firm evidence of the capabilities of people living with dementia. This is particularly true of the core co-designers from the Alzheimer Scotland Bridgeton Resource Centre in Glasgow all of whom were in the early to moderate stages of their early onset dementia.

The co-design explorations and practices were significantly beneficial in creating purpose and providing additional value to the services provided to the users of the Resource Centre at Bridgeton. The evidence suggests that the participants in the co-design show accountability and ownership in their design practices. Their contributions were significant and none of the co-design projects would have been completed without their depth of engagement in the design process.

During the co-design practices, many differing experiences occurred. Some projects were full and engaged in almost every step of the design process. Others were short term, rapid and skipped over certain aspects of what was deemed to be the full design process. The resultant designs, therefore, indicate greater or lesser meaningfulness of some projects against others. Although in reflective interviews it was not uncommon to find almost every project appeared to supply value to the co-designers, this indicates that even some of the projects perceived to have less significance resonated with different people in different ways. A fine example of which was when one participant recalled making the Mackintosh light and the stages and materials involved in doing so almost a year after the workshop.

The co-design workshops involved in this project developed many themes that have been broken down in the following sections and indicates how the projects supported people living with dementia in rich engaged and purposeful ways that appear to demonstrate high levels of capability, engage people socially and empower them to act on behalf of themselves and others.

As one co-design participant stated in his recorded interview:

*"You have got Alzheimer's but you can still be here and things can happen"*

(Gordon interview, 2020)

### 7.5.2 Collective achievements

This PhD is peppered with highly visible examples of the people living with dementia as co-designers in action and the products that they have created. These are testimony to the significant body of work that they have produced and markers of capability. What is clear is that in their production, people have surprised both themselves and the public.

The projects in the image above (Figure 7.1) are very limited in their description of what has been achieved within the fifteen projects. It shows the broad scope of creative endeavours and reminds the reader of what was achieved by the co-designers, whose projects this work has studied. In and throughout their endeavours, the connected possibilities of their thinking, designing and making, research and explorations, material investigations and prototypes has indicated how this work serves to highlight a process that moves far beyond art therapy - especially the kind of art therapy observed in Chapter 1 of this thesis. Instead, they have developed unique ideas that belong to them, combined influences through trips to venues, set agendas based upon what they have seen, stimulated (and even sometimes conceived) the brief that projects must respond to or follow.

### 7.5.3 Time and Dementia

Their actions have been situated in the present and have focussed on the things that they have found stimulating by working in their groups over varying timespans. Their work

rarely required reminiscence or a sense of living in the past. Alternatively, they were able to enact processes that started in the here and now, before evolving to look towards future events, e.g., the exhibition and the *designed with dementia* shop. The groups were able to act upon recently experienced workshops, visits or events and projects could easily work across periods of time where collaboration could not occur.

Projects could last as little as a couple of sessions, over a month or two through to ongoing iterative actions that bridged between one project and the next over six to eighteen months. The most common way of keeping momentum, renewed interest and to remind participants of what had happened previously was to have a five-minute refresher at the start of a workshop. On visits, clear instructions of the task in hand or expectations were all that was required. Most commonly, this consisted of a statement such as 'remember the theme is now to photograph what appeals to you'.

The length of time that projects and processes could resonate with participants was surprising. It was not uncommon for project details to be more easily recalled by the participants than the design researcher!

Rarely was time an issue in achieving the completion of workshop tasks and if there was a need to resume a task next time, that was what happened. A pause in the doing aspect didn't happen very often but when it did, it did not cause any notable issue. The planning of workshops to occur within 1-1.5hr periods was important as this supported valued action but did not allow for fatigue to develop. On one occasion, a co-designer was having an off-day and removed himself from the process but returned to contribute to the group working in the next session. The workshop planning acknowledged that this could happen but that it would not disrupt the flow and sequence in delivering design outcomes.

Giving people time to act and speak was important. Not rushing to help or complete a task or statement until asked became important. Here, the soft skills of a designer are very

important, e.g., reading body language, noticing agitation or frustration and being ready to support is key.

#### 7.5.4 Social Inclusion and Camaraderie

There is significant evidence supporting how the projects enhanced a cohesive development of existing groups. There is also evidence that the practice of the co-design projects provided opportunities for new relationships to develop. What developed within each group was togetherness in tasks, where everybody displayed helpful, supportive behaviours. The shared objectives and participation in directing projects provided opportunities for personal and collective learning through action. In this sense, the learning as identified by the participants proved to be seen as valued even when, as one participant stated, "We're learning, we might not remember but we are learning". This kind of statement also showed the humour that was shared. It also aligned with the sense that, through having purposeful actions that stretched their minds, the co-designers acted with togetherness, trust and compassion for each other. The impact of participation in the project provided further evidence of this, when the second Bridgeton co-design group was formed. Initially, the group and social dynamics appeared guarded and difficult to read. Side comments often appeared dismissive or divisive. Initially, this led to concern that the group might not work together in a complementary fashion. However, during the *Stained-glass Coat of Arms* project, change was very evident. On completion of the tasks, it was clear that acting together was an essential part of the design process that in turn, had led to camaraderie.

For this group emphasis on new care provided to one another was particularly evident when a project was completed for one participant (based on her design) by her peers. They took on board her visual design and delivered the physical outcome at a stage when she could not attend.

Supporting each other was also nurtured through the co-design approach relating to prototyping in tasks that required physical contributions by all of the participants, e.g.,

when the cushions were made, smiles, positive conversation and laughter played a significant part in the sessions.

In these examples, the co-designers reinforced each other and provided help to one another when it was needed; providing clear indication of the development of their own creative communities. They became their own inclusive support network with new and common bonds. In this network, they also became empowered to control projects, and to disrupt workshops, to suit their own explorations. Together, they influenced, aided and abetted each other.

These strong empowered positions were also developed with good humour. It became clear that the methods supported these kinds of actions and led to poking fun at the researcher in a way that posited that he was as equally part of the group. Often statements like, "You've got what we've got", showed a dark humour but also one that said, "You are one of us."

This aspect of being an insider with the groups, an accepted member seen as an equal to be challenged, made fun of and sometimes directed in tasks made conducting the research highly enjoyable and very challenging. To remove oneself from being involved with the group as completion of the research drew near was personally challenging. Therefore, it might sound odd to state, but in some ways Covid-19 solved a difficult problem. As an invested member of the groups who felt welcome and part of something special, it was difficult when people involved in the co-design process left or their condition resulted in deterioration of their health and ability to remain involved. In the worst scenario, one member passed away during the time of the investigation. These are the truly difficult aspects of conducting such studies especially when they occur over a longer period of time.

#### **7.5.5 Esteem and empowerment**

This research has aimed to address the development of personal and collective esteem and active empowerment through co-design. This means that the co-designers had to feel

capable of making valued impact within projects and through the development of their work. The many ways that the co-designers were able to display their own capabilities supported this position. Their integration was recognisable through ongoing participation but also, through strong indication that the co-designers developed personal narratives within projects that had shared ownership. Within this co-design approach, people living with dementia proved adept at using design processes and explorations to fulfil their own interests and desires *en route* to creating propositions, designs and services. Through the collected commentaries explored, how such things as the shop and exhibition allowed the co-designers to see the value in their work. Possibly more important, was the way in which the co-designers became increasingly active in projects, willing to offer their views, knowledge and insights. This enriched the processes of participation and allowed the co-designers to feel valued. In particular, this became obvious when narratives of personal histories and experience were shared. These points of view often supported the people living with dementia in presenting themselves as experts, for example, when one participant broke the rules in collaging because she had "done it all my life" or when another shared knowledge and experience of book binding, becoming the teacher of the group and the design researcher in this instance.

In Gordon's scanning service, we learned of a man driven to achieve things for other people and who became empowered to run his own service. Through this project, he had found purpose again and stood up in front of a crowd to talk for the first time in a long time, something his wife found very powerful and that made her proud. Effectively, he took the power he had and made things happen.

Even the simplest of examples that we have seen in this thesis, such as the co-designer fighting to say "I did this" when talking about making cushions, expresses the value the participants found in the projects. It also showed the esteem he, in particular, felt from being able to make the point.

What has been clear throughout the projects is that once trust and understanding was developed, the co-designers became excited about sharing what they knew and

exploring what they could do. Their participation gave them opportunities to express themselves and in doing so, they developed skills and understanding, the results of which displayed empowered decision making and designing. Through the action of designing and the resultant products, services and exhibitions, through to the public experiencing and purchasing their designs ,the sense of personal and collective esteem has been significant.

#### 7.5.6 Impact for Individual Participants

The co-design process appeared to support emotional enjoyment, satisfaction and meaning. It was unfortunate that this could not be examined further through deep discussions in a review method with the co-designers. The commentaries received were indicative of enjoyment and fun but the deeply emotional value probably came through most forcibly in the interviews conducted with Gordon and his wife. Gordon used highly emotive statements, such as occurred when he exclaimed the project had given him his life back. He also regularly shared tears as he talked, which produced very emotional situations that , nevertheless, were positively charged.

What was also evident in the responses was how connected the individuals were to the work they were undertaking and their co-design team. The behaviours of individuals shared a welcoming sense of belonging with the design researcher. In this sense, connectivity and belonging did not exist in a form of subject and researcher but friends working together.

Mood response to the discussions recorded with Gordon and his wife and comments in regards to his scanning lab reflected his eagerness and saw animated conversations in which he enthusiastically talked about what they were achieving. The positive and continuing series of chats in the car on the way home from his time running the lab proved to have lightened his mood and given a real sense of purpose. Another discussion with the wife of one participant who had been involved in making the 75BC collection,

and in the cushions and stained glass projects after that, explained that he had been excited to visit the shop and to see his work on display. Here, purchasing his own creations had been highly important and again, had shown a sense of personal achievement as well as a happiness and eagerness towards the co-design experience which had over-spilled into his private life after the workshops.

#### **7.5.7 Reflections from researcher as participant in co-design research**

In undertaking the research, personal concerns developed around the inclusive nature of co-design and the position of influence this could afford me as a researcher. As a participative researcher, the process required planning, facilitation, involvement in visits and creative actions, responsive reactions to the co-design participants and the development of camaraderie within the co-design practices. As a reflective researcher, there was a need to be impartial, incorporating an ability to separate from the inclusive quality of the projects and the social qualities of being involved in co-design in order to look objectively at what was happening, how and why. Flipping between being intrinsic to projects and then acting as a reflective observer, required practice and often felt complicated. In this approach, personally framed motivations, expectations and a desire to make things work needed to be accepted as influences in the process. Regular reflection on the work undertaken was important to ensure that too much influence was not occurring as the research was conducted.

When conducting this kind of research, it is important to accept that you, the researcher, will be both emic (insider), deeply involved in collaboration, conversation and interaction and then and etic (outsider), dispassionate, detached and looking at the process and its participants as subjects to be interrogated.

### 7.5.8 Pushing back against well-formed opinions and ideas of capability

The initial investigations of this PhD through literature reviews, site visits, network participation and both observation and engagement in care settings, helped to develop a broad understanding of how people with dementia are cared for and where limitations in their ability to shape their own care might exist. Most processes pushed the idea of doing things *for* people living with dementia or, in a kindly way, *to* them. Within these investigations, notable risk aversion occurred and much of the practices seemed to form comfort-based subduing of the people in attendance. Art therapy, music therapy and reminiscence were used to think of the past to placate people, fitting them into weekly closed units of cared for happenings. Connections between things from one week to another didn't appear to be a consideration, although there was obviously considerable programming of these events, facilitations and stimulus.

Much of the supporting documentation, websites and other forms of guidance that was reviewed talked of overarching interventions that treated everybody with dementia as being the same. Guidance on how to communicate with people living with dementia provided by 'deep' (DEEP, 2020) was such an example and indicated how often broad solutions might not be fulfilling. As the early investigations indicated, there was significant scope to question and push back against this kind of received wisdom.

A significant exception to this was the National Dementia Working Group (NDWG) which is a campaigning body of people living with dementia in Scotland. The group is run and constituted by people living with dementia and working on behalf of people living with dementia. This highly progressive and forward-looking organisation revealed how people living with these conditions can help themselves and shape suitable resources for other people. Its approach and views were refreshing and showed a desire to enact and to not be pigeon holed. Both as individuals and as a collective, NDWG has proved the capacity for people living with dementia to be empowered.

Considering what had been witnessed and what NDWG was achieving, the research looked to disrupt normal art-based care practices and to challenge ideas of what forms suitable pastimes for people living with dementia. The work did so with considerable effect and has proven that looking into practices based now, and in the future, can be highly suitable for people who are in the earlier stages of their dementia journeys. The clear capabilities of groups of people working on projects over long periods of time was common within this investigation. It was highly uncommon for projects to require support or recollection between one workshop and the next and the retained knowledge skills and practices often got discussed as new projects started or older ones were re-engaged with. It is thought advisable to have five minutes of discussion at the beginning of each workshop, visit or event but experience was that this was never more than might be expected for any series of workshops. In working regularly with multiple groups and individuals on projects that could span long periods of time (between six to eighteen months), there was evidence that complex ideas and projects could be investigated.

Throughout these projects, prodding at what might be deemed suitable has challenged received wisdom. Simply put, these might be small interventions or practices focussed on individual capabilities, from photography to pinning cushions, working with small delicate pieces or using scissors, but they are the kinds of things that show trust in people and that might reaffirm capability. Some might perceive giving somebody with dementia a digital camera as risky, but it is more than possible to offset any risk with the rewards that were evident in people taking photographs and engaging with exhibitions or visits in a proactive rather than passive manner. These processes reinforced many attributes required in the co-design methods in terms of trust, belief, entitlement and expectation of action between the co-designers and the design researcher. They acted as rewards that built esteem and this was displayed through an eagerness of the co-designers to undertake tasks and their verbal commentaries above.

## 7.5.7 Obstacles and gatekeepers in design with dementia research

### Primary Carers

A large issue when attempting to arrange the initial workshops was stimulating sign-up. It appeared that protective behaviours might be stopping engagement. This was explained by many of the professional caregivers and resource suppliers, as suspicion of the unknown, where a fear of exposure shapes a view of 'best not to bother'. In other words, that people become protective of their loved ones when they are diagnosed with dementia and that any situation that is new and that might challenge daily 'normality' should be avoided. There are many reasons that this occurs but it is often summarised in the view that both carers and people living with dementia have a propensity to withdraw from social settings, interests and new opportunities thanks to a concern of how challenging or unsettling those situations might be (Chapters 2 and 3). Through discussions with expert network facilitator Ruth McCabe, it was suggested that primary carers often decrease participation of people living with dementia due to their perceptions of the capabilities of their loved ones. Here, as gatekeepers, they often act this way to protect their loved ones or to avoid potentially unfortunate behaviour from arising. However, as this work explains, this may also mean that valued stimulation and experiences that have the potential to improve moods and behaviours, wellbeing and self-directed actions, might be bypassed.

### People living with dementia

In experience, people living with dementia can also be restricting their own participation. Here, the lack of confidence or present perspectives of themselves becomes an issue. This work has always intended to empower and reinforce the individual participants' rights to choose, including what feels right for them, what interests them and the right not to get involved.

In some circumstances, people were proposed as great candidates to be involved, however, they had constructed their own perception of their personal limitations and could not negotiate them. Take the example of a gentleman who was a former architect-

designer who thought he had no existing skills. He expressed the view that his thoughts or knowledge were of little consequence and would bring no value to a workshop setting. Here, manifested in one discussion was a clear lack of self-worth, self-belief and confidence.

In the same conversation, it was all too evident that he had been, and still was, a very knowledgeable and talented man. He went on to speak of his wide range of experiences nationally and internationally working on massive projects, such as designing an airport, and reviewing the complications of undertaking such work. It was evident in the discussion that his insight was sharp enough to recall complexity in planning and execution and yet he became hung up on whether or not he had the ability to create artistic outputs. Testing his ability through action became an evidently unsettling proposition. Arguably in this moment, an unexpected contradiction occurred, where the intent to empower and reassert individual capability through design, instead became a debilitating prospect.

That is not to say, that the individual might have developed a greater sense of self-worth and might have been able to connect to his own history through participation. However, his reticence and obvious discomfort became something that could not, and should not, be forced.

The conversation had an unfortunate reality in that his actions and thought process or deduction and reasoning during this discussion showed a distinct ability to recognise and organise relevant experience. His understanding of design processes had him already thinking about the end point or solution before engaging with any task, which made him fear his ability to contribute meaningfully. This high-level thinking provided evidence that leads towards what Paul Dolan expresses as:

*"Making predictions of what the production process will look like: what you will attend to, in what ways and for how long."*

(Dolan, 2015; p.104)

By doing, so he was inadvertently showing a sense of self, an understanding of valuable past experiences and a position of judgement, all of which could inform a collaborative process of design thought and action.

Ethically it was important to recognise that no matter how valuable his participation might have been (for all parties involved), the individual's comfort and safety had to be paramount.

## Organisations

Any invitation to take part in the study has been directed at individuals who had been diagnosed with dementia although it had also required secondary sign-off by somebody responsible for that person's wellbeing. This contradicts issues in regards to individual rights but also explains where institutional behaviour becomes another form of gatekeeping, from project ethical approval by Lancaster University through to the organisational approval from Alzheimer Scotland. Behaviours which are risk averse have the potential to over-rule the right of the individual to take part in opportunities or to undertake tasks. In particular, this can appear a route to increasing a perception of incapability of the person who has dementia and arguably, goes against their rights as laid out in such political documents as the 'Charter of Rights for People with Dementia and their Carers in Scotland' (Oldfather, 2009) where it states a key principle is "*respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*".

This form of gatekeeping might restrict behaviours, actions and intentions of co-design projects such as this one but keeps the organisations protected and as such, becomes one to which it is necessary to adhere.

## 7.6 A Framework for Developing Co-design Projects

The following framework has been developed to support people interested in undertaking co-design projects with people living with dementia. It incorporates how the insights and analysis generated throughout this research might be applied to the development of new projects for researchers in the field.

<p><b>6 Rules for engaging in co-design with people who are living with dementia</b></p>	<p><b>Intellect</b></p> <ol style="list-style-type: none"> <li>1. People living with dementia should be treated and communicated with as an equal. You should learn from them and let them surprise you</li> <li>2. People living with dementia are capable of great things</li> <li>3. People living with dementia can set agendas, shape and re-form projects</li> <li>4. Listen and act upon insights proffered by co-designers</li> </ol>	<p><b>Connected</b></p> <ol style="list-style-type: none"> <li>5. Build relationships to build trust</li> <li>6. Let the group learn from one another to develop working relationships</li> <li>7. Allow space and time for creative relationships and practices to grow</li> <li>8. Encourage lots of discussion, fun and collaboration</li> </ol>	<p><b>Empowered</b></p> <ol style="list-style-type: none"> <li>9. Provide tools and techniques that are accessible and usable for all</li> <li>10. Be flexible with approaches providing diversity and adaptability</li> <li>11. Let the co-designers run with their ideas</li> <li>12. People living with dementia will use their capabilities to think around ideas and opportunities</li> </ol>	<p><b>Valued</b></p> <ol style="list-style-type: none"> <li>13. People living with dementia are capable of great things</li> <li>14. Everyone should be valued, respected and treated with dignity</li> <li>15. Design workshops with people living with dementia should provide learning opportunities</li> <li>16. The actions you undertake are likely to resonate for longer than you think</li> </ol>	<p><b>More in-depth</b></p> <p><b>Intellect</b></p> <p><b>Connected</b></p> <p><b>Empowered</b></p> <p><b>Valued</b></p> <p><b>Knowledge</b></p> <p><b>Adaptable</b></p>
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Recommendations: A Guide for Undertaking Co-design with Dementia		More in-depth guidance when working with people living with dementia			
6 Rules for engaging in co-design with people who are living with dementia					
<b>Intellect</b>		<b>Intellect</b>			
1. People living with dementia should be treated and communicated with as an equal. You should learn from them and let them surprise you		Capabilities	You should enter into design research with people living with dementia, with the knowledge that you will be regularly surprised by what people are capable of. You must be willingly dynamic in your practice and research agenda and humble enough to work with people rather than dictate to them. You will be given powerful contributions by the people you are working with if you respect their history and experience. Do not be restricted by what you think you know or understand in relation to dementia. As often as possible put the power into the hands of the people you are working with and do not refrain from tasks that might be complicated, the PLWD are capable but they might just need turned into accessible units of investigation.		
2. People living with dementia are capable of great things		Communication	People living with dementia should be talked to, not around. Talk to the person and not their support team, you are there to find interest in them as a human being and they must be treated with this respect. Ask them for their permission, for them to take part in a study/workshop, allow them to say how they feel and if they desire to be involved. Respect the person with dementia, there is no need for you to emphasise their condition in your discussions, this might set a sense of differentiation or otherliness and unless it is central to your investigation it is unlikely to matter within the collaboration. If the participant wishes to talk about them and their dementia or the condition as a whole, that is fine. It is highly likely you will be informed of their situation by the participant co-designer respect this and engage them appropriately for the situation at hand.		
3. People living with dementia can set agendas, shape and re-form projects			The language used during sessions should be uncomplicated and should avoid design specific terms but should never talk down to people living with dementia. If an unknown term is questioned by the co-designers discuss it with them and find ways of making the concepts accessible.		
4. Listen and act upon insights proffered by co-designers		Knowledge	Thinking, memory and knowledge should be made use of as much as possible. People living with dementia want to feel that what they have to offer in terms of experience and knowledge are valued and can be made use of. Asking questions of people and asking them to question situations, scenarios or problems is good. The answers might not always flow freely and they may get frustrated by this but be open and supportive through the soft skills that you have developed. Read the situation and be ready to step back if required. However, using their memories, valuing their knowledge and asking for their opinions is beneficial within the design project context and to them as co-designers.		
<b>Connected</b>					
5. Build relationships to build trust		Adaptable	People living with dementia can shape and re-form projects.		
6. Let the group learn from one another to develop working relationships					
7. Allow space and time for creative relationships and practices to grow					
8. Encourage lots of discussion, fun and collaboration					
<b>Empowered</b>					
9. Provide tools and techniques that are accessible and usable for all					
10. Be flexible with approaches providing diversity and adaptability					
11. Let the co-designers run with their ideas					
12. People living with dementia will use their capabilities to think around ideas and opportunities					
<b>Valued</b>					
13. People living with dementia are capable of great things					
14. Everyone should be valued, respected and treated with dignity					
15. Design workshops with people living with dementia should provide learning opportunities					
16. The actions you undertake are likely to resonate for longer than you think					
				Serendipity can play a large role in the co-design of a project when working with people living with dementia. You need to be agile and ready to adapt to the emerging situation. What you think should happen has to be open to change in order to support independence and project ownership by the people you are working with. Ultimately you want to get to a position where you no longer see distinction of ownership in the collaborative process, you will even feel as though you have relinquished control. Confusion and conflict are likely to occur as project directions and outcomes develop, particularly in these unexpected situations rather than fight against them. They are likely to be much closer in alignment with your co-designer's wishes and project agendas. If a project or practice re-forms into something different to its original intention it is because of your process and its successful uptake, as opposed to any failure.	
		Insight	People living with dementia can set agendas, so where relevant support the people you are working with to give you ideas and potential briefs. These are likely to resonate with the people you are working with, as they may come from their views, opinions or desires. Be open to the approach and suggest and think in ways that allow these things to be opened up.		
		Connected	Relationships	Build relationships to develop trust and to encourage togetherness. Do not be stranger or distant, consider your position as one of an outsider being invited into a private group. You are a guest and over time you are likely to be seen as a welcome visitor or even, to a degree, a friend. Be human, warm and considerate, be positive and ebullient and feel genuine with the people you are working with. Have humour and humility, you are likely to be poked and prodded in the manner that you might be by friends. Acceptance or indeed integration to a group is what will make you a collaborator in the eyes of the people you are working with.	
		Respect	Everyone should be valued, respected and treated with dignity. Diversity within any collaborative group is very likely, different backgrounds, financial security and cultural identities are likely to form the selection of people you are working with. You are likely to be surprised by what you learn about yourself and your own histories. Particularly what people have been capable of because this forms part of the personal identity make-up which is so important to the individual. Each of them has a unique set of experience and knowledge to draw upon which is finite, material; parcels of information become triggered by co-design projects and can be openly even informing what happens next or an individual's position of authority for a short period of time. Remember everybody has something to offer and that they are all likely to take something positive from your engagement.		
				During projects you might experience a difficult episode, understand that this is likely to be a normal part of the process.	

	individual involved may need to break-away for a minute or even longer. They may even go off to do something else. Try to encourage them to stay involved but also be keen to let them do something else if required.		In learning new ways of working, adapt, let go of people you no longer may have a place in, do with what is likely to be your passion, like, as you support the people these have roles they
No-judgement	<p>Do not make judgements about people, learn from them</p> <p>It is a challenge not to judge from your own perceptions and experiences or from learned expectations, the people you are working with are likely to change your outlook. Often their involvement in a process and their humanity in doing so will lead to unexpected revelations. Skills may emerge, knowledge may be provided, guidance will be given or alternative ways of doing things might be directed by the co-design participants. Their dementia may interrupt the communication or practice of what is being learned by you the researcher directly from them but through open and accepting communication and a little interpretation you will likely have your own experience, knowledge and skillset expanded.</p>		<p><b>Valued</b></p> <p>Resonance</p> <p>The actions you undertake in the practice of working with dementia are clear that certain approaches are effective. These feelings and memories are important. Equally the relationships between the researcher and the person with dementia can be long lasting. Research in dementia is a long-term endeavour. The researcher should be clear about their expectation and desire for the person with dementia to have significant periods of time to explore.</p>
Space and time	<p>Allow space and time</p> <p>Things can slow down in 'dementia-time' (Rodgers. 2017, Winton and Rodgers 2018) tasks will take a little bit longer but remember you are going to be working with people who are highly unlikely to be design literate or used to creating things. You will be teaching them new ideas and skills as you undertake collaborative design research-practices. These will take time to understand, time to learn and time to use. Do not rush with the expectancy of somebody with experience in these acts. Allow time, see what is working and understand what is difficult, support without taking on responsibility and become a tool of your collaborators. You might have to be somebody who is directed to undertake supportive tasks by the people you are working with. This obviously helps to have a team involved in the facilitation rather than you as the sole practitioner.</p> <p>Dementia-time does not solely respond to action or practice-based work but also to the discussions of project subject matter. It is common that people with dementia may not find the words to express themselves quickly or succinctly, take time to hear what is being communicated and to respond to those comments. You may feel compelled to finish peoples sentences for them but when possible try let people complete what they are saying as this reinforces their capacity to express their sentiments and thinking.</p>		<p>Appreciated</p> <p>Engaging with the real world environments can be beneficial. Environments can also be used to reveal interests and to reveal what people like. Use cameras and give tasks to people to generate and gather data. Support the whole design process and encourage exploration.</p> <p>Through showing trust and respect that they will willingly get involved.</p>
	<b>Empowered</b>	<b>Time</b>	
Prowess	<p>The actions they connect with and complete are likely to last.</p> <p>The acts of doing design involve a plethora of endeavours, acts, conversations, tasks, diversions and disruptions all informed and delivered by the co-designers. In making connections between workshops and the tasks people living with dementia will start to provide their own interpretations and meanings. These will be informed by their own history and being able to act on the skills and knowledge they have will underpin their capability.</p>	Project Duration	<p>The insights supplied will come from projects over six years.</p> <p>Co-design projects can be long-term. Some projects may even span decades. Each project should have set stages. Participation is evolving throughout a project.</p> <p>Although projects might be important for the participants, it is the process that is important. Therefore, identifying the role of the co-designers is important. This involves reflection and celebrating the process.</p>

<p>if doing things they will make connections between themselves and the opportunities or influences within a be seen as the fine details that will give real value to Be feeling empowered to act other aspects of self-e will become apparent through creative actions.</p>	Wc Du
<p>take are likely to resonate for longer than you think</p> <p>ing with people living with dementia it can become approaches have resonance and can stimulate good s that continue long after the completion of a task. o you build up can mean that your value within the asting and wilfully called upon for more. Designing s therefore likely to have no particular end and the open to long relationships and the development of e for the collaborations to exist and develop over imie.</p>	Prc
<p>-world should be embraced</p> <p>the real world together, being outside or in new beneficial for health and well-being. External be rich places to generate group focus, to develop participant's personal insights. By all means hand out s that encourage the co-design participants to ata for them to use in later workshops or tasks. sign process from inspiration through to actualisation ative new ways of seeing things.</p>	Fac
<p>in and appreciation of the co-designers, it is likely get involved.</p>	Ap
<p>within this guidance were developed from a series of in that time 15 projects occurred.</p> <p>an be quite open and might not have a definitive end.olve into opportunities for new projects to developuld follow a design model which contains a series of n within the stages should be open and inclusive,nd responding to the achievements being made.</p>	
<p>ht occur over a period of weeks, months or years, it is cipation to develop meaningful designed outcomes. what is an acceptable project end-point with the co-. These end-points provide succinct points for ion upon what has been achieved.</p>	

workshop rations	<p>Designing with people living with dementia should be limited to 1.5hr workshops 2.5hr visits at any one time.</p> <p>Concentration in prolonged activities is difficult never-mind when it is somebody who is living with dementia. Too much in any one sitting can be tiresome for the co-designers (participants), can lead to disinterest and can overwhelm leading to a sense of stress or disappointment. Prepare to work to the time and not the task. If a task has to be returned to or re-visited, that is ok. Remember, the intention is an enjoyable and digestible achievement. At the end of each workshop or activity summarise what has been done at the end of the session informing the group what you have viewed as positive. Ask their thoughts, understand what they are saying and agree the next step together. If, for example, that is the continuation of a task, start the next session by reintroducing the task, why they were doing it and how far they got, then continue. Remember the intention is enjoyable achievement summarise what has been done at the end of each session and reinforce the positive. Ask their thoughts and agree the next step together.</p>
ject pace	<p>Designing with people living with dementia should be given time.</p> <p>To allow for real evolution and project development time must be given to every aspect of the design process. Viewed as a journey with highlights, landmarks, deviations and rest periods the process should allow and embrace change, with this in mind the tempo and delivery of workshops, visits, investigations, actions, thinking-time and discussions will vary but is likely to take time. Action periods might be intense and happen over a number of consecutive days or weeks, time is also needed to reflect on what has been done and what might happen next to allow for periods of inaction. Remember what you have is a relationship that needs to be nurtured and valued. Too much in a short period of time reduces the likely commitment by all parties to a prolonged and continuous relationship.</p>
cilitation proaches	<p>Tools should be accessible and usable for all drawing might be seen as a barrier so it is not necessarily a good method. People tend to announce that they can't draw and see this as a skill they will never master. As such using it as part of the design processes might be exclusionary.</p> <p>Design tools and processes should be understandable and should avoid unnecessary complexity, for example, computing technology may at times be more of a hinderance than a support, whereas tactile making process such as collaging can be instantly undertaken. Simple methods focus the approach on what is being communicated and assembled over the method in which it is achieved. Think about risks and how to negate them e.g. scissors. It is often suggested that you shouldn't give people living with dementia scissors - experience however, suggests that people know how to use them and merely need guidance and supporting eyesight to ensure successful operation. Supervision and support here is key.</p>

Figure 7.7 Recommendations: A Guide for Undertaking Co-design with Dementia

## 7.7 Summary

The study has provided rich co-design project-led experiences which have allowed for the generation of insights which were rewarding for this study but that also provide valuable guidance and lead to recommendations for future studies which will be provided in the concluding chapter.

Through analysis, the evolution of the fifteen projects has shown a progressive, reflective development which enriched each project that followed another. Produced as recognising a progressive design process with various steps, each project has been open to evaluation in terms of participation and ownership which has been aligned to the 'Co-design Participatory Power Pyramid'. This has supported valuable ways of understanding to what extent co-design has been achieved within this investigation.

The discussion occurring throughout this chapter has revealed capabilities, practices, meaningfulness and value but has also been supported with an understanding of things that have to be addressed in producing such work. Included in this discussion is the need for overcoming hesitancy and protectionist behaviours of organisations and individuals that might reduce opportunities for people living with dementia.

The review also allows for understanding that this kind of project takes considerable time and personal involvement by the researcher who will act as both insider and outsider to groups and tasks. The personal engagement in undertaking such projects is considerable and should be recognised.

What follows in the concluding chapter are summaries of the key learning from this PhD investigation and how these have resulted in contributions to knowledge.

It will also set-out new opportunities for continued studies.

## Chapter 8: Conclusions and Future Work

This chapter explains who this work has benefitted and how it will support future explorations in the area of co-design and dementia with a particular focus on people with early onset dementia. In doing so, it presents the contributions that this work makes to the field and explains what has been valuable throughout the investigation. It looks again at the research questions to identify how these have been addressed and finishes with future propositions in development of this work.

Through investigating co-design as a meaningful integrated medium-to-long term process for working with people, this PhD has explored what is meant by co-design and how it can be evaluated in terms of inclusivity. The process has engaged people living with dementia in a co-design approach that demands participation throughout the design journey from conception to completion. Evaluation of the various stages involved throughout the design process supports inclusivity whilst demanding that people living with dementia provide valued contributions. Through independent and collective actions, the evidence has shared what people living with dementia can contribute and achieve despite their diagnosis. By mapping participation to recognised design stages, the participation can become enduring, purposeful and results-focussed. In this case, meaning that results are tangible or useable designs and services.

At the heart of this study has been a view that; *“people living with dementia should be encouraged to make decisions or partake in decisions that affect them and the ways in which they pro-actively live for as long as possible, to maintain their dignity and self-esteem”* (Winton and Rodgers, 2019). Co-design has reaffirmed the belief in themselves to act with insight, meaning and purpose and it is hoped that this has echoed into other aspects of their lives. The following conclusions and recommendations support views upon this theme and give insight as to how this has occurred.

## 8.1 Conclusions

This work has developed ways of considering to what extent the collaborative aspect of co-design can be successful, when working with people living with dementia. The integration of the co-designers in every stage of the process has identified ways of making them informed and formidable collaborators. Invested to act throughout the duration of a project through their thinking, proposing and acting, the co-designers proved themselves adept at providing, developing and utilising rich content. The act of running projects which are highly inclusive has been fundamental to the research. However, it also looked to find ways of using design as a tool for empowering people through their own involvement and actions. The approach encouraged personal exploration and discovery of, and development of, friendships or camaraderie which formed supportive communities of creative practice. The results achieved group-led design projects that in varying ways displayed co-design group's ownership. Termed within the study as 'by' the co-designers these projects express their ability to adapt to opportunities to develop them and to turn them into what they viewed as suitable solutions or designs.

By the nature of this kind of working, the participants have expressed the ability to deliver richly detailed and highly considered designs that became marketable. These formed expressions of their prowess particularly demonstrated in the delivery of desirable tangible objects that the public purchased. In other cases, the provision of services extoled the capability of somebody living with dementia to affect change and to make things happen.

These clearly express ways in which design, and co-design in particular, was able to enrich the lives of participants, carers, support workers and wider aspects of society.

The fifteen projects presented here show how the co-design methods and tools used can enable people living with early onset dementia to make a significant contribution to society after diagnosis. Specifically, this work has shown how design thought and action can contribute to changing the perception of dementia showing that personhood

remains. Moreover, the fifteen co-design projects have helped reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and keep the person with dementia connected to their local community. The widespread assumption that people living with dementia cannot take part in mainstream activities, and that they have no quality of life or capacity for pleasure and positive involvement, has been dismantled by this work. Along with expressing their abilities to do stuff and most importantly to do stuff that society has appreciated, the evidence suggests that as part of their involvement the co-designers found ways in which to connect with their own identities, values and experiences. This provided them with a reconnection to their personal esteem and dignity and allowed them to be identified as capable of influencing their own lived experiences.

In these projects, people with early onset dementia have reframed themselves, projecting new self-belief and expressing a desire to show the world that they can do so much more than what is expected of them. The method by which they might achieve some of their goals is likely to be more complex, adaptive and deviational than a trained designer's processes but this is not always a bad thing. In these projects, people living with dementia have set the standards, changed their expectations and driven desired solutions because the belief in their capacity to do so was shared with them. From outlining new ideas for social ventures to creating networks and workshops for collaboration, the tools developed for and with them, afforded the chance to still make valuable changes to the world in which they live. Being the drivers of ideas that lead to shared practices and goals became possible because the tools were made accessible to them. The value in which the projects outcomes are best measured are in the commentaries of the participants and the actions that they have displayed. If empowerment is embodied in the narratives that people share of themselves and their actions, which are underlined by their own beliefs, then the most significant aspect of this work is how people changed the opinions about themselves.

In terms of producing new ways of providing support and care, primary and professional caregivers have recognised that these design projects have developed new ways of engaging with and empowering people living with dementia. They have provided scenario-based opportunities for medium-to-long-term practices that have allowed new ways of connecting cultural engagements. The design-based approaches have provided valued outcomes whilst sharing ways of developing positive lived experiences in a care resource setting. The work has been lauded within Alzheimer Scotland and provided inspiration for continued practices. It has also allowed the participants to develop their own funding to support ongoing design-led initiatives at the Bridgeton Resource Centre.

The investigation and resultant fifteen projects clearly explain the opportunities that co-design can provide to people living with dementia. It defines how the practices can enhance lived experiences. Most importantly, it proves that working through codesign with people living with dementia is highly suitable, versatile, responsive and valued in the provision of medium-to-long-term care. This should be noted as being part of a blended multidisciplinary approach to care, as expressed in Chapter 1, and expresses a powerful example of how design, and in particular co-design, can provide highly positive additions to the care and support of people living with early to moderate stages of dementia.

## **8.2 Contributions to Knowledge**

The primary contribution to knowledge in this work is concerned with undertaking long term co-design with people with early on-set dementia and who have mild to moderate conditions.

Within this context the research makes the following contributions to knowledge:

- 1. The work maps co-design activities to the product design process to evaluate collaboration and capability with people living with early-to-moderate stages of early onset dementia in a new way. This will help co-designers plan better more engaging projects.**

Much of this is explored in Chapters 3, 4, 6 and 7 but responds to a solution that identifies activities as belonging to groups themed as:

- **Proposal**
- **Research**
- **Concept Design**
- **Evaluation**
- **Design Development**
- **Testing and Production**

Where the co-designers engaged with workshops and tasks under these themed groupings (stages) as long as the project supported or required the fulfilment of those stages, through being integral at each stage, with the co-designers being embedded in tasks and practices, a true collaboration has the potential to occur. It then becomes a matter of the extent to which the co-designers are directed and are instrumental in collaboration in idea generation or shaping processes, or in the most empowered way, fundamental to activities, directing practices, setting goals and independently acting.

By mapping participatory and collaborative activities of the co-designers to Rodgers and Milton's (2011) model of the 'product design process', an understanding of how to fully form collaboration within the process could be achieved.

2. The 'Co-design Participatory Power Pyramid'. This tool can be used for reviewing where co-design occurs within a view of design done 'to', 'for', 'with' and 'by' which indicates the level of participation in a design project and the extent to which it moves beyond initial consultation at the inception of a project.

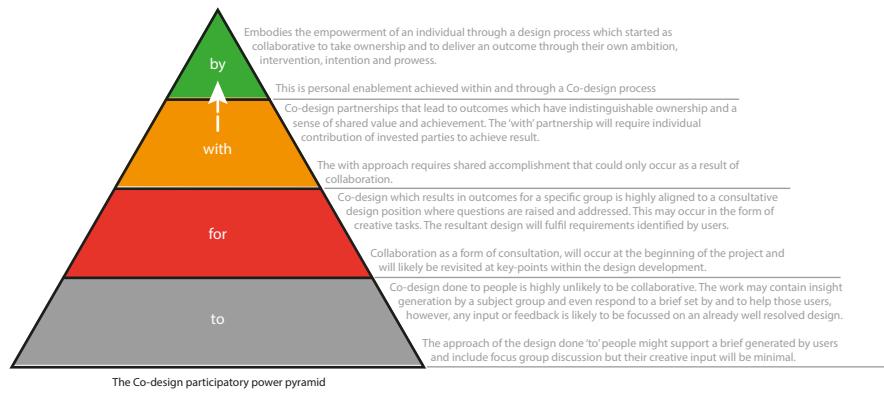


Figure 8.1 Co-design Participatory Power Pyramid

First introduced as an evaluation tool in the Literature Review (Chapter 3), the 'Co-design Participatory Power Pyramid' was devised in order to understand the differing kinds and extent of what co-design projects in the area of dementia appeared to be doing and achieving. This was required as many authors talk of co-design but the depth of collaboration can vary greatly. In Chapter 7 'Results, Analysis and Discussion', how the tool was influenced by existing theories was posed. This explanation was provided to understand how this tool plots the relationship of co-design in practice explored in Chapter 3 and theoretical propositions and how the results of the fifteen projects contained within this study could be measured and understood.

The 'Co-design Participatory Power Pyramid', when linked to the mapping of co-design as outlined above, allows for frameworks that support an understanding of depth of collaboration. In key, these are identified as design done 'to', 'for', 'with' and 'by' where 'by' represents the highest level of minimally-supported and undirected actions by co-design participants. This provides a sense of learning applied, capacity to act, capability to deliver design solutions. It suggests a transference of knowledge and skills that remove the expertise of design from the design research into the empowered hands of the co-designers.

3. Co-design extends value beyond contemporary conventional therapy as a means for long-term purposeful and impactful approaches when working with people living with early-to-moderate stages of early onset dementia.

In the development of this study, much art therapy was observed in terms of tasks or activities provided as stand-alone time fillers. The acts appeared to generate good humour and provided instant personal achievement. The projects were highly directed and on completion, served little to no longer-term purpose. Where the projects were displayed, *i.e.*, within the spaces that people living with dementia attended, the results were appreciated for a week or two before being replaced.

Through co-design the creative activities became staged points within bigger connected projects, often completing a cycle at one stage before entering another design cycle later on, *e.g.*, 75BC fabrics and their associated design, products and exhibition. Each project might last weeks or months and were imbued with connection to past or future visits, explorations, information gathering or creative endeavours. They involved learning new process and exploring materials along with manufacturing techniques and therefore demanded thinking, action, further thought, application of ideas and much more. By forming medium-to-long term integrated pathways, the evidence supports co-design as achieving more than art-therapy had done for the participants and this was especially evident in the production of goods sold to the public and providing income to support the groups future activities.

4. The framework in how to undertake medium-to-long-term co-design with people living with dementia. Presented in the previous chapter, the framework was derived from the research, and undertaking co-design investigations. This can be used to stimulate and frame new research projects in the field (Figure 7.7)

### 8.3 Summary of Addressing the Research Questions

- Throughout this thesis explanation of actions, participation and value have illustrated how the socially imbued co-design practices have undertaken developed creative capabilities of people living with dementia. These have proven through the involvement of others, the generation of new products and services and the testimony of carers and participants to support individual personality, individuality and efficacy.
- The benefits for people living with dementia have been in areas of camaraderie and self-esteem along with unexpected levels of personal empowerment within projects. Through testimony the evidence also supports that the individuals along with their primary carers and private caregivers have reported improved mood and belief which has stimulated enriched conversation and sense of purpose as a result of working in a design-led manner.
- The practices explained as design skills and design processes have afforded people living with dementia to be decision makers and drivers of projects where they have shaped ideas from inception to completion. As a result, there have been regular presentations of identity and capability resulting in individual and shared ownership, belief in their own creative prowess and empowerment to inform scenarios.
- Throughout this research practice there have been consistent approaches to shaping ways in which co-design provide creative relationships which provide high levels of cognitive stimulation, encourages action and requires creative participation. Through the design process, which has been presented as a series of platforms for collaboration, this research has shown how designers and people

living with dementia work together for holistic engagement that was equally beneficial to all parties involved.

- Through fifteen design projects, that represent long-term collaborative relationships, people living with dementia have achieved wonderful things. They have generated research. Shaped their own research into feasible products, services and solutions. These have been accessed by the public in the form of purchasable goods, exhibitions and interactions. These views have been apparent in the collected views of people visiting the shop and exhibition spaces along with accounts provided by people living with dementia themselves. These views have challenged ideas around capability and preconceptions about cognitive capacity surrounding people living with dementia. The results have been the formulation of appropriate methods of developing design-led care practices which include people living with dementia to the fullest possible mental and physical extent.

## 8.4 Future Work

### Kirrie Connections Collaboration

In regards to the continuation of work developed within this research and in response to the COVID-19 situation, new networks of collaborators are already being spoken to. As such, a proposal for a project to work with a new partner centre in Kirriemuir, Scotland, has been made and the proposition will look to develop the co-design practices undertaken in this research through face-to-face interaction and creative collaboration. The approach from Kirrie Connections suggest that the work discussed within this thesis appears to be well suited to augmenting the services, resources and methods for engaging with people living with dementia to make a telling contribution in the future and to rebuild opportunities to socially connect post pandemic.

### **Funded further services delivery - distance based**

If future funding was sought for continuation of the study, a response to the pandemic would be explored in particular, how to future-proof the modes of co-design care that were demonstrated throughout this work. The aim would be to provide service-driven process that blended online and offline systems. The key task would be to provide courses in which widely spread groups could be formed and that would create alternative respite care under similar conditions to those we have experienced for the last eighteen months.

### **Further co-design with dementia - presence based**

Important for the project was the presence-based participation in the co-design process. Being with one another allowed for dynamic connections to occur. The uptake of the projects, actions and collective disruption by the participants was highly symbolic of Greenfield (2011) and Fredrickson's (2013) intense moments of connection and shared understanding. Unfortunately, the Covid-19 pandemic disrupted the influence of this aspect of the project. As such, under the reconstitution of services and presence-based opportunities further exploration as to motivations and depth of connectivity would deserve further investigation.

### **Co-design paper - 'Co-design Participatory Power Pyramid'**

A final expectation from this work will be to produce a paper based upon the 'Co-design Participatory Power Pyramid' devised for this project. It is thought that this holds important value in the field of design for dementia but that much of the co-design discussion might also have broader value.

### **Collaboration with Neurological Specialists Centering on the Effects of Co-design**

The final aspect of this work that could offer interesting opportunities for future funding would involve working with neurologists to see how the creative practices have stimulated

the brain of people living with dementia. In researching this work, I came across a number of specialists who suggested that creativity builds new use of underutilised parts of the brain, triggers new neurological pathways and stimulates the creation of new memory in different aspects of the brain. In this work, there were a few instances of new, lasting memories being formed and high degrees of recollection of detail and values triggered by the design activities. The results were never analysed under this context and would need to be part of a collaborative venture featuring medical testing but could provide an interesting basis for future research.

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## Appendices

Empowering People Living with Dementia Through Designing

By Euan Winton

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## **Appendix 1. Ethical Approval**

The following content was submitted for ethical approval as part of standard practices at Lancaster University in the Faculty of Arts and Social Sciences.

### **Appendix 1: Ethical Approval**

#### **Appendix 1.2 Ethics Forms Updates**

**Faculty of Arts and Social Sciences and Management School Research Ethics  
Committee (FASS-LUMS REC)  
Lancaster University**

***Application for Ethical Approval for Research – General Guidance***

**Instructions** [for additional advice on completing this form, hover PC mouse over 'guidance']

**A. How to apply to the committee:**

The FASS-LUMS REC forms should be used for **all projects by staff and research students, whether funded or not, which have not been reviewed by any external research ethics committee**. If your project is or has been reviewed by another committee (e.g. from another University), please contact the FASS-LUMS research ethics officer for further guidance.

In addition to the completed form, you need to submit **research materials of direct relevance to your application** such as (but not limited to):

- i. Advertising materials (posters, e-mails)
- ii. Letters/emails of invitation to participate
- iii. Participant information sheets
- iv. Consent forms
- v. Questionnaires, surveys, demographic sheets
- vi. Interview schedules, interview question guides, focus group scripts
- vii. Debriefing sheets, resource lists

For all sections of the form, be specific but concise in the information you provide. The reviewers are academics from the different departments in FASS and LUMS. They will not necessarily be from your subject area or discipline, so make sure to avoid subject-specific terminology and be as clear as you can.

**For all applications you need to:**

Submit the FASS-LUMS REC application form and any relevant materials listed under A by email to [fass.lumsethics@lancaster.ac.uk](mailto:fass.lumsethics@lancaster.ac.uk) as a **SINGLE** attachment preferably in Word format. *If this is not possible submit the documents in a single PDF. Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing show markup>balloons>show all revisions in line.*

You can submit applications at any time.

Projects involving existing documents/data only or the evaluation of an existing project with no direct contact with human participants will be dealt with via chair's action.

All projects involving human participants will be reviewed by at least two reviewers. A lead reviewer will be appointed from the FASS-LUMS REC who will be responsible for providing comments and feedback to applicants. The lead reviewer may contact you for any clarification of your application if needed.

Depending on the project and the ethical issues it raises, your application may be discussed by the full FASS-LUMS REC at their monthly meetings and as applicant you may be asked to attend this meeting. We will contact you if your application will be discussed at the committee meeting. Please ensure you are available to attend the committee meeting on the day that your application is considered, if required to do so.

Committee meeting dates are listed on the [FASS-LUMS REC website](#).

**Projects involving social media and participants recruited or identified through the internet require full consideration by the FASS-LUMS REC.** This is in particular the case if the understanding of privacy in these settings is contentious or where sensitive issues are discussed and where quotes and visual images the researcher intends to use may be identifiable. For example, as part of your study you may be using data from an online context that is publicly available. But this does not mean that the participants/members of this context also perceive it to be public. Any study involving online interviews, online ethnography or any other use of data from private or semi-private internet sources is considered to involve contact with human participants and therefore needs a full ethics review.

## **B. What level of review is required for my project?**

In order to help the committee decide what level of review your project requires, please consider question 1 below, points a-i.

### **1. Does your research project involve any of the following?**

- a. Human participants (including all types of interviews, questionnaires, focus groups, records relating to humans, use of internet or other secondary data, observation etc)
- b. Animals - the term animals shall be taken to include any non-human vertebrates, cephalopods or decapod crustaceans.
- c. Risk to members of the research team e.g. lone working, travel to areas where researchers may be at risk, risk of emotional distress
- d. Human cells or tissues other than those established in laboratory cultures
- e. Risk to the environment
- f. Conflict of interest
- g. Research or a funding source that could be considered controversial
- h. Social media and/or data from internet sources that could be considered private
- i. Any other ethical considerations

**If the answer to question 1 above is:**

**Yes** - complete Section 1,3 and 4

**FASS-LUMS RESEARCH ETHICS APPLICATION FORM**

**SECTION ONE [Must be completed by all applicants]**

**Title of Project:** Designed With Me –

How can design empower people living with dementia to transform local communities?

**Name of applicant/researcher:** Euan Michael Martin Winton

**ACP ID number (if applicable)\*:** 31921265  
Doctoral Award

**Funding source (if applicable)** AHRC Collaborative

**Grant code:** AH/M007677/1

**Type of study**

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, two and four of this form**

Includes *direct* involvement by human subjects (including but not limited to interviews, completing questionnaires, social media and other internet based research). **Complete sections one, three and four of this form**

**1. Appointment/position held by applicant and Department within FASS or LUMS** PhD Student**2. Contact information for applicant:**

**E-mail:** e.winton@lancaster.ac.uk  
you can be contacted at short notice)

**Telephone:** 07725020003 (please give a number on which

**University Address:** Imagination Lancaster, Lancaster University, LICA Building, Bailrig Lancaster, LA1 4YW

**3. Names and appointments/position of all members of the research team**

Euan Winton  
Professor Paul Rodgers, Imagination, Lancaster University, LICA  
Dr Emmanuel Tsekeveles, Imagination, Lancaster University, LICA

**3. If this is a research student project, please indicate what type of project by marking the relevant box:**

Masters by research  PhD

**4. Project supervisor(s):** Professor Paul Rodgers and Dr Emmanuel Tsekeveles

## SECTION THREE

**Complete this section if your project includes *direct* involvement by human subjects**

**NOTE:** In addition to completing this form you must submit all supporting materials (see general guidance on page 1 of this form).

1. Summary of research in lay terms, including aims (maximum length 150 words):

The aim of this project is that through design activity focussed workshops intergenerational co-design will occur, which involves people aged 18-25 years of age and people who have a diagnosis of dementia (undetermined age) working together. The purpose of the approach is to explore how design activities can support intergenerational relationships that are mutually beneficial and that might lead to positive societal impact. The societal impact will be documented and reviewed through the development, application and production of design outputs shared in local community settings. An objective of the project is to reveal ways of working through intergenerational co-design that highlights and values the skills and knowledge that participants possess. The approach anticipates outcomes that demonstrate design as social activity where new intergenerational understanding can lead to insightful societal change. Here designed outcomes will suggest new ways of considering the creative prowess of less centralised citizens in affecting local change.

2. Anticipated project dates (month and year only)

Start date: 03/17 End date 03/19

3. Please describe briefly the intended human participants (including number, age, gender, and any other relevant characteristics):

Participants will be invited to take part from three main demographics, however, a subsidiary group have the choice to play a proactive role and supporting facilitators may be required:

- 1) Young People aged between 18 and 25 years old. The project is non-gender specific.
- 2) People with a diagnosis of dementia with a recognisable degree of independence. There are no age or gender specific criteria.
- 3) Care workers, primary care givers or other support members. There are no age or gender specific criteria.

4. Are members of the public involved in a research capacity, for example as data collector (e.g. participatory research) and if so, do you anticipate any ethical issues resulting from this?

The ethical issues resulting from this project will largely be to do with photographing or audio recording the results of the project outcomes and personal commentaries gathered during the process (particular discussion of this occurs in section 6).

To the most practicable the following approaches will be adhered to in the fullest.

## Personal data

The only personal information gathered will be the first name of participants. The name is to identify people in recordings of discussions and will be held within the data collected. For dissemination of outcomes and discussion of project methods, application and influence each participant's name will be anonymised.

#### Knowledge of the participants as to what and how the generated data will be used

Through 'Participation Information Documents' (submitted here) the Participants will be fully informed of the expectations of the researcher as to how data will be generated and collected.

The decision to participate is that of the participant, as such they are invited to take part in this research and the choice to be involved is of the individual.

#### Activities

The activities, though design focussed, are of the type commonly experienced by anyone openly partaking in a Dementia drop-in facility. Craft making, discussion, thought provoking and walking are likely to form the basis of most activities. With no greater perceived risk than those undertaken as routine daily activities or already existing within open drop-in dementia cafe culture there are no obvious ethical issues.

#### Where

The primary spaces of the project are within centres that have formal connections with Alzheimer Scotland. The spaces for the workshops are already programmed for pre-existing dementia group activities.

#### Management and supervision

The project will be developed and run by the Researcher who has had a Protection of Vulnerable Groups (PVG) assessment and is certificated to work with vulnerable groups under Scottish legislation. As such he is certified as a suitable person to manage such workshops and research activities.

The decision to support the project as a facilitator is that of the individual, as such they are invited to take part in recording research and will make the choice to be involved. Any facilitator will be made aware that their image may be captured in the data collection process. Facilitators will be briefed before events to make them aware of their role, expectation and to raise awareness of the kinds of issues that might arise. Training on working with people living with dementia has been offered through Alzheimer Scotland. Facilitators will also come from the support workers and carers from Alzheimer Scotland and the other support networks and groups previously mentioned.

### **5. How will participants be recruited and from where?**

#### Young people

Under the context of Young Scot, young people are those aged between 13 and 25, in this study the participants will be aged between 18 and 25, as such the decision has been made to recruit students or interested parties within the 18-25 year old age range, young people will not solely be recruited through Young Scot but also from local universities and community centres through the attached posters. Young Scot the 'National Youth Information and Citizenship Charity' have suggested that they will support the project and promote sign-up opportunities through their usual online channels.

#### People Living with dementia

People with a Diagnosis of Dementia will be recruited from networks and support groups that are affiliated to Alzheimer Scotland, Eric Liddell Centre (Edinburgh) and Open Door Cafe (Edinburgh). Through networking, attending meetings and participating as a volunteer at weekly events, the intent and expectation of the workshops will be shared. Posters, fliers and the supporting website will share the workshop dates and content. Sign up can be achieved through the online environment

([www.designedwith.me](http://www.designedwith.me)). In addition, Alzheimer Scotland Link Workers, existing support groups and their staff may contact the researcher on behalf of any person with a diagnosis of dementia who wants to be involved.

**6. Briefly describe your data collection methods, drawing particular attention to any potential ethical issues.**

Recording of Data

During the workshops data will be recorded through field notes, photography and semi-structured interviews (questions attached); and in the form of the artefacts generated in the making process of each workshop. Audio recording will be used as a method of recording data during the workshops.

Note taking and semi-structured interviews

During the workshops any note taking interviews (semi-structured approach – questions attached) or conversations will be recorded through a first name only basis. If two or more participants share the same first name the use of a numeric additional identifier will be used.

Use of photography for academic publications or other dissemination

The focus of photography is based upon wide shots of the group and close up ‘actions of doing and making’ where the focus is not upon an individual’s face. At anytime when an individual’s face is recognisable pixelation will be applied to protect anonymity

Use of audio recordings for academic publications or other dissemination

Any recordings that will be transcribed will be treated confidentially; as such the data will be used and shared in the following ways.

- Participant’s names will not be used in any conference or academic papers. This work is part of an on-going PhD study and will likely form the basis of papers for academic conferences and publication and the production of a PhD thesis.
- Audio - It is possible that short extracts from the audio transcriptions may be used in sharing the project through web-based platforms, in conferences and public disseminations and the PhD thesis. In extension audio transcriptions are likely to form part of the wider conversation of the project. Participants have been advised of this in the Project Information Sheet and each participant must grant their permission through a consent form (supplied). Any audio transcription in which the commentaries or actions of the participating group are shared will be used in a manner where no names, ages or location identifiers are used.

**7. Consent**

7a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? Yes. If yes, please go to question 7b. If no, please go to question 7c.

**7b. Please explain the procedure you will use for obtaining consent? Please include sample participant information sheets (PIS) and consent forms in your application. If applicable, please explain the procedures you intend to use to gain permission on behalf of participants who are unable to give informed consent. Please include copies of any relevant documentation.**

On signing up to the workshops, participants will be emailed or sent a participant information sheet stipulating that the workshops are a research activity and that by taking part the participant understands that they will be recorded through observations and field notes, audio-recording and photography. This information will be clearly outlined on the online environment prior to any sign up. Before starting each workshop, if a participant has not already submitted their consent, they will be asked to sign the same form consenting to the following:

- that they understand that the project is a research project.
- agreement to their image, comments, or audio within recordings taken during the research project be used in the research process.
- that first names may be recorded in data collection but will be anonymised in any dissemination, materials development or within academic conferences or papers.

Recruitment and the decision to take part in particular for somebody who has diagnosis of dementia will be such that participant will have a recognisable degree of independence. Individuals participating will be those early in their journey who have the ability to make decisions about their involvement. Guidance on participant and comprehension ability will be sought and taken from careworkers, support organisations and networks e.g. Link Workers, Alzheimer Scotland and dementia support workers from recognised Dementia Support Centres and Networks.

**9. How will you protect participants' confidentiality and/or anonymity in data collection (e.g. interviews), data storage, data analysis, presentation of findings and publications?**

During the collection of data, which will occur during the workshops, all participants will be asked to use first names only. No other personal information will be collected. People from the youth group of the study will be defined with a (Y) in any note taking or analysis of notes, semi-structured interview, audio and photography.

Data concerning any personal details in relation to an individual will be stored separately to any data collected during the study. All data will be stored in a lockable cabinet and where digital it will be encrypted and password protected.

All digitally generated data in the form of photographs and audio recording will be stored on password protected digital platforms, which are suitably encrypted. Any photographs will be uploaded immediately to the aforementioned, encrypted and password protected, computer on the completion of the workshops and deleted from the camera.

**12. Whilst there may not be any significant direct benefits to participants as a result of this research, please state here any that may result from participation in the study.**

The project has the intent of getting people young and old to participate in a creative process that is equally beneficial.

In relation to a person with a diagnosis of dementia this collaborative approach should support the development of self-esteem and will encourage social interaction, communication and/or activity along with stimulation of fine motor skills.

For younger participants there will be opportunities to develop their communication and fine motor skills. At the same time they will be afforded the first-hand opportunity to understand more about dementia.

14. What are your plans for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

As stated in section 9: Data concerning any personal details in relation to an individual will be stored separately to any data collected during the study. When physical this data will be stored in a lockable cabinet and where digital it will be encrypted and password protected. Hard drives will be stored in two secure locations in fire resistant coded safes.

All digitally generated data in the form of photographs and audio recording will be stored on password protected digital platforms, which are suitably encrypted.

Any defining recording of personal information that may occur in audio collection can be made public or publicly available and as such will be struck from research data shared freely under the requirements of open access to research materials.

15. Please answer the following question *only* if you have not completed a Data Management Plan for an external funder.

**15a How will you make your data available under open access requirements?**

**[To note, if making research data available to other researchers (open access) this needs to be clear on participant information sheets & consent forms]**

All relevant files with documentation will be offered to the UK Data Archive as per the standard ESRC procedures. If the UK Data Archive will not accept the offered data, it will be stored in Lancaster University's data repository (via Pure) where it will be preserved according to Lancaster University's Data Policy for a maximum of 10 years. All original audio files will be deleted on completion of the PhD examination by the end of 2020.

**15b. Are there any restrictions on sharing your data for open access purposes?**

Restrictions will be made upon original imagery and audio files shared on an open data platform. Where anything may contravene the participants right to anonymity the original files will not be made available. For instance transcripts of audio files will be made available though the original digital files will not. Any photographic imagery will be anonymised. There will be little risk of identification through collected data other than the visual content. The content will lack any names and age data and will not allow for facial recognition. Photographic imagery will focus on actions and where faces are captured pixilation will be used to protect participant anonymity. To the fullest extent in accordance with the use of this visual data an individual will be anonymous. The raw data/original sources within this situation are identified for deletion post examination and as such only edited anonymised versions will be made available through any open access platform (see 16b).

**16. Will audio or video recording take place?**  no  audio  video

**16a. Please confirm that portable devices (laptop, USB drive etc.) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.**

Any digital storage device used in this project will be encrypted. The lap-tops, computers and external hard drives connected to this project will not at any time be left exposed or available for outside parties to interfere with. Hard drives will be stored in two secure locations in fire resistant coded safes.

**16b. What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?**

The digital photographs and audio will be stored on paired external hard drives that are encrypted and secured in fire resistant key-coded safes. Edited content and raw materials will be stored on Digital Versatile Discs where appropriate in duplicate in the same manor as the hard drives. As has previously been stated the collection of personal information is limited to first names only. The consent forms supporting this work will be filed as paper archive. It is perceived that the personal data relevant to the audio will not carry a risk.

Due to its more sensitive nature (and in keeping with university policy) the digital audio will be destroyed on the completion of all examination and publication involved with this PhD study. The PhD study is due for completion in 2019 and allowing for the consideration of a prolonged assessment period (allowing for any re-writes) the timescale for the deletion of all original audio files will be the end of 2020.

All anonymised data will be stored for a maximum of 10 years during which time it will be available on open access research platforms discussed already.

For the purposes of its use within papers and the PhD thesis full transcription will be undertaken.

**16c. If your study includes video recordings, what are the implications for participants' anonymity? Can anonymity be guaranteed and if so, how? If participants are identifiable on the recordings, how will you explain to them what you will do with the recordings? How will you seek consent from them?**

**Copied from Section 6 - Use of audio recordings for academic publications or other dissemination**

Any recordings that will be transcribed will be treated confidentially; as such the data will be used and shared in the following ways.

- Participant's names will not be used in any conference or academic papers. This work is part of an ongoing PhD study and will likely form the basis of papers for academic conferences and publication. The location, facilities and partner groups can not be linked directly with the participants therefore no direct inference of an individual's identity can be drawn from any knowledge of those partners.
- It is possible that short transcribed extracts from the audio recordings may be used in sharing the project through web-based platforms, in conferences and public disseminations. In extension of this, audio transcriptions are likely to form part of the wider conversation of the project. Participants have been advised of this in the Project Information Sheet and each participant must grant their permission through a consent form (supplied).

**17. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis. Please also include any impact activities and potential ethical issues these may raise.**

The data collected will be used in a PhD thesis. Academic papers will be submitted for academic conferences and journals, the approach may be shared at partner/healthcare conferences.

**SECTION FOUR: Statement and Signatures**

**By submitting and signing this form, I confirm that**

- I understand that as Principal Investigator/researcher/PhD candidate I have overall responsibility for the ethical management of the project and confirm the following:

- I have read the Code of Practice, [Research Ethics at Lancaster: a code of practice](#) and I am willing to abide by it in relation to the current proposal.
- I will manage the project in an ethically appropriate manner according to: (a) the subject matter involved and (b) the Code of Practice and Procedures of the university.
- On behalf of the institution I accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- On behalf of the institution I accept responsibility for the project in relation to the observance of the rules for the exploitation of intellectual property.
- If applicable, I will give all staff and students involved in the project guidance on the good practice and ethical standards expected in the project in accordance with the university Code of Practice. (Online Research Integrity training is available for staff and students [here](#).)
- If applicable, I will take steps to ensure that no students or staff involved in the project will be exposed to inappropriate situations.

**Please note:** If you are not able to confirm the statements above please contact the FASS-LUMS research ethics committee and provide an explanation.



Applicant electronic signature:

Date 28/02/17

**Student applicants:**

Please tick to confirm that you have discussed this application with your supervisor, and that they agree to the application being submitted for ethical review

**Project Supervisor name:** Professor Paul Rodgers  
28/02/17

**Date application discussed**

**Students must submit this application from their Lancaster University email address, and copy their supervisor in to the email with this application attached**

**All applicants (Staff and Students) must complete this declaration:**

I confirm that I have sent a copy of this application to my Head of Department (or their delegated representative). **Tick here to confirm**

**Name of Head of Department** Professor Rachel Cooper

## Participant information sheet

I am Euan Winton, a PhD student at Lancaster University and I would like to invite you to take part in a research study – **Designed With Me** – *Exploring Codesign Intergenerational Activities With People Living With Dementia*

Please take time to read the following information carefully before you decide whether or not you wish to take part.

### What is the study about?

**Designed With Me** aims to pair young people with people living with dementia, to work together in ways that will explore the exchange of ideas and knowledge on route to designing something together.

### Why have I been invited?

I have approached you because you are either:

a person living with dementia and you are interested in sharing and exchanging knowledge, skills and insights with a young person, whilst exploring design approaches, to improve the local community.	Or	a young person with an interest in working to improve your local community in collaboration with a person living with dementia
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I am interested in how you will work together with someone who has a different view, set of skills, and experiences from yourself.

### What will I be asked to do if I take part?

Take part in 1 to 2hr workshops	Taking part will require you to attend 6 workshops where you will work with somebody with differing experiences to yourself, to design something for a wider audience to enjoy. The workshops require no design expertise. You will be guided through the creative processes involved in producing designs.  Each workshop will last between 1 and 2 hours.
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The workshops may be audio recorded and photographs will be taken during the creative sessions. Written notes will also be taken during the workshop. I am interested in your opinions and actions within the project and will ask you to share them with me. I will ask you some questions during the workshops in order to understand some of what is occurring. During the audio recording, no personal information will be recorded or shared, and your name will not be used at any time.

### **What are the possible benefits from taking part?**

<b>New creative skills development, personal esteem and social collaboration.</b>	<p>This intergenerational project has the intent of getting people young and old to participate in a creative process that is equally beneficial.</p> <p>For a person living with dementia this collaborative approach will support the development of self-esteem and will encourage social interaction, communication and/or activity along with stimulation of fine motor skills.</p> <p>For the younger participants there will be opportunities to develop the same skills and attributes as those being experienced by a person living with dementia and at the same time they will be afforded the first-hand opportunity to understand more about dementia.</p>
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### **Do I have to take part?**

<b>No.</b>	It is completely up to you to decide to take part or not.
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### **What if I change my mind?**

<b>You can withdraw your involvement up to 6 weeks after the workshops end.</b>	<b>You are free to withdraw at any time during the workshops and up to 6 weeks after the workshops end. If you want to withdraw, I will remove any views, ideas and insights and information you contributed to the study and destroy it. However, it is difficult and often impossible to take out information from one specific participant when this has already been anonymised or pooled together with other people's data. Therefore, you can only withdraw up to 6 weeks after taking part in the study.</b>
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***At anytime during the workshop processes or resultant outcomes/events you are anybody you are working with becomes uncomfortable or distressed the offending situation will be dealt with immediately. In this situation any party involved has the right to stop their participation or stop the activity that has led to the situation.***

### **What are the possible disadvantages and risks of taking part?**

<b>None.</b>	There will be no disadvantages in taking part.
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## Will my data be identifiable?

<b>No.</b>	<p>After the workshops only I, the researcher conducting this study, will have access to the data you share with me along with my supervisors Professor Paul Rodgers and Dr Emmanuel Tseklevs. The only other person who will have access to the data is a professional transcriber who will listen to the recordings and produce a written record of what you and others have said.</p> <p>I will keep all personal information about you (e.g. your name and other information about you that can identify you) confidential. That is, I will not share it with others. I will anonymise any audio recordings and hard copies of any data. This means that all personal information will be removed.</p> <p>Participants in the workshops will be asked not to disclose information outside of the group and with anyone not involved in the workshops without the relevant person's express permission.</p>
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## How will my data be stored?

<b>Your data will be stored securely.</b>	<p>The data will be stored as encrypted files (that is no-one other than the researcher will be able to access them) and on password-protected computers.</p> <p>I will store hard copies of any data securely in locked cabinets in my office.</p> <p>I will keep data that can identify you separately from non-personal information (e.g. your views on a specific topic).</p> <p>In accordance with Lancaster University guidelines, I will keep the data securely for a minimum of ten years. The anonymised relevant files and documentation will be offered to the UK Data Archive as per the standard ESRC procedures. If the UK Data Archive will not accept the offered data, it will be stored in Lancaster University's data repository (via Pure) where it will be preserved according to Lancaster University's Data Policy for a maximum of 10 years. Except for audio-recorded files or any images that cannot be anonymised which will be deleted on completion of assessments by the end of 2020.</p>
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## How will we use the information you have shared with us and what will happen to the results of the research study?

<b>I will use the data for academic purposes only</b>	<p><b>I will use the data you have shared with me in the following ways:</b></p> <p>I will use it for academic purposes only. This will include my PhD thesis and other publications, for example journal and conference papers. I may also present the results of my study at academic conferences or inform policy-makers about my study. It is proposed within the workshop structure that you will publicly display the designs created within the study and that these designs might appear reproduced on the project website and any printed or visual dissemination of the processes that have been explored</p> <p>When writing up the findings from this study, I would like to reproduce some of the views and ideas you shared with me. When doing so, I will only use anonymised quotes and opinions so that although I will use your exact words, you cannot be identified in the outputs.</p>
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*If anything you tell me in the interview (or other data collection method) suggests that you or somebody else might be at risk of harm, I will be obliged to share this information with my supervisors. If possible I will inform you of this breach of confidentiality.*

### Who has funded the project?

This study is funded by the Arts and Humanities Research Council. The funder expects me to make my data available for future research and use by other researchers. We will only share anonymised data in this way and will exclude all personal data from archiving.

### Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Arts and Social Sciences and Lancaster Management School's Research Ethics Committee.

### Sources of support

This project is in collaboration with Alzheimer Scotland who offer support and guidance relating to dementia for further information visit: [www.alzscot.org](http://www.alzscot.org)

### **What if I have a question or concern?**

**If you have any queries or if you are unhappy with anything that happens concerning your participation in the study, please contact myself, Euan Winton, at [EWinton@alzscot.org](mailto:EWinton@alzscot.org), or Professor Paul Rodgers at [p.rodgers@lancaster.ac.uk](mailto:p.rodgers@lancaster.ac.uk), Professor of Design, ImaginationLancaster, Lancaster University, LICA Building, Bailrigg, Lancaster, LA1 4YW, UNITED KINGDOM**  
**t: +44 (0) 1524 594520**

**If you have any concerns or complaints that you wish to discuss with a person who is not directly involved in the research, you can also contact:**

***Frank Dawes Head of Department (Until Easter 2017)***  
**ImaginationLancaster, Lancaster University, LICA Building, Bailrigg, Lancaster, LA1 4YW, UNITED KINGDOM**  
Tel: +44 (0)1524 593246  
Email: [f.dawes@lancaster.ac.uk](mailto:f.dawes@lancaster.ac.uk)

***Professor Judith Mottram Head of Department (After Easter 2017)***  
**ImaginationLancaster, Lancaster University, LICA Building, Bailrigg, Lancaster, LA1 4YW, UNITED KINGDOM**  
Tel: +44 (0)1524 XXXXXX  
Email: [j.mottram@lancaster.ac.uk](mailto:j.mottram@lancaster.ac.uk)

**Thank you for considering your participation in this project.**

# CONSENT FORM



**Designed With Me – Exploring Co-Design Intergenerational Activities With People Living With Dementia**

Name of Researchers: Euan Winton

Email: [EWinton@alzscot.org](mailto:EWinton@alzscot.org)

## Please tick each box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. If I withdraw within 6 weeks of the completion of the workshops my data will be removed. As a participant in a workshop-based investigation any content or data generated will remain part of the study.
3. I understand that any information given or developed during the workshops may be used in future reports, academic articles, publications or presentations, but my personal information will not be included.
4. I understand that my name/my organisation's name will not appear in any reports, articles or presentation without my consent.
5. I understand that any interviews or workshop participation will be audio-recorded and transcribed and that data will be protected on encrypted devices and kept secure.
6. I understand that during the workshops photographs will be taken and that in reproduction of photographs for any purpose in the study or sharing of the research materials will be anonymised (through pixelation) especially where and when my face may be seen.
7. I understand that data will be kept according to University guidelines for a maximum of 10 years after the end of the study. I understand that the anonymised data will be made available on an open sharing platform. I also understand that any original raw audio data will be destroyed on completion of Euan Winton's PhD assessment and that this will occur by the end of 2020.
8. I agree to take part in the above study.

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Name of Participant

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Date

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Signature

**I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.**

**Signature of Researcher /person taking the consent** \_\_\_\_\_

**Date** \_\_\_\_\_ Day/month/year

**One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University**

Sample flyer and poster used in existing dementia activity groups to generate interest and participation.



## designed with me

**Designed with Me Workshops** aim to pair young people with people who have a diagnosis of dementia, to work together in ways that will explore the exchange of ideas and knowledge, ultimately to design things together. Over 6 workshops, design approaches will be used to build collaborations and understanding, you will work together to explore the power of design as social transformative activity. By working with someone with a different view of the world, you will exchange ideas and skills, learn new ones and devise outcomes that might just change local areas for the better.

**Where and when?** The Eric Liddell Centre, Morningside, Edinburgh running on Saturdays from 10:00 on XXX, XXX, XXX Month. Other dates will be announced later. **Duration 2 hours.**

**Why me?** If you have been diagnosed with dementia and want to proactively inform, influence and change local communities or environments, through design exploration and working with young people, then come design with me.

If you would like to take part in this exciting project please contact  
 Euan Winton by email: [EWinton@Alzscot.org](mailto:EWinton@Alzscot.org)  
 For further information visit: [www.designedwith.me](http://www.designedwith.me)  
 Or call: 447 4520



Sample flyer and poster used in Edinburgh Napier University and distributed through local email system to generate interest and participation.



## designed with me

**Designed with Me Workshops** aim to pair young people with people who have a diagnosis of dementia, to work together in ways that will explore the exchange of ideas and knowledge, ultimately to design things together. Over 6 workshops, design approaches will be used to build collaborations and understanding, you will work together to explore the power of design as social transformative activity. By working with someone with a different view of the world, you will exchange ideas and skills, learn new ones and devise outcomes that might just change local areas for the better.

**Where and when?** The Eric Liddell Centre, Morningside, Edinburgh running on Saturdays from 10:00 on XXX, XXX, XXX Month. Other dates will be announced later. **Duration 2 hours.**

**Why me?** You are a young person (18-25 years old) with an interest in working to improve your local community, in collaboration with a person living with dementia, through design explorations. No design experience is required.

If you would like to take part in this exciting project please contact  
Euan Winton by email: [EWinton@Alzscot.org](mailto:EWinton@Alzscot.org)  
For further information visit: [www.designedwith.me](http://www.designedwith.me)  
Or call: 447 4520



## **Semi-Structured Interviews in Understanding Workshop Activities**

The purpose of the semi-structured interview approach here is to understand the motivations, abilities, thinking and participation of people working in creative collaboration undertaking workshop related activities. The activities will be the catalyst for the conversations and as such are underpinned by the semi-structured interview approach. The approach will develop a greater understanding of how and why the participants have been involved in a design process within the workshop setting. Furthermore, the approach will look to understand the ways in which the knowledge, skills and backgrounds of participants have informed the design approach or outcomes.

The semi-structured interview approach allows for participants to give qualitative information that is focused upon the tasks they have been undertaking. Exploring their feelings, motivations, thinking and engagement.

The key themes to be covered by the semi-structured interview approach are:

- Design as a social activity
- Participation in collaborative working practices
- Learning from each-others experiences and how they inform design exploration
- Influence within the process
- Motivations and thinking within the project activities
- Perceived personal limitations within design exploration

## **Semi-Structured Interview Questions**

1. How are you tackling the problem/opportunity?
2. What informed the approach you took?
3. How did you work and think through the problem/opportunity?
4. Can you define the limits of the design problem/opportunity?
5. How have you informed the design process through your thoughts and actions?
6. To what extent have you been able to build upon your own experiences or knowledge within the process?
7. Can you tell me about your experience of working within your group or with your partner(s)?
8. Have you managed to learn from or share insight with your partner(s) that has helped the process?
9. What might you do differently if you had a little more time?
10. Do you think you could achieve more and if so what would help to make that happen?

## Participant information sheet

I am Euan Winton, a PhD student at Lancaster University and I would like to invite you to take part in a research study – **Designed With Me** – *Exploring Codesign Intergenerational Activities With People Living With Dementia*

Please take time to read the following information carefully before you decide whether or not you wish to take part.

### What is the study about?

**Designed With Me** aims to pair young people with people living with dementia, to work together in ways that will explore the exchange of ideas and knowledge on route to designing something together.

### Why have I been invited?

I have approached you because you are either:

a person living with dementia and you are interested in sharing and exchanging knowledge, skills and insights with a young person, whilst exploring design approaches, to improve the local community.	Or	a young person with an interest in working to improve your local community in collaboration with a person living with dementia
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I am interested in how you will work together with someone who has a different view, set of skills, and experiences from yourself.

### What will I be asked to do if I take part?

<b>Take part in 6 x 2hr workshops</b>	<p>Taking part will require you to attend 6 workshops where you will work with somebody with differing experiences to yourself, to design something for a wider audience to enjoy. The workshops require no design expertise. You will be guided through the creative processes involved in producing designs.</p> <p>Each workshop will last for 2 hours.</p> <p>The themes of the workshops are:</p> <ol style="list-style-type: none"> <li>1. A Local Picture (Designing a Stained Glass Window).</li> <li>2. Map My... (making maps for research).</li> <li>3. Ideation (coming up with ideas based on the previous mapping project).</li> <li>4. Prototyping (using making methods to propose designs).</li> <li>5. Crafting Your Project (making the most of your ideas).</li> <li>6. Show and Tell (making an exhibition of your designs).</li> </ol>
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The workshops will be audio recorded and photographs will be taken during the creative sessions. Written notes will also be taken during the workshop. I am interested in your opinions and actions within the project and will ask you to share them with me. I will ask you some questions during the workshops in order to understand some of what is occurring. During the audio recording, no personal information will be recorded or shared, and your name will not be used at any time.

### **What are the possible benefits from taking part?**

<b>New creative skills development, personal esteem and social collaboration.</b>	<p>This intergenerational project has the intent of getting people young and old to participate in a creative process that is equally beneficial.</p> <p>For a person living with dementia this collaborative approach will support the development of self-esteem and will encourage social interaction, communication and/or activity along with stimulation of fine motor skills.</p> <p>For the younger participants there will be opportunities to develop the same skills and attributes as those being experienced by a person living with dementia and at the same time they will be afforded the first-hand opportunity to understand more about dementia.</p>
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### **Do I have to take part?**

<b>No.</b>	It is completely up to you to decide to take part or not.
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### **What if I change my mind?**

<b>You can withdraw your involvement up to 6 weeks after the workshops end.</b>	<b>You are free to withdraw at any time during the workshops and up to 6 weeks after the workshops end. If you want to withdraw, I will remove any views, ideas and insights and information you contributed to the study and destroy it. However, it is difficult and often impossible to take out information from one specific participant when this has already been anonymised or pooled together with other people's data. Therefore, you can only withdraw up to 6 weeks after taking part in the study.</b>
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### **What are the possible disadvantages and risks of taking part?**

<b>None.</b>	There will be no disadvantages in taking part. You will however, be asked to commit to 2 hours a session for a total of 6 sessions.
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### **Will my data be identifiable?**

<b>No.</b>	<p>After the workshops only I, the researcher conducting this study, will have access to the data you share with me along with my supervisors Professor Paul Rodgers and Dr Emmanuel Tseklevs. The only other person who will have access to the data is a professional transcriber who will listen to the recordings and produce a written record of what you and others have said.</p> <p>I will keep all personal information about you (e.g. your name and other information about you that can identify you) confidential. That is, I will not share it with others. I will anonymise any audio recordings and hard copies of any data. This means that all personal information will be removed.</p> <p>Participants in the workshops will be asked not to disclose information outside of the group and with anyone not involved in the workshops without the relevant person's express permission.</p>
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### **How will my data be stored?**

<b>Your data will be stored securely.</b>	<p>The data will be stored as encrypted files (that is no-one other than the researcher will be able to access them) and on password-protected computers.</p> <p>I will store hard copies of any data securely in locked cabinets in my office.</p> <p>I will keep data that can identify you separately from non-personal information (e.g. your views on a specific topic).</p>
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	<p>In accordance with Lancaster University guidelines, I will keep the data securely for a minimum of ten years. Except for raw videoed and/or audio-recorded files which will be deleted on completion of assessments by the end of 2020.</p>
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## **How will we use the information you have shared with us and what will happen to the results of the research study?**

<b>I will use the data for academic purposes only</b>	<p><b>I will use the data you have shared with me in the following ways:</b></p> <p><b>I will use it for academic purposes only.</b> This will include my PhD thesis and other publications, for example journal and conference papers. I may also present the results of my study at academic conferences or inform policy-makers about my study. It is proposed within the workshop structure that you will publicly display the designs created within the study and that these designs might appear reproduced on the project website and any printed or audio/visual dissemination of the processes that have been explored</p> <p><b>When writing up the findings from this study, I would like to reproduce some of the views and ideas you shared with me.</b> When doing so, I will only use anonymised quotes and opinions so that although I will use your exact words, you cannot be identified in the outputs. It should be noted if small videos are produced to communicate the approaches used in the workshop your image and words will be used as delivered by you.</p>
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***If anything you tell me in the interview (or other data collection method) suggests that you or somebody else might be at risk of harm, I will be obliged to share this information with my supervisors. If possible I will inform you of this breach of confidentiality.***

### **Who has funded the project?**

**This study is funded by the Arts and Humanities Research Council. The funder expects me to make my data available for future research and use by other researchers. We will only share anonymised data in this way and will exclude all personal data from archiving.**

## **Who has reviewed the project?**

This study has been reviewed and approved by the Faculty of Arts and Social Sciences and Lancaster Management School's Research Ethics Committee.

## **What if I have a question or concern?**

**If you have any queries or if you are unhappy with anything that happens concerning your participation in the study, please contact myself, Euan Winton, at [EWinton@alzscot.org](mailto:EWinton@alzscot.org), or Professor Paul Rodgers at [p.rodgers@lancaster.ac.uk](mailto:p.rodgers@lancaster.ac.uk), Professor of Design, ImaginationLancaster, Lancaster University, LICA Building, Bailrigg, Lancaster, LA1 4YW, UNITED KINGDOM  
t: +44 (0) 1524 594520**

**If you have any concerns or complaints that you wish to discuss with a person who is not directly involved in the research, you can also contact:**

***Professor Rachel Cooper***  
Tel: +44 (0)1524 510871

## **Sources of support**

This project is in collaboration with Alzheimer Scotland who offer support and guidance relating to dementia for further information visit: [www.alzscot.org](http://www.alzscot.org)

**Thank you for considering your participation in this project.**

## Participant information sheet

### **Designed with DeMEntia –Codesign Activities With People Living With Dementia**

Please take time to read the following information carefully before you decide whether or not you wish to take part.

#### **What is the study about?**

**Designed With Me** aims to use design to empower people living with dementia to transform local communities.

#### **Why?**

I have been working with and aim to continue working with you because you living with dementia and you might be interested in exploring, generating, sharing and exchanging knowledge through design approaches?

#### **What will I be asked to do if I take part?**

<b>Take part in an ongoing programme of workshops</b>	<p>The workshops require no design expertise. You have and will be guided through the creative processes involved in producing designs.</p> <p>Each workshop lasts for 1 hour and are based upon your excursions and revelations.</p> <p>The projects occur as part of your regular events hosted by the Bridgeton Resource Centre.</p>
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#### **Data Collection**

Photographs of hands and actions are taken during the creative sessions (no facial pictures will be captured). Written notes will also be taken during or straight after the workshop. I am interested in your opinions and actions within the project and will ask you to share them with me as we go along. Discussions during tasks will inform what is

happening and why you are doing something. The designs generated form a core part of the research evidence and will be used to share possible outcomes and to create design opportunities.

## **Anonymity**

No personal information will be recorded or shared, and your name will not be used at any time.

## **What are the possible benefits from taking part?**

<b>New creative skills development, personal esteem and social collaboration.</b>	<p>This project has the intent of getting people to participate in a creative process that is stimulating, beneficial and leads to the creation of designs.</p> <p>This collaborative approach will support the development of self-esteem and will encourage social interaction, communication and/or activity along with stimulation of fine motor skills.</p>
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## **Do I have to take part?**

<b>No.</b>	It is completely up to you to decide to take part or not.
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## **What if I change my mind?**

<b>You can withdraw your involvement at any time</b>	<b>You are free to withdraw at any time during the workshops.</b>
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## **Will my data be identifiable?**

<b>No.</b>	After the workshops only I, the researcher conducting this study, will have access to the data you share with me along with my supervisors Professor Paul Rodgers and Dr Emmanuel Tsekleves. I will keep all personal information about you (e.g. your name and other information about you that can identify you) confidential. This means that all personal information will be removed. Participants in the workshops will be asked not to disclose information outside of the group and with anyone not involved in the workshops without the relevant person's express permission.
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## **How will my data be stored?**

<p><b>The data will be stored securely.</b></p>	<p>The data will be stored as encrypted files (that is no-one other than the researcher will be able to access them) and on password-protected computers.</p> <p>I will store hard copies of any data securely in locked cabinets in my office.</p> <p>No data that can identify you out-with the group will be taken.</p>
	<p>In accordance with Lancaster University guidelines, I will keep the data securely for a minimum of ten years. The anonymised relevant files and documentation will be offered to the UK Data Archive as per the standard ESRC procedures. If the UK Data Archive will not accept the offered data, it will be stored in Lancaster University's data repository (via Pure) where it will be preserved according to Lancaster University's Data Policy for a maximum of 10 years. Except for audio-recorded files or any images that cannot be anonymised which will be deleted on completion of assessments by the end of 2020.</p>

### **How will we use the information you have shared with us and what will happen to the results of the research study?**

<p><b>I will use the data for academic purposes only</b></p>	<p><b>I will use the data you have shared with me in the following ways:</b></p> <p><b>I will use it for academic purposes only. This will include my PhD thesis and other publications, for example journal and conference papers. I may also present the results of my study at academic conferences or inform policy-makers about my study.</b></p> <p><b>It is proposed that the workshop design outcomes will be publicly displayed incorporating the designs created within the study and that these designs might appear reproduced on the project website and any printed or visual dissemination of the processes that have been explored</b></p> <p><b>When writing up the findings from this study, I would like to reproduce some of the views and ideas you shared with me. When doing so, I will only use anonymised quotes and opinions so that although I will use your exact words, you cannot be identified in the outputs.</b></p>
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## **Who has funded the project?**

**This study is funded by the Arts and Humanities Research Council. The funder expects me to make my data available for future research and use by other researchers. We will only share anonymised data in this way and will exclude all personal data from archiving.**

## **Who has reviewed the project?**

This study has been reviewed and approved by the Faculty of Arts and Social Sciences and Lancaster Management School's Research Ethics Committee.

## **Sources of support**

This project is in collaboration with Alzheimer Scotland who offer support and guidance relating to dementia for further information visit: [www.alzscot.org](http://www.alzscot.org)

## **What if I have a question or concern?**

**If you have any queries or if you are unhappy with anything that happens concerning your participation in the study, please contact myself, Euan Winton, at [e.winton@lancs.ac.uk](mailto:e.winton@lancs.ac.uk), or Professor Paul Rodgers at [p.rodgers@lancaster.ac.uk](mailto:p.rodgers@lancaster.ac.uk), Professor of Design, ImaginationLancaster, Lancaster University, LICA Building, Bailrigg, Lancaster, LA1 4YW, UNITED KINGDOM  
t: +44 (0) 1524 594520**

**If you have any concerns or complaints that you wish to discuss with a person who is not directly involved in the research, you can also contact:**

***Frank Dawes Head of Department (Until Easter 2017)***  
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**Thank you for considering your participation in this project.**

# CONSENT FORM

**Designed with DeMEntia – Co-Design Activities With People Living With Dementia**

Name of Researcher: Euan Winton

Email: e.winton@lancs.ac.uk

**Please tick each box**

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. As a participant in a workshop based investigation any content or data generated will remain part of the study.
3. I understand that any information given or developed during the workshops may be used in future reports, academic articles, publications or presentations and designs, but my personal information will not be included.
4. I understand that any conversations may be noted and that this data will be protected on encrypted devices or archived and kept secure. No personal information will be recorded.
5. I understand that during the workshops photographs will be taken but never of my face.
6. I understand that designs, photos and notes will be kept according to University guidelines for a maximum of 10 years after the end of the study. I understand that the anonymised data will be made available on an open sharing platform.
7. I have agreed to take part in the above study and wish to continue to do so.

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Name of Participant

---

Date

---

Signature

**I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.**

**Signature of Researcher /person taking the consent** \_\_\_\_\_

**Date** \_\_\_\_\_ Day/month/yea

### **Semi-structured Interview Questions for Co-designers**

1. Tell me about the design projects you have done with me?
2. Can you tell me about what we did and how the design projects developed?
3. Can you think of the visits that we did that informed your designs?
4. What did you enjoy most about the projects?
5. Do you think your own experiences or knowledge were used to develop these design projects?
6. Can you tell me about how important it was to do these projects within this group and how you worked with other people?
7. Have you managed to learn from other people in these projects?
8. What would you like to do differently in regards to any of the projects?
9. Do you think you could achieve more and if so what would help to make that happen?
10. What else would you like to do as a design project
11. How would you describe any of your design projects to other people?

## **Semi-structured Interview Questions for Co-designers**

1. What do you think has been achieved in the design workshops?
2. How have the co-design participants responded to the workshops?
3. Have you been aware of anything unexpected from any particular participant regarding their participation?
4. Can you tell me how you've perceived their working within the groups?
5. Can you tell me about individual working that you have witnessed?
6. Have there been any statements that you recall about the projects and processes?
7. What might you do differently if you could change what we have done?
8. Have you found new ways of working with this group or similar groups through what you have seen and taken part in / if so can you tell me more?
9. What has been especially positive?
10. What was perceived as being negative?
11. Do you think you the co-designers could achieve more and if so do you have any thoughts as to what that might be?
12. Can you tell me if you ever noticed any behavioral, emotional or mood-based responses to what we have been doing?
13. How would you describe the projects to other people?
14. Is there any recommendation you would give regarding anything you have seen or experienced in the projects?

### **Questions Regarding the Co-design Workshops for the Co-designer's Partners, Loved Ones or Carers**

1. How aware of the co-design workshops we have been undertaking are you?
  
2. Has your loved one shared any stories of what they have been doing in the creative workshops?
  
3. Have there been any statements that you recall about the projects and processes?
  
4. Do your loved ones often tell you of the visits or activities they have undertaken?
  
5. Have you noticed anything in terms of moods or behaviours of your loved ones after they have taken part in a workshop day?
  
6. Is there anything that has been perceived as being negative?
  
7. Have you ever had the projects described to you by staff or your loved one and if so how would you explain the projects as you have been told them?

## Appendix 2. Project Timeline

A timeline of workshops and events occurring in the co-design projects.

Dates of Visits and Workshops							
Project or Event	Workshop Dates	Workshop	Visit Dates	Duration	Attendees	Location	Group
Kilmarnock Resource Centre			22/01/2015	3h	2	Alzheimer Scotland Resource Centre, Kilmarnock	AS Resource Centres
D. Cally Dementia Research Workshop		Facilitation	19/01/2016	5h	23	Northumbria	Daniel Cally PhD Research Group
Intergenerational Training Course		Attendee at Intergenerational Training	26/01/2016	6h	15		Generations Working Together
Scottish Dementia Working Group			28/01/2016	5h	31	Coxon Street, Glasgow	Scottish Dementia Working Group
Jennifer Risk		Interview	22/02/2016	2h	2	Alzheimer Scotland Resource Centre, Kilmarnock	AS Resource Centres
Helensburgh Dementia Resource Centre			08/02/2016	3h	8	Princes Street, Helensburgh	AS Resource Centres
Letham Dementia Network			09/02/2016	3h	30	Alzheimer Scotland, Drumsheugh, Edinburgh	LDN
Intergenerational Training Course		Attendee at Intergenerational Training	26/01/2016	6h	15		Generations Working Together
Dementia Dog			28/04/2016	1h	10	Edinburgh	
Eric Liddell			05/10/2016	3h	12	Eric Liddell Centre, Edinburgh	Dementia Day Group
Open Doors			15/10/2016	3h	7	Open Doors, Meadowside, Edinburgh	Dementia Art Day Group
Open Doors			19/08/2016		7	Open Doors, Meadowside, Edinburgh	Dementia Art Day Group
Ageing Research Network			30/09/2016	2h	24	Merchiston, Edinburgh	Ageing Research Network
Eric Liddell			29/11/2016	3h	12	Eric Liddell Centre, Edinburgh	Dementia Day Group
Eric Liddell			18/01/2017	3h	12	Eric Liddell Centre, Edinburgh	Dementia Day Group
Scottish Dementia Working Group			20/01/2017	5h	29	Alzheimer Scotland, Drumsheugh, Edinburgh	Scottish Dementia Working Group
Re-design Sundays			29/10/2016	1h30m - Fix, Improve, Bring Back	N/A	2hr + 1hr working lunch	14 Alzheimer Scotland, Drumsheugh, Edinburgh
			20/01/2016			2h	28 Alzheimer Scotland, Drumsheugh, Edinburgh
			28/03/2019	presentation and review	N/A	1h	32 Quaker Meeting House, West Port, Edinburgh
78BC			19/05/2017	Initial Discussion	N/A	2h	5 Bridgeton Resource Centre, Glasgow
			28/07/2017			2h	5 Tramway, Glasgow
			04/08/2017	People's Palace 78BC Visit		2h	5 People's Palace, Glasgow
			18/08/2017	Collaging Workshop		1h 30m	5 Bridgeton Resource Centre, Glasgow
			01/09/2017	Pattern Workshop		1h 30m	5 Bridgeton Resource Centre, Glasgow
			01/09/2017	Fabric and Collection Workshop		2h	5 Bridgeton Resource Centre, Glasgow
			17/11/2017	Cushion Making Workshop		1h 30m	4 Bridgeton Resource Centre, Glasgow
Travel Postcards			26/07/2017	Travel Postcard Collage		1h	5 Bridgeton Resource Centre, Glasgow
			10/08/2017	Riverside Museum		1h 30m	5 Riverside Museum
Burns and CTC			19/02/2018	Burns Stamp Workshop		1h	5 Bridgeton Resource Centre, Glasgow
			09/03/2018	CTC Stamp Development		1h	4 Bridgeton Resource Centre, Glasgow
			14/03/2018	CTC Event Luncaster		2d	0 Lancaster
Glasgow Stained Glass			27/07/2018			1h 30m	5 Scotland Street School
			10/09/2018			1h 30m	5 St Mungo's
			17/08/2018	Macintosh Light		1h	5 Bridgeton Resource Centre, Glasgow
			21/09/2018	Glasgow Coat of Arms		1h	5 Bridgeton Resource Centre, Glasgow
			02/11/2018	Glasgow Stained Glass Investigation PT1		1h 30m	5 Bridgeton Resource Centre, Glasgow
			21/12/2018	Glasgow Stained Glass Investigation PT2		1h 30m	5 Bridgeton Resource Centre, Glasgow
			01/02/2019	Souvenir Making		1h	5 Bridgeton Resource Centre, Glasgow
Floating Heads Plates			22/02/2019			1h 30m	5 Kelvingrove Galleries
			01/03/2019	Floating Heads			5 Bridgeton Resource Centre, Glasgow
Table Top Gardens			15/03/2019	Tramway garden photography	2h	4 Tramway, Glasgow	Day Opportunities Group
			22/03/2019	Pollock Park Photography		6 Pollock Park	Day Opportunities Group
			03/05/2019	Designing through Collage		1h	5 Bridgeton Resource Centre, Glasgow
			17/05/2019	Garden Making		1h 30m	4 Bellahouston Allotments
Razzle Dazzle			26/04/2019			1h 30m	5 Riverside Museum
Designed with Dementia Group			20-23/06/2019	Visit to their pop-up shop in St. Enoch Centre		2h	7 St. Enoch Centre, Glasgow
			02/12/2019	Pop-up shop INU			Edinburgh Napier University
			16/02/2019	Pop-up shop BRC			123 Bridgeton Resource Centre, Glasgow
Ballatholme Allotments Sign			11/11/2019	Brief Development		1h	5 Bridgeton Resource Centre, Glasgow
			22/11/2019	Lightbox making		1h	4 Bridgeton Resource Centre, Glasgow
			24/01/2020	Material Explosions		1h	4 Bridgeton Resource Centre, Glasgow
			02/03/2020	Making Process Development		1h	5 Bridgeton Resource Centre, Glasgow
			06/03/2020	Immel production process		1h 30m	0 Edinburgh Napier University
Gordon's Scanning Lab			26/04/2019	First Meeting with Gordon		2h	4 Bridgeton Resource Centre, Glasgow
			11/11/2019	Scanning project launch		2h	4 Bridgeton Resource Centre, Glasgow
			06/01/2020	Artefact and Gordon's Public Lab		2h	4 Bridgeton Resource Centre, Glasgow
			13/01/2020	Gordon's Scanning Lab		2h	20 Bridgeton Resource Centre, Glasgow
			09/03/2020	Scanning Lab Review		2h	4 Bridgeton Resource Centre, Glasgow

## **Appendix 3. Transcripts**

Two key transcripts from the research reflection. One the feedback from the co-design group at BRC and the other from the third recorded session with Gordon and his wife.

Appendix 3.1 Day-ops

Appendix 3.2 Gordon and his wife

### 3.2 Day-ops

“We enjoyed them all.”

“This one I found really fascinating because it was a big long acetate kind of thing but we coloured the other side of it and it was really effective how the colours came out the other side”

“I’ve just found everything fascinating”

“It was smashing”

“Once we’d all been colouring in she just got different pens and she was just doing a big swirl of many colours but once it dried in it was just like a bit of modern art.”

“What I liked when we did the... you showed us the picture of the Rene Macintosh upturned cup and saucer but then when we were actually doing it. It was really interesting and then when you put the wood round the picture and the frame kind of thing it all fitted. You used the different coloured paper and stuff. It was good.”

“How did you feel when I handed you a camera?” (EW)

“Ahh aye that’s been good aye.”

“I really, really enjoyed that. I love, yeah, just yeah know its good to have a camera you know for something like that (photographing garden visits) because you see, pick out different things you know.”

“It was really good but, because mind when you were here - we had taken out pictures from different books and you had done yours so we had the kind of picture of what yours should look like. So we were quite happy to do yours.”

“Is it as good as you wanted?” (EW)

“Aye... if it wisnae I would’ve just ripped out and started again”

“But it was nice to have the stones as well as the colours of the flowers”

“You done flowers dead vibrant didn’t you? How they doin?”

“Doin really well. The part of the garden a’ve got it in, we’ve got grass there and roses there but it just sits between us ‘n’ our neighbour whose round the corner... there was nothing there... it just fits there great. It still gets light n a bit of rain n whatever when it needs it but it’s certainly still growing fine”

“Mines is going on my garden table n it can be a focal point, a talking point.”

“Fantastic, well that’s the thing - I like the term a talking point because that’s really what the pop-up shop was.” (EW)

“Aye know, we enjoyed ourselves doing that didn’t we?”

“Em n everything was set out really well you know, it was good as well to have the different, it was like questions you had to put in, put a point forward, questions. Get the grey matter going.”

How did the we engineering things go?

“Ah they went brilliant.” (EW)

“See me and XXX and thingwied right into them.”

“You did lots of group work how did you feel about it?”

“We were alright about that weren’t we? We got a laugh n things like that.”

“We were yeah cos we all got on well. We all had our own bits to and whoever was doin that bit we just moved on so it wasn’t a problem. It was just thoroughly enjoyable”.

“Aye the groups ok init”.

“Everything that was suggested it was interesting to see how it would turn out cos I couldnae tell how it would turn out.”

“It’s like brain storming isn’t it you take everybody’s ideas and develop it.”

“Uhu”

“Yeah”

(on the art installation at Kelvingrove) “I did get what it was supposed to be but I dindae think much of it.”

“That’s xxxx personality right enough it does come out like that she’s creative very creative”

“I liked how whatever was done how kind of, you know it was, obviously I canna draw, but I loved seeing something coming, the finished article.”

“The finished thing.”

“But there wasn’t a need to draw though was there?” (EW)

“No that’s why I thoroughly enjoyed it.”

“It’s always enjoyable to either go to the parks and to go to the museums. And there’s so many things to see at the museums. It’s good to develop it into something you know.”

“I would still say its art but.”

“It’s good to see the end result as well though.”

“I’ve like it because it is art but it’s not actually painting or drawing anything but you still see something substantial there, you know. At first when you see all the bits n pieces that you might be using but then once you actually start putting it together, it’s not quite like a jigsaw but its along those lines. When you’ve got different kinds of material about the place, just getting them to fit into”

“Colour has got a big part to play.”

“A lot of people come in think we just sit here we don’t do anything. People with dementia can do great things.”

“Ah know a lot of people think that dementia people can’t do a thing.”

“We don’t know anything.”

“No we don’t know nothing”

“It’s unique nobody has something like that”

“I liked when the you know when we did the stained glass light frame. Not necessarily the light frame. That was the thing that I was talking about we had, there was coloured like tissue paper, we had to put it together into a wee picture, like a box wee picture... when it all fitted together it was like a frame and when the bulb was switched on it gave lovely colours... Each of the corners of it had different colours. The way that came about I did”

“The way that came about I kind of did it by accident but I thought I like that. I surprised myself.”

“Well done you... its been thoroughly enjoyable”

“and a pleasure.”

“really interesting and learning how to do all the different things as well.”

“How did you feel about the exhibition/pop-up shop?” (EW)

“I thought that was absolutely brilliant.”

“It was, it really was...I didnae think, I thoroughly enjoyed making whatever, but I still didn’t think it was good enough to sell kinda thing “

“and it was”

“it definitely was”

“It certainly made you feel quite good (laughs).”

“It’s good for your morale and good for your confidence.”

“Thats the thing about it is what you value you canna buy.”

### 3.2 Gordon and his wife

“Originally I thought that was door in the back of the original photo and then once I started to colour it up and I started to realise ah that’s what it is. The plant life is not quite right but there is a shelf with chinese or Japanese vegetables on the back and then I started to realise there is a bento box on the back work surface. So its just all these little bits that begin to pull the whole thing together. But hopefully that gives you more of an idea of the colour idea you were looking for” EW

“Its same with the plate here, I started to paint in some of the decoration on the plate and these ones probably need a similar thing but whether or not you will notice that when I come to doing it will be a different thing. Its almost there, I have added a bit of a dark brown hue to the rafters” E

“So what is your format thing, is it just a case that we are rolling pictures” G

“The format for the final thing?, Im not sure, what do you think would work best something like that rolling pictures so people can see things coming around ” E

“We have had the members outside and we have been taking their pictures for them, for people who have lost their photographs, so there will be quite a lot of them aswell.

“The Japanese bit. I got told, when I started doing the Japanese one and talking to the members, down there, and somebody just told me that I was able to start talking better about it and getting back into ma, that the brain was coming back in, and people had said to me and that’s it, you’re getting the bits and pieces coming up.” G 2.00m

“There is something here in this building and it would allow people to see it and the problem is, I don’t know how we are going to do it.” G

“Well that’s partly my problem and maybe I will have a wee discussion, so one of the things I have done in my other project, the group have been designing and making products which have been sold to the public and they have made some money and my intention is to gift, once all my costs are out of the way, is to gift all the money back to the groups to help support them in their creative tasks and I wonder if I have a conversation with the group that I have been working with if there is scope for a screen that we can get put and we can a usb put in and it would play a rolling programme. Other people could use it but its default setting would be the pictures you have collected and the Japanese photo collection that is your original artwork” E

“I have to say when you stood up and talked, it blew my mind the last time so when I put together those slides, those images for you seen them for 5 minutes and you stood up and talked to the group for a good half an hour” E – 3.50

“That’s what somebody said to me, the group were in the seats and I started talking about kobi beef and bits and pieces, and somebody said to me, you have actually been able to speak and let it come out without..” G

“You weren’t fighting for it” E 4.28

“ I wasn’t no” G

"I think that's one of the things that would be great to highlight that not just for me but for everyone out there who has alzimers and saying that there is things that you get. Lets hope in the future that they have got stuff that they can turn it around it and make it even better" G 4.50

"you can take that television screen and that television screen and even if it's a case that we have a special party and someone gets down there and - that's someone who is still living with altzeimers.

"Altzeimers is a complete noggin by the way, I just cant...I just don't like it, because other people, why I am saying its that, Im talking about the bad men in my head but I have been trying but its hard. There is times, when my good friend, I can be pretty bad" G 6.00

"That's understandable, the things are that you don't know how to control, you cant do much about and you kind of find it difficult to find a reason why, and that's absolutely understandable. But for me, what was great at the very beginning of the project and I want to hear a little bit more about what you have been doing when you have been working with the network or the group you have created, what was that thing where you stood up and you owned those pictures when you presented them and it just flowed. You just took on something that we disussed and put together, but those moments when the colours came through you were just like, you were so articulate and vivid about discussing that and to me that was really a wonderful thing to see and I really appreciate I could be here to do so. That's why this picture getting in amongst your collection is so important aswell because you always wanted to have this bit coloured up, and we will get this into what is your artwork, so you can take it home and if you want to see it on the computer then you can do at home" E

"The good thing is this started you getting other people to start bringing in pictures aswell and I have already seen one or two people who have said they have brought their photos into see Gordon" E

"The thing is people were forgetting their photographs of their holidays or just something like a party. The thing that sort of gets me round sort of rolling is where they can look at it and very big virtual and to make it come to life. Whether, it could be some detail. You have got Altzemiers, but you can still be here and things can happen(8.53)"

I am just putting this on in the background as you said it just looping round, it just allowed for that discussion to help support you didn't it. There is an approach that they say and it started in Japan actually and it's a thing called Petcha Kutcha, and I believe it Japanese for chit chat and it's a process that artists and designers use" E (laughter)

"I chatter all the time" G

"Well its 20 slides, 20 seconds a slide and basically you talk about what's there and you put together what's there, but you spend that time. It works out at just over 7 minutes and that's really a similar process to what you were doing" E

"In my head is that we have a café and we could be better with the café, not you know and the way that you were talking about letting people see whats happened and maybe pictures, gordons pictures. And things like that, and its trying to say to people, if you have lost your photograph what we have done is we will get you back, we will get it back for you as best as we can" G **10.30.**

"Lets look at something that says Alzheimer's [people] don't have to be frightened, you know but be friendly with everybody" (*Gordon was very emotional at this point*) G **11.12**

"That's an excellent way to think and an excellent way to be, and what you wanted was to talk to everyone out there and say ive done this what would you do and you have started to collect photos and I left you with a scanning system and your wife" E

"You were like, no I am not sure about that, how did you get on? " E

"When we got it, that kit was there and then ? did the bits and pieces and at the end of the day people came up with photographs that they had lost and some of them were colleagues in the café and I said to them come on. Most of the people after were good as we got pictures from everyone that wanted to. It's hard to say, Alzheimer's is not just there for one or anybody you know, there's other people and friendships. Remember we talked about the big ball and I think if we can get, I think its going to come up.

"Maybe there are two ways we can look at it, because you talk about the dynamic and about the change and stuff being good but you are also saying this big wall of stuff would be good, now it does take me begging and asking for favours from people but I think I can get quite a sizable print done, so we could try and put all these images up so that it becomes a collection and that might just be a temporary thing and you might have moving pieces as well that they can both support each other. They can be there on their own and they can be there together and that would be something. This was always about for the group of people that you know here, you work with here and you talk to here and how you actually put something back in the space that continues to support discussion and ideas and so I am really looking forward to getting this stuff together and making those things happen. For me its been fascinating for me leaving you with the kit and saying that you guys are going to get on with it and that takes away that I don't control anything, its your project and that's always been really important. So you were the instigator, you were the guy who had the idea, you had more than the idea you had the photos and you wanted the café to do even more and there is potential to do more and I find that brilliant" E

"You have got a café but there is more to the café what it can do, because some people who have altxemiers and maybe the don't feel and feel downhearted and I think that is about time that people and powers at be should get the backsides out and start talking because we have got young kids and I think its I would be sitting saying to people and lets get this. If its problems, if its mechanical – we don't want our young children not being able to work because people who have had Alzheimer's knows what happens" G

"I think its important to get those messages from people like yourself who have dementia or Alzheimer's to say you are capable of something and you have stuff to share and that's valuable to other generations as you were just mentioning. For me, because of your historic interest or not just interest but your work was in audio visual, cameras and all that kind of stuff and then to get

you working on to technical equipment here – how did that feel because it is kind of making a link to part of your past aswell” E

“Well I mean work had with the companies selling equipment and eventually take you to Japan. My boss said he would pay for it. Its just that type of gentlemen but all the other chaps, guys were saying why are making him.

“Because I've got alzeminers I tend to chatter to much but its to try and help people but its to say you can still have a life with it and with good people, you know” G

“I think there is a lot of good people doing a lot of good things but its always such a challenge because not everyone experiences exactly the same things and it's a bit like life and all out lives are totally unique, and I suppose it's not a surprise as when things start to alter and change its not going to be in exactly the same way. But for me this has been a great process and being able, I am in a unique position with my experience and background and I don't have the same pressures on a day by day basis as I am not dealing with large groups and so I can spend time designing for you – not designing for you, you designed it, but working with you and I am just making it work for you and that's been great and been able to bring into a relationship these historic images and your desire to make something happen for other people, bringing in some of your background through the photographic images and equipment and hopefully building up a really good collection. Now we need to grab the collection and get me to something with it.

“We have the café, they have there wee cuppa tea, but its more than that as we want to try to say to the members without being derogatory to say it right that if there is that big wall up, eventually at one particular time it can go up and to tell that there is still a life within the person who has Alzheimer's, that's way that I see it. (Gordon is emotional and crying) I don't mind it when I cry, because I cry quite a lot to this young lady, but it's when you look into the café. The café is not busy today because of weather and people have to grab toilets and other things. The way I looked at it at the end of the day when I had that box, I thought ok what could I do with that. Something has got to be done. It's to say to other people and its ok there are going to be other members of staff that are not going to be here the way that I look at it. Its to keep the membership and to member know what happened” G

“Yeah making sure that these things continue to grow or have the next version or have the next life” E

“Young people, football young people. I think it's a case, that people in high places you have life here, you have people with young children. It will go bang and bang” G

“Hopefully in a subtle way this will do that banging for you” E

“I guess what we need to think about is if we have this wall of things

“I don't know whether to do the wall or not or outside” G

“Well do you know that tv has never been used if you want a tv to use somewhere” *Facilitator*

“It would be great, that kind of thing would really make an impact so if we can use then great” E

*A lot of information between 23.00 to 29.56 is not relevant as they are referring to a different experience and they have went off topic.*

29.56

“So is that why it is important to you so that people can see these things in the café at the café so that it stays with people at all times” – Facilitator

“I think one of the things, all the things of the people. It could be me, it could be you it could be everything” G

“I think that’s one of the things I have always known from our discussions and meetings is that you are a man who is very interested in people and kind of what is good for people and that’s why I think the way you have driven this project it has been so powerful because you have gone it could just be for me but it could also be very good for other people. That’s why I’ve gone and met other people and they have turned round and said *“oh yeah we have got our photos in”* that shows that you have been able to grow something, make something that other people have found value in and I think that’s why you see opportunities” E

“I get a bit when we first came for the café and you just don’t know anybdy but we ended up with good members of staff and we got stuff that we were able to do stuff with, fun and games and things like that. Its to make the people in the café and that’s, we would have to look about how is there a way to do that. Now even if its just photographs when you in come on the wall, im just manage a bit of walking rule through” E

Ladies enter

Walkng rule

“The other option might be to think about it as a projected thing, but there is so many ways to approach it and you have to think what is right and what is going to work in the space. We were talking about the wall or the physical pictures on the wall, I was wondering if it was almost like Japanese scrolls. Big role at the top and a bit at the bottom, I was almost thinking based on the background influences, if we were to get three of those printed up with the pictures on, so they are physical and can be taken anywhere and they are to be shown to anyone and then you have your more screen based thing or projected thing that’s almost permanent here and that would be a nice combination” E

“it’s a really good idea, but I would say I would go with it buts its funds and the people who have got to deal with it” G

“That’s where I am a little bit fortunate, as where I am, I can tap into things as part of the time I am a student and part of the time I’m working at Napier University over in Edinburgh” E

“I’ve not been in there for a while” G

"We have got great workshops and things like that and so there is every chance I can get the technicians to help me make stuff like that up, I was thinking about the printed stuff, and the walking wall is something that I would be able to do, but we can figure this out" E

*Talking to lady who just entered the room – Facilitator 2*

"Whilst you are here, how did you find the scanning Lab" E

"The scanning was alright, once we figured it out properly, it was alright, it was just getting the photographs in the right position or the right way round, it was alright" Facilitator 2

"I helped Gordon move the mouse and things like that"

"Gordon did say earlier on, that you did do a lot of the work that he couldn't do or was struggling to get done and you have worked well as a team to get that done and make that happen, its really good. I was saying I am now going to have to take the stuff away and do something with it" E

"A lot of people have put photographs on aswell and there are a few good stories" Facilitator 2

"Have you manage to capture those stories" E

"I've not been able to collect them no" Facilitator 2

"but that might come back to what Gordon was talking about before is that the idea is that some people might want to stand up and talk about theirs, a bit like Gordon did on the very first day, and that then continues the values of these things. You might end up having a never ending soap box out there with people standing up talking"

"The thing is as well, it might actually encourage other people to bring photographs in when they see exactly what it is, and although they can all bring photographs in and they will scan them or whatever but when they actually see their fruits of their labour so to speak I think that I think they will encourage other people to bring photographs in which would be great and just carry on"  
Facilitator 2

I think you managed to get a couple of stories, I think you recorded a little bit" Facilitator 1

"I managed to record a couple of stories, so we might be able to extract a little from them possibly, but it wouldn't be the whole story. But what you definitely could notice and maybe you guys might be agreeing it was wonderful to actually hear people talk about it because they started with a few sentences and then it became a whole story" **Radio person 36.35**

"They started with, this is the photograph and then it got into a great big explanation of what they photograph was, and it was really good. The Nelson Mandela one, the lady who did one, that was amazing. She was in South Africa and they had a tour around Nelson Mandela's house and we have got photographs of it and the deceleration. It was just brilliant, brilliant" Facilitator 2

"She was just like one of us" G

We were talking about a walking wall and we were trying to say to people in the café you know, you've got pictures, you've got photographs but what's the other things that you can part with" G

"I think people felt really valued as if they were going to be listened to, as in we are really interested in seeing your pictures and it gave people permission to bring in pictures that they had been dying to talk about " Facilitator 2 38.08

I think a lot of people were like, Oh I will bring them in next week, and then they were like, Oh I forgot to bring them in, but it great because once this is up and running and they see everything there, they will be like Oh am gonna bring in my photographs and maybe it will just snowball" Facilitator 2

"So do you think it will be a good idea to keep the kit here a bit longer then" E

"I think so, if its alright with you" Facilitator 2

"I think once they see other peoples photographs going up then they will be like, aww that's mine and I remember this and I did this and I did this and then they will be like aww I can bring my thing in and ill tell you all about that as well, so it might just be a catalyst to other people bringing in lots of things – I think it will be good" Facilitator 2

"Can I ask, what did you get out of seeing your pictures, what are you getting out of this experience" Facilitator 1

"My life" Gordon

and everyone goes silent

"you know its something that, I would of thought that I would never of seen it again until the box opened up, it started first in the café and we started talking about other schools and things and there she is , my friend, I love to try and find what her name is, she is a classical girl, she married a Scottish guy" G

"You have gone through this idea, and that is gave you life in terms of you have already said that you have been able to stand up and talk about stuff in front of people 20.24

"How did you feel about that aspect of it because most of your discussions been about doing it in a kind of selfless way and its about making it for other people but how have you felt about that" E

"if the people want to look at the photographs and look at the pictures then we say to them

*little bit of confusion on what he is talking about*

"you want to try and look to say look everybody down here in the café we all have altzeimers, lets do something and whether it can be a bit funny, brain and happy" G

"So has this made you happy?" E

"Oh yeah it makes me happy" G

"Well that's very good thing and I think that as you said, hearing other peoples stories and finding out, I mean the mandela situation, all of that stuff, you would never have known that without this process" E

"The person went on holiday and she saw them at some point in time" G

"Its margaret that I am thinking of, and she is a wonderfully and very interested lady" E

"Steven was travelling all over the world with the marathons didn't he" Faciliator 1

"and someone else brought Gordon Brown things as that's his brother in law, there was a few, there was loads" Faciliator 1

"if my brain ...they are not allowed to touch the beef and people are like what do you mean? And I am like well you don't, that beef is very expensive" G

"its probably the price of gold" E

"Then they tell you the cattle are far better for you and they are taken out and they are massaged - if it you had a bite to eat it is absolutely gorgeous" G

"I think again you touched on a point there because it comes back to my pint of view, you said all this stuff is tied to this building for this resource, but you've kind of wanted people from outside to realise that there is more going on than meets the eye sort of thing and if some of that stuff could go outside then people see it in a different context" E

"The thing being is that there are times that we can go to other bits and units and we can take the thing with us, even with yourself. We don't want to take it in the aspect of it just sitting and then if we do it that way there are ways of finding funding's, I mean I did the evening times paper and that went well. The way I look at it, in the café the café is good for everybody but I think it could be better because some people within their own set up maybe don't feel as if its there. I think its something ..." G

"I suppose to some degree, from what I am getting from you is that the café is there as a structure for the people/members are you refer to them, as the people that you have collaborated with, the people are then the members to drive and take control of the situation to a degree and lets do something, lets try something, lets try something new and if you are a model for that then that's been a great model to kind of realise the potential, its now making sure that we communicate that as clearly as possible and hopefully that suggests that people to try and to think about things that then continue that where the members have a degree of your influence or a degree of your control in what they experience when they have these types of meetings and get togethers because the café is there for lots of purposes but here is you adding a level of enrichment to it also which has been great.

"There is biscuits and cakes here and everybody likes that, but there is more to alzheimers and what they want to do , some people don't want to do but some people will do" G

"Its funny, the café nourishes you but these activities nourishes the mind and soul, as I said before its that enrichment" E

"And anne is must have been quite interesting for you when I turned up with equipment and said you guys are going to be running this" E

Its been a right good experience and talking to people, because I am myself quite shy but its been great getting to meet people and its been really interesting being able to talk to different people and to learn about there different experiences and be like WOW you have been here and you have done this, its really been a good exercise for me as well and I have enjoyed it" Facilitator 1

"its been great to hear for both of you that its been good then" E

"Can I ask, what did you think of Gordon's presentation that day" Facilitator 2

"I was so proud of him, it was really good" Facilitator 1

"Its along time since her has done it and he is used to standing up in front of people and doing presentations, because you were chair person of a lot of commitees and he put himself out there and he was really involved but then it progressively got less and less. So to stand up in front of all these people was really a big thing for him" Facilitator 1

"What I was saying to Gordon was that, what I was absolutely amazed at was he had seen what I had done and I wasn't sure, I had some expectation and I certainly didn't expect him to stand up and talk for as long as he did and with the depth that he did and to do it with such and to do it so fluidly. Ok so he knew the photos but these were a different way they were presented"

"The thing is, this was so long ago, some 30 years ago it was a long time ago" Facilitator 1

"He had only seen the thing for 5 minutes and then went [Clap]" E

"initially when we said he was going to have to stand up and talk, he was reluctant and said he didn't want to do it, you are going to have to do it for me [referring to the facilitator] and I said I don't want to do it" Facilitator 1

"but when you got up, it just started and it just came out"

"It was a great moment" Facilitator 2

"but then what this thing has done is given you a role in the group for the 6 or 7 weeks since you have had the kit" E

"What have you noticed in Gordon since he has done this project" Facilitator 1

"he has been talking a lot about it, and all the people who have been bringing in photographs. When we have been driving home he is like aww that persons photograph with this and that and it sorted of just twinged something, its been good" Facilitator 2

"The way you have got to look at it is that life is so much and that it is a privilege to have a life" G  
irrelevant chat 54.00 to

"The thing for me, its to keep on telling the story" G

When we did it on day one, kynne has said to me, he has just talked the whole way through that.

"I wonder if there are other interests that you have had in your life that might begin to spark an interest, I don't know if the trains are a recent thing" E

"My dad worked in the railway, and my mother.

"It might of even been the flying Scotsman"E

"we were supposed to be going on the orient express

Initial Extracted points:

"There is still a life within the person that's got Alzheimer's" G.

"I thought ok, what can I do with that. Something's got to be done with it" G.

"High People in high places have start getting things... you have life here" G.

"Can I ask, what did you get out of seeing your pictures, what are you getting out of this experience?" A1 "Me? My life. You know it's something I thought that I would never see it again" G

"Look everybody down here in the café today, we've all got Alzheimer's so let's try and say let's do something. Whether if it can be a bit of funny, because there's, funny, brain and happy, that sort of things" G.

"So, does this make you happy?" E "Aw, it makes me happy" G.

“There’s times where we could go to other bits of other units, and take the things with us, you know even with yourself. Because, we don’t want to take it in the aspect of it just sitting, and then if we do it that way, there’s ways of finding funding” G.

“The way I look at it in the café, the café is good for everybody but I think the café could be better.” G “

## **Appendix 4. Additional considerations supporting main body text.**

What follows has been removed from the main body text of this thesis but provides additional consideration of certain discussions.

Appendix 4.1: Continued framing of care provision and the effects on carers

Appendix 4.2 Open Door; Sample Activity

Appendix 4.3: Design of Resource Centres by Graven

Appendix 4.4: Academic Privilege

Appendix 4.5 Who are the results of this PhD for?

Appendix 4.6 Addressing the Research Intentions

#### Appendix 4.1: Continued framing of care provision and the effects on carers

For some, the sudden and deep immersion of becoming a carer can even appear to be like a 'prison sentence' constricting time and freedom or restricting personal rights and responsibilities (Marriot, 2011). Inversely, for some 'care' is liberating, gives purpose and defines their being. Care is paradoxical in that it can both nurture and destroy and as such can lead to even more unmetered complexities. For those giving and receiving family focussed care the situation can be highly emotionally charged. Through two interviews conducted during this investigation carers shared that they felt a sense of duty and fear of not providing or more importantly being seen as not providing care in a stoic manner. Their views were such that the pressure of care resulted in stress and a minimising of each carers identity. Their conversation insinuated that their purpose and responsibility was to work within difficult changing circumstances but to not be seen as increasing any burden elsewhere. As Marriott (2011) explains the situation can be ever changing resulting in confusing personal relationships to the situation:

*"There are millions of people... Millions! All grappling with the same difficulties. All assailed, from time to time, by guilt and doubt and loneliness and despair. All doing something that is necessary, worthwhile and, dammit, wonderful."*

(Marriott, 2011, p50)

Marriott's first-hand accounts elucidate the complex position that a carer executes and the duress under which activities of care are performed. Through conversations, meetings and workshops undertaken, between 2015-18, with carers and PLWD in Edinburgh, the patterns and concerns illustrated in Marriott's discussion were often repeated. It became apparent that within this context 'care', most commonly identifies the PLWD as the person of primary concern, appearing to down grade the rights of the carer and their 'personhood'.

It is within this stressful consideration of care, based upon pre-existing relationships, that many of the key concerns for individuality and personal wellbeing comes to the foreground. Personhood for both the person being cared for and the carer becomes muddled and individual representations of self, unclear. Although support for people who are carers is recognised as being widely improved, problems persist, especially in the form of isolation and the loss of personal identity. As such it is arguable, that a system that forces a person into a position of care and that requires a carer to 'give-up' on themselves requires further exploration and opportunities for change. As one workshop participant stated *'There is a need to care for*

*carers, a need for changing perspective*".<sup>1</sup> In continuation of this thinking during an interview with care professional, Becky Rawlinson, she stated "*If design can help in any way with carers, it should help in being proactive not reactive to carers needs, identifying when carers need help much earlier, we need early intervention and prevention*".<sup>2</sup>

As previously alluded to, it appears in current processes of care support and care assessment that the discussion of carers is taken predominantly from the person being cared for's perspective. Age UK in Improving Later Life: Services for Older People Caroline Glendinning (2014) suggests that as such, the ways in which care is managed and assessed from the carers perspective are unsatisfactory at best. For example, questions, as to whether or not people want to be in a caring role are not asked. The impact includes disjointed assessments of the parties involved, which, in many ways, suggest at least disinterest, and at worst neglect of the lived experiences of carers.

Within the workshops and interviews undertaken in this research, talk often occurred around the responsibility to care; a sense of 'It is my wife or husband, or mother, or father and therefore it is my responsibility to care' is a common reasoning of the undertaking of the role, and that this is usually tempered with the view that an individual does it for a sense of love. As Glendinning (2014) identifies systems of support need to be adaptive; responsive to changing needs and mind-sets or flexible enough to adapt. As one carer noted it's good to recognise that "*not everything is wonderful*", "*black humour is required*" and "*carers need fun space and time*".<sup>3</sup>

In a social context, the ongoing discussions of care from carers points of view reaffirmed that caring for somebody with a degenerative condition can create a sense of isolation compounded by dislocation from the historic personal endeavours and activities that comprised social inclusion. The very activities and identifiers of what used to be the interests of the individual carer become forgotten or out of reach. 'Caring for carers' (Winton, 2017) therefore, requires reinforcement of a person's esteem and reassurance of their capacity to be involved with the kinds of things that they identify themselves with. To ensure continued

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<sup>1</sup> Note from carer at workshop whose husband had recently gone into care and left her without a role or purpose

<sup>2</sup> Notes from interview with Becky Rawlinson (2017) a professional caregiver and former care provider for Alzheimer Scotland.

<sup>3</sup> Interview with a former carer (2017). She was struggling to come to terms with her role after her husband was moved into full-time residential care.

value of carers during and after the role they perform, there is likely to be a requirement for new opportunities to be considered and proposed.

#### Appendix 4.2 Open Door; Sample Activity

The activities designed for the group by the care support team incorporated game play, music and creative making. One of the projects they undertook during a visit was to apply seaside themed designs to letter forms that became a new internal sign for the Blue Door activity space. Prior to the activity, the group discussed themes of the seaside and their thoughts or memories of the topic. The group were arranged around a large central table that encouraged viewing of what was being done by other people and a centralising of materials to make them accessible. The support centre staff and the other people in attendance arranged themselves between the participants in order to aid in the process. The additional helpers included two teenagers who were grandsons of one of the group members and a nursing student who was supporting and learning from the group to help advance her studies and knowledge of Dementia.

The main seaside activity undertaken during this particular visit helped the participants to express their own thoughts and ideas. It encouraged the use of a range of materials including paint and tactile objects (buttons, string, plastic seaside creatures or forms, shells, glitter...) glued to a cardboard letter form. The approach required stimulation of the eyes, choice making in the colours and materials applied to the form. It also showed understanding of process and the ability of people to follow instruction and to adapt the approach for their own desired outcome. The tactile quality of the project encouraged the use of fine motor skills picking up pieces to be applied and then gluing and setting them in place. On completion of the task, the group appeared to display joy and a sense of personal and collective achievement.

#### Appendix 4.3: Design of Resource Centres by Graven

The spaces created have been developed to be welcoming, useable and adaptable places that respond to and understand the needs of people using them. Modern design aesthetics of clean lines, defining colour ways and localised graphical representations have made the centre an enjoyable space in which to spend time. The graphic content anchors the centre into its locale bringing modern representations of the surrounding town into the interior design of the centre itself. The scheme designs appear to sit somewhere between modern community centre and a coffee shop, however, the service they supply can vary greatly. How the spaces are used is often reinterpreted and reorganised to facilitate the calendar of activities. Core to the public areas of the Resource Centre is the arrangement of the kitchen/caf  space. It is a self-service environment where people using the space can serve themselves and each other. Though most of the production of teas, coffees and food appears to largely be provided support workers, who are hosting events or activities, observations during visits to the sites noted that some people who have Dementia also play a role in production and serving. As such, the centre has a homely feel whilst being a modern place in which to relax and spend time. The furniture in the spaces reinforces this sense of modernity utilising contemporary styles and fashions. The approach is game changing in as much as the centres do not attempt to force historic furniture or nostalgic settings on those using them. The popular reminiscence through scene setting that often occurs in similar environments is noticeably absent which appears to present a sense of forward-looking dynamism. This in particular is interesting in as much as it is an allegorical representation that Dementia support doesn't have to be anchored in the past or focussed upon what a person used to be. It suggests that their future can be a positive existence as well.

#### Appendix 4.4: Academic Privellage

It should be noted that the above review of design and dementia is largely focussed within an academic context and that there are significant contributions made to the field by projects such as those undertaken by Studio LR founder Lucy Richards who has been working with people living with dementia to develop better wayfinding and communication systems created with PLWD but suitable for everybody<sup>4</sup>. However, for the purposes of this PhD the academic grounding of the research is an important dynamic in design

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<sup>4</sup> Studio LR is a SME design agency based in Edinburgh, Scotland. They have been awarded funding from the Life Changes Trust to develop a universal set of symbols for better communication of services and wayfinding that has been made free to download. [https://www.ads.org.uk/public\\_places\\_foreveryone\\_studiolr/](https://www.ads.org.uk/public_places_foreveryone_studiolr/)

and dementia. This academically situated perspective highlights that such a position is often heavily linked to a designer and researcher engaged within an educational and research setting because of the freedom that being an academic affords. Research and educational establishments are equipped to allow their design experts to explore ideas, to follow hunches, to find financial support and to provide resources to engage in this kind of work. Furthermore, access to teams of researchers including students provide the potential for research projects to gain momentum and scale relatively quickly. Both a help and a hinderance, academic action is tied to and shaped by funding, by theoretical and practical influences, by goals and objectives of the institution and by ethics-based restrictions, along with the many other complexities involved in being a design researcher. Politically astute and ensconced in juggling influences it appears as though the mind-set of the academic designer-researcher is likely to be more quickly and keenly attuned to working across situational complexity and to navigate issues. This is posed, not to undermine the very rich contribution that design agencies make within the dementia landscape but, because of the way in which academia supports investigation. As already stated academic framing opens the opportunity to funding, to extension of projects, to communication or dissemination of findings and to testing of theories within a supported and esteemed position. It is therefore more conceivable that an academic design-researcher can gain traction, to develop communities and to make impact thanks to what is a privileged position. This position supports great collaboration and nurtures positions where working with groups can become highly effective.

With this in mind, a key aim of this PhD research is to develop a number of disruptive design interventions (e.g. products, systems, services), based on a Co-design approach that fulfils a more complete design process and which might eventually encourage design 'by' people living with dementia.

Many co-design techniques and tools, however, assume particular skills, expertise, and processes that rely on certain levels of communication, cognitive, and creative skills on the part of the participants. As such, many well-established co-design tools and techniques may not be appropriate and need adjustment (Wilson et al., 2015). Indeed, when working with people with cognitive and other impairments such as dementia, researchers may have to develop and adopt highly individual co-design approaches and methods (Hendriks et al., 2015). The motivation behind the projects presented here has been to ensure that everyone involved is engaged fully. As such, great care has been taken to consult with people living with dementia, their family members, and care support workers about how they wanted to be involved

throughout the projects before they started and during the evolving processes. In particular, it was vital that the planned but responsive co-design projects supported the person living with dementia and that it paid respect to their personhood and their right to be treated as a unique individual (Kinnaird, 2012). A co-design approach acknowledges that each individual has their own strengths and weaknesses that they bring to the co-design process. Consequently, the projects presented here have been carried out with people living with dementia who, it is hoped, will benefit from the experiences. Indeed, the key objective behind this work is to care better for people living with dementia and to break down widely held and largely negative preconceived ideas about what people living with dementia are capable of doing.

*"In reality, creativity has always been a highly collaborative, cumulative and social activity in which people with different skills, points of view and insight share and develop ideas together."*

(Leadbeater, 2008; p.7)

In Leadbeater's (2008: p.7) view that "...at root most creativity is collaborative" how equality in a process can be achieved needs to be framed. In a creative process not, all projects need equal participation though many elements must be structured, organised and compiled in order to achieve the desired outcome. Co-design through a 'with' approach accentuates the idea of providing collaborative parity that embodies a range of sociable and inclusive acts that bring people, ideas and diverse points of view into the mix. The approach unifies points of view that results in sophisticated thinking that might often appear to be comparatively simple. The approach when undertaken with parity becomes both research method and design process by supporting input rather than assuming knowledge. The co-design approach is complicated to undertake especially when the intention is to keep the 'participants' at the core of the intent and final outcome delivery. However, when applied appropriately, it is an evolving and pliable approach that flexes with and responds to the discussions and outcomes generated by those participants.

Leadbeater (2008: p.7) suggests that the economic innovation model of the future will increasingly empower people through working together "*central issues will be how more people can collaborate more effectively in creating new ideas*" which could also be argued will be valuable in the evolution of health and social care. Further to his argument he suggests that collaborative people-centric approaches to living and working must give participants what they value the most: "*recognition for the worth of their contribution, the value of their ideas, the skills of their trade*" (Leadbeater, 2008: p.21). In the context of the co-design approach taken with people living with dementia this value of the individual is of utmost importance.

Heath and Heath (2011) suggest that in design interventions, disruption or 'change' based scenarios are not perfect solutions. However, there are arguably perfect problems which are likely to require the application of a range of approaches and variant depths of sophistication to affect and to overcome a particular scenario. The exploratory nature and proposition of trying new things through disruptive paradigms allows for a relationship to develop that can change perceptions and methods of engagement. In the context of this work, this reveals itself through the formation and reinforcement of capabilities of the individual and collective participants. Important in making these accessible and inclusive was the acceptance that playfulness should form part of the enquiry. As Stuart Walker (2011) explains in such a process "*eventually, some of these explorations might be developed into a material culture that is not only in clear accord with environmental and social issues but also with more meaningful understanding of human happiness*" (Walker, 2011: p.3).

With this in mind, the co-design methods developed within this research have aimed to engage ways in which design as a specialism can make meaningful and valuable, playful and disruptive interventions. Ones which respond to the challenges and complicated nature of design for dementia. Herein, designed interventions, workshops and interactions in a variety of guises form ways in which to empower and affect lived experiences. The purpose of which is to understand designs capacity to support 'change' or to build insight in regards to people living with dementia and in support of people who care for them. Using design activities as a socially imbued method of enquiry. This research explores the value of personal esteem in regards to projects and processes that hope to build upon personal emotional intelligence and the importance that people living with dementia have of feeling connected to the positive things they can achieve. Also, with whom they can achieve them. This co-design proposition will develop emotional investment in both processes and outcomes in order to affirm of personal identity, social inclusion and personal empowerment in new ways.

#### **Appendix 4.5 Who are the results of this PhD for?**

This PhD serves to provide new ways of thinking about how designers might better engage people living with dementia, how care providers might do things differently and how researchers might find common

grounds with groups that can create opportunities for design-led investigation. This work therefore provides evidence that is useful for:

### **8.1.1 People living with dementia**

The evidence provided within this thesis indicates that people living with dementia have huge amounts to offer for their peers, for care providers and for society. They have been able to build resilience through strong networks of practice and through feeling empowered to deliver thinking-actions-solutions in a deeply connected manner.

The tasks asked of along with the interventions encouraged from the co-designers have proven their mental capacity, the ability to learn new ways of engaging, challenged themselves mentally and physically and developed confidence along with new skills. Within the approach the participants have regained the right to undertake actions and proven capability to do so, such as photographic exploration. The systems devised have helped to illuminate capabilities in terms of sight, dexterity, application of personal knowledge, sense of purpose and value along with other attributes such as taste, composition and personal decision making.

In undertaking the projects these fabulously talented individuals have supported one another in making propositions, setting out goals, disrupting processes and delivering real world designs. This is not art therapy but design in practice.

Throughout the process people living with dementia have proven to themselves and to the audiences that their work has reached that they have much to offer after diagnosis.

### **8.1.2 Care providers and researchers**

It poses new ways of working over prolonged periods of time on purposeful and meaningful projects with people who are living with dementia and therefore provides guidance for researchers and care providers as to how that might occur.

The approach shares how projects can be thoroughly inclusive and that themes and ideas can permeate into other opportunities. The result meaning the value given to each workshop and task has proven to pervade and can result in project planning that does not need to focus on short-term proposals. At the beginning of each workshop a short reminder is often all that is needed to simulate new action. This means that projects can be dropped and re-engaged with at other times as long as flexibility and adaptability forms part of the planning.

Key to the results of this work is that people living with dementia are highly capable of making valued and telling design contributions during the early to moderate stages of their dementia journey.

In section 8.2.1 guidance is set out as to how medium-to-long-term projects can be conceived and developed.

### **8.1.3 Primary carers and loved ones**

The results of the opportunities expressed within this thesis suggest that significant aspects of wellbeing, self-esteem, and mood enhancement have been achieved whilst undertaking these projects and how those have continued after the workshops or tasks had been completed. The sense was the projects provided optimistic outlooks underlined by statements of how for people living with dementia this had provided a sense of perspective changing where participants commented on their abilities and how what they had achieved went beyond their expectations. These have therefore provided valuable examples of why it is important to be open to new opportunities and can provide loved ones and primary carers hope that enjoyment of tasks can occur for people living with dementia and that these things can underpin their personhood.

The limited examples of feedback from primary carers indicated that the joy was evident in what was done and that this had provided a sense of purpose to their loved ones. The suggestion of which was that this created better moods for those involved.

## 8.6 Addressing the Research Intentions

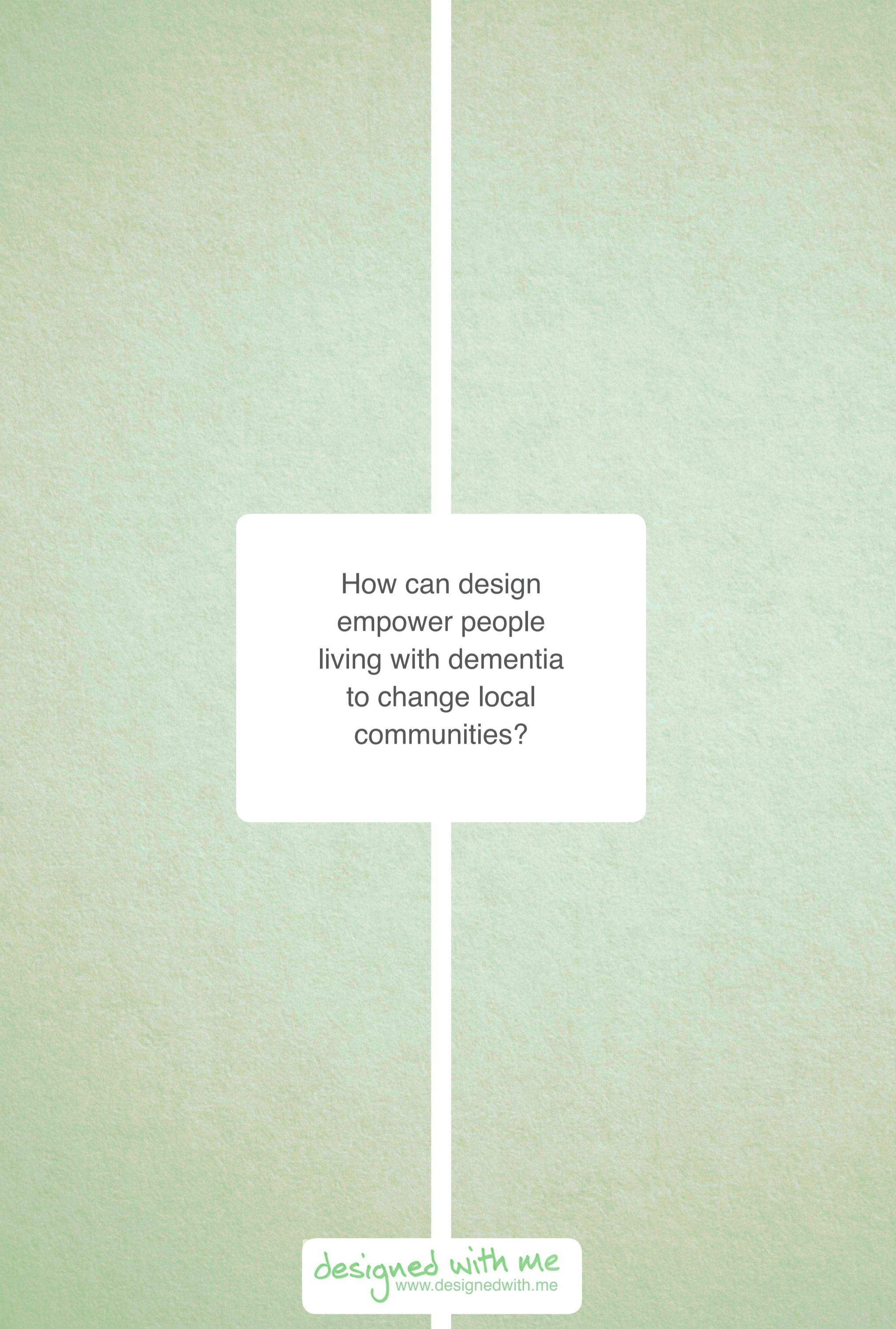
The key aim of this study is to:

*Empower People Living with Dementia Through Designing*

Which encompasses aims aligned to Hendricks and Wilkinson's (2017) question of "how design research can be an enabler within the context of care and dementia" where the investigation targeted:

- How acts of Co-design develop or reinforce capabilities of people living with dementia?
- What are the benefits of working with people living with dementia in a designerly manner?
- What can design skills and processes afford people living with dementia in terms of self-actualisation, ownership, creative prowess and empowerment?
- What approaches should designers take when working with people living with dementia?

These themes have been explored throughout the main body of the thesis and have led to the following novel contributions resulting from the study. Much of the analysis and discussion explain that the effects of the study have resulted in positive, prolonged relationships where partaking in co-design has developed a sense of belonging and purpose of the people involved in the process. It has also indicated much wider influence (provided through their designs) on carers and family, professional care services, communities and the public. As such the projects they have delivered have been full of examples where self-actualisation and empowerment have been demonstrated.



How can design  
empower people  
living with dementia  
to change local  
communities?

# How can design empower people living with dementia to change local communities?

*Designed With Me* is the working title for the on-going PhD work of Euan Winton and is situated within design for dementia. In work offers an open approach to learning and using the latent personal creative abilities and making use of an individual's personal knowledge and skills (Kelley and Kelley, 2015). Through workshops people living with dementia will be invited into a collaborative design approach where their input and collaboration will be valued and held in the same esteem as any other participant and collaborator. In the *Designed With Me* approach collaboration is focussed upon the empowerment and inclusion of people with a diagnosis of dementia, along with support workers, carers and the general public, to inform, influence and change local communities. In the process participants will become collaborative designers helping to propose possibilities, choose solutions, provide services and to 'make things happen'.

In particular the intention is to use design activity in a manner that, through sociable interactions and collaborations, changes existing patterns of behaviour and community limitations. But, why design?

Design is, by its very intent: a means for change, a platform for proposing and acting in order to make things better. Design proposes and makes objects, places, spaces, facilities and services by working with and for people. The act of designing has historically been mooted as a form giving styling and clever production for commoditised economies. This is undoubtedly one of designs' roles, however, the most contemporary understanding of designers and acts of design can involve vastly different purposes. Increasingly the concerns of a designer are built upon the act of living and all that entails, including: social, environmental and economic responsibility, the power to make a difference to the current paradigm.

Increasingly it is accepted that designers have the ability to produce tools of empowerment. It means that designers feel themselves empowered to challenge preconceptions and existing situations through ways of thinking, planning and - most importantly) - acting upon propositions. Design is best represented as thoughtful actions but it is also a highly sociable, inclusive act capable of bringing together diverse points of view, unifying simple and sophisticated thinking. In design there are no perfect solutions, however, there are arguably perfect problems (Heath and Heath, 2011), which are likely to require a range of approaches to affect change or even to overcome the scenario. Design as subject often talks of intervention, the opportunity of which is frequently experimental and iterative, in many situations. As a route that involves greater numbers of people in experimental approaches applying interventions and allowing iteration the process itself becomes more interesting and engaging, and socially charged than traditional problem solving techniques.

In terms of design activities directly informing, challenging and intervening in dementia, the RSA (Royal Society of the Arts) and the Design Council have been working with communities, agencies, carers, charities and those living with dementia to develop alternative ways of addressing the lived complexities that dementia brings.

In the introduction to the Design Council's *Living Well With Dementia* we are informed of the value of "social innovation [that] demonstrates design's potential to confront a truly global problem and change real lives for the better." (Design Council, 2012). Furthermore, in *Connected Communities* the RSA's Mathew Taylor proposes that design actions support a largely "communitarian aspiration that public service interventions encourage and empower people to contribute to meeting their own needs" and lauds the demonstrable "impact of initiatives based on strengthening social networks on wellbeing" (Buddery, 2015).

Within this discussion and the prominent work of creative practice champions there is a proven sense of the potential of design to valuably impact the situation. In respect of changing support strategies design will be increasingly applied in its multitude of guises in

order to develop objects, tools, systems and services but also to engage and motivate communities and seemingly disconnected groups.

## So, Why Design?

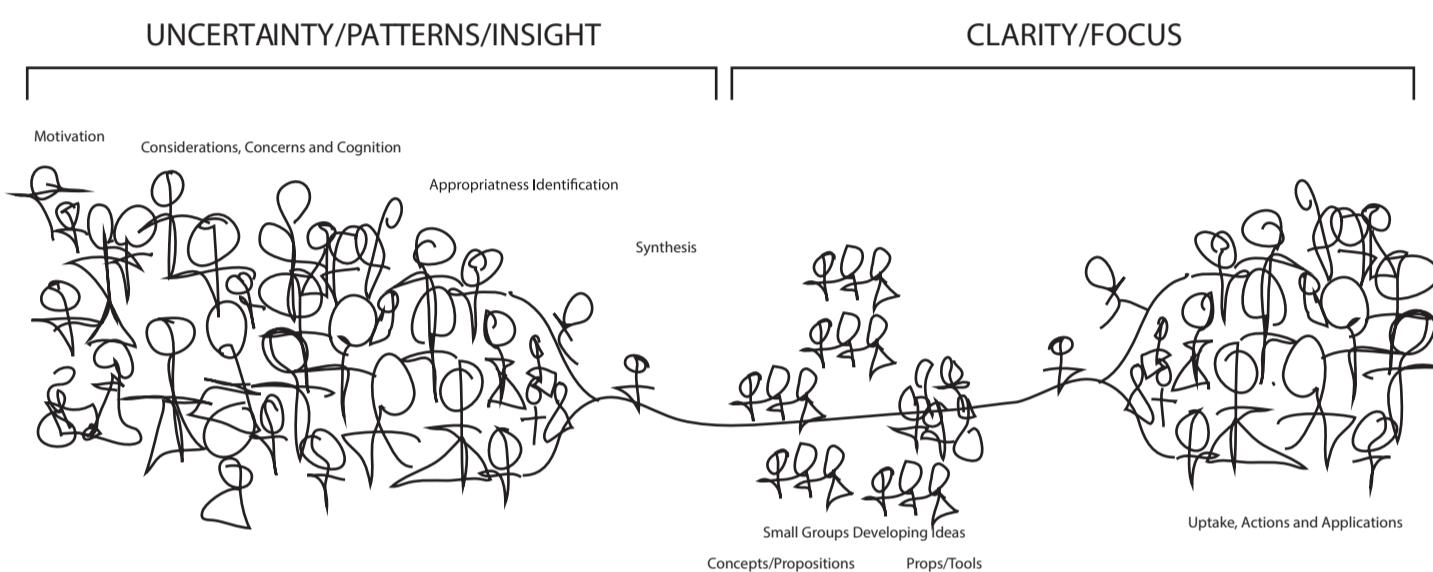
Because, designers offer powerful inclusive ways to respond, to opportunities and problems, that support the most appropriate acceptable change to the stasis with the best hope of improving lives. Design is also different to most other working disciplines in that it leads to physical and visual, systematic and tangible change that enriches the world. Most of all, if designers do their job well, the results or actions should be fun, creative, productive and inclusive in ways that no other approach is capable of.

# Co-design Let's Collaborate, Think, Disrupt and Change

Co-design is the process used to approach opportunities for creative intervention with people who have a vested interest in a specific situation. At its core Co-design practically and actively builds upon the processes of 'design thinking' (Cross; Brown, et al.). Design thinking being an open approach to investigating complex problems, situations or issues that results

a difference in the world around us. Change scenarios develop the collective togetherness in approaching problems and situations. In this scenario, the actions of the designer and the people that they work with are inter-linked by collective responsibility and the desire to make a difference. Work in the *Designed With Me* project hopes to manifest such change by working with people who have a diagnosis of dementia and other people whose lives have been affected by dementia. The incentive for change actions and opportunities for co-design do not center round resolving the condition of dementia instead

with the suggestion that if something works share it. Training in dementia has been widely and eagerly supported with over a million citizens taking part in learning how to understand the needs and requirements of someone living with dementia; they have learned to identify when somebody might require help and have generally become more inclusive by merely caring about and understanding about people who live around them (Taggawa, 2015). As such Disruptive Design as a process that does not follow the normal paths and rules is increasingly being accepted by organisations and governments as



in the creation of tools, devices, goods, Services and other kinds of intervention. Design thinking is increasingly involved in scenario modeling and management of complex issues. Co-design is the open and inclusive framework that invites those with a vested interest to get involved, but more than that good Co-design should facilitate participant ownership. Allowing for personal investment, along with personal and collective empowerment where those involved drive the momentum collectively. Historically Co-design has taken the lead in the generation of a brief. But the capabilities, resources and practical sophistication of modern society is reinventing the process making it conclusive from beginning to end. The model that I have developed above changes the idea of brief generation in to a format of collective investigation, smaller groups exploration and solution modelling, which then feeds a larger group activity of making something happen that may be an intervention, a tool or a movement for 'change'.

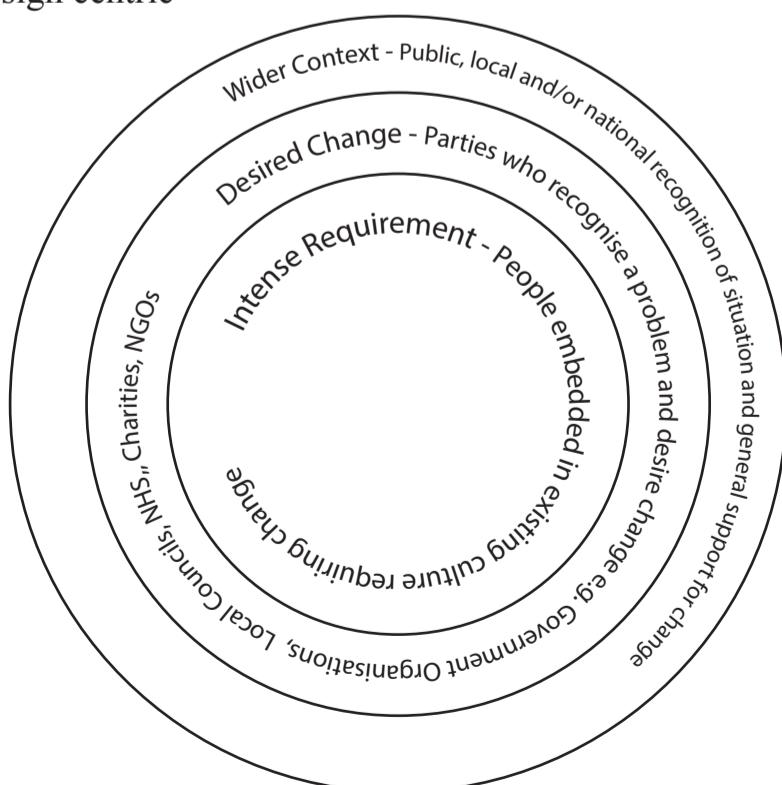
Increasingly Co-design is involved with what is called 'change' (Brown; Heath, et al), which relates to making

this work is interested in the power of the individual, the value of their lived experience and their continuing inclusion in society.

Ultimately the purpose of this project is to do stuff with people; to try things out for people; and to accept occasional failings as long as action has been undertaken and the results evaluated, and used to improve the next approach.

This brings us to the final design centric consideration of *Designed With Me* – 'Disruptive Design' (Rodgers, 2013). This method does not try to conform to accepted modes of doing things and is focused upon the actions of undertaking design processes and applying design practices to make an impact. In Japan society has been reformed in how people living with dementia are supported and included. The government have actively supported citizen activists and citizen designers to 'try things out'

a means to 'making things happen'. It encourages the removal or at least avoidance of barriers to doing things and increases opportunities for making a difference. Disruptive Design has a slightly rebellious attitude that doesn't ask why not, it does it anyway. However, rebellious as the movement may be the societal intention of disruptive processes is driven by the same intentions as change movements and those are to enrich lived experiences.



# Workshop 1: Understanding shared areas of interest from which a brief can be generated

On 29th November 2016, I was invited to run a session for the *Edinburgh, Mid and East Lothian Dementia Action Network* based upon my research interests in design for dementia.

Here a new approach to the project was trialled. The day explored how I might get peoples opinions as to what is important for them and from which I may generate a design brief or briefs. Participation in the generation of information, thoughts and wishes by the attendees of the meeting created the central focus of future workshops.

The group, all of whom had a diagnosis of dementia, were invited to respond to everyday questions or statements by filling in answers on the back of a set of purposely designed postcards. The questions invited personal and collective opinion utilising the terms "I" and "we" the purpose of which was to solicit participant's opinions; to think and talk about their thoughts, hopes, wishes or desires.

The hour long session stimulated much conversation and created food for thought. Free flowing in thinking and chat the result was a collective views peppered with personal insights and particular fascinations.

On these pages the supporting slides to the event are displayed. The materials generated by the participants are displayed on the following pages.

The responses on the cards were produced by or in discussion with the participants of the workshop supported by the facilitators of the Lothian and Borders Dementia Network.

The overall intention of the day was to build upon the kinds of approaches that the Scottish Dementia Working Group are focussed upon, in particular campaigning on behalf of, working

for and the supporting of people with dementia by people with dementia. With this in mind, the proposal of the workshop was to, ultimately, generate a situation where people with dementia identified areas of potential in which design intervention could make a difference for people living with dementia. It was also viewed that if the right mix were to occur the proposal could have further reaching value and impact in terms of local communities. Bearing this point in mind, the cards that fulfilled the recording of discussion and activity were openly ambiguous. Though they might well be answered from a very personal consideration the open nature invited wider thinking, collective discussion and agreement. During the session an attempt to not direct or influence the participants in their thinking was taken. However, as the discussion was open and shared freely, and included questions being asked and answers given it would be impossible to state that no influence existed. Rather the conversation and collaborative inclusion of everybody in the room started to take shape as a result of shared thinking where all the parties involved were equal and mutual.

Gaining the thoughts and wishes of people who are living with dementia is essential to the intention of the research approach. This approach, looks to understand the potentials of Co-design (the activity of creating designs with other people) as a means of raising awareness and developing the voice of people living with dementia. In particular keeping them essential infused in the process of defining a brief, idea generation, concept refinement and design delivery. The approach of the brief generation as was kick-started at the first event gave opportunities for further discussion and exploration in the following workshop and in particular allowed the formulation of a one sentence brief that brought the key components of the first workshop to the fore.

# Why design?

Design is involved in the creation, production and curation of:

- Products
- Tools
- Services
- Support systems
- Buildings
- Entertainments
- Enjoyments
- Communities

improve

We really need to improve...

[www.designedwith.me](http://www.designedwith.me)

change

It would be great if we could change...

[www.designedwith.me](http://www.designedwith.me)

fix

I'd really like to fix...

[www.designedwith.me](http://www.designedwith.me)

imagine

Imagine if we could...

[www.designedwith.me](http://www.designedwith.me)

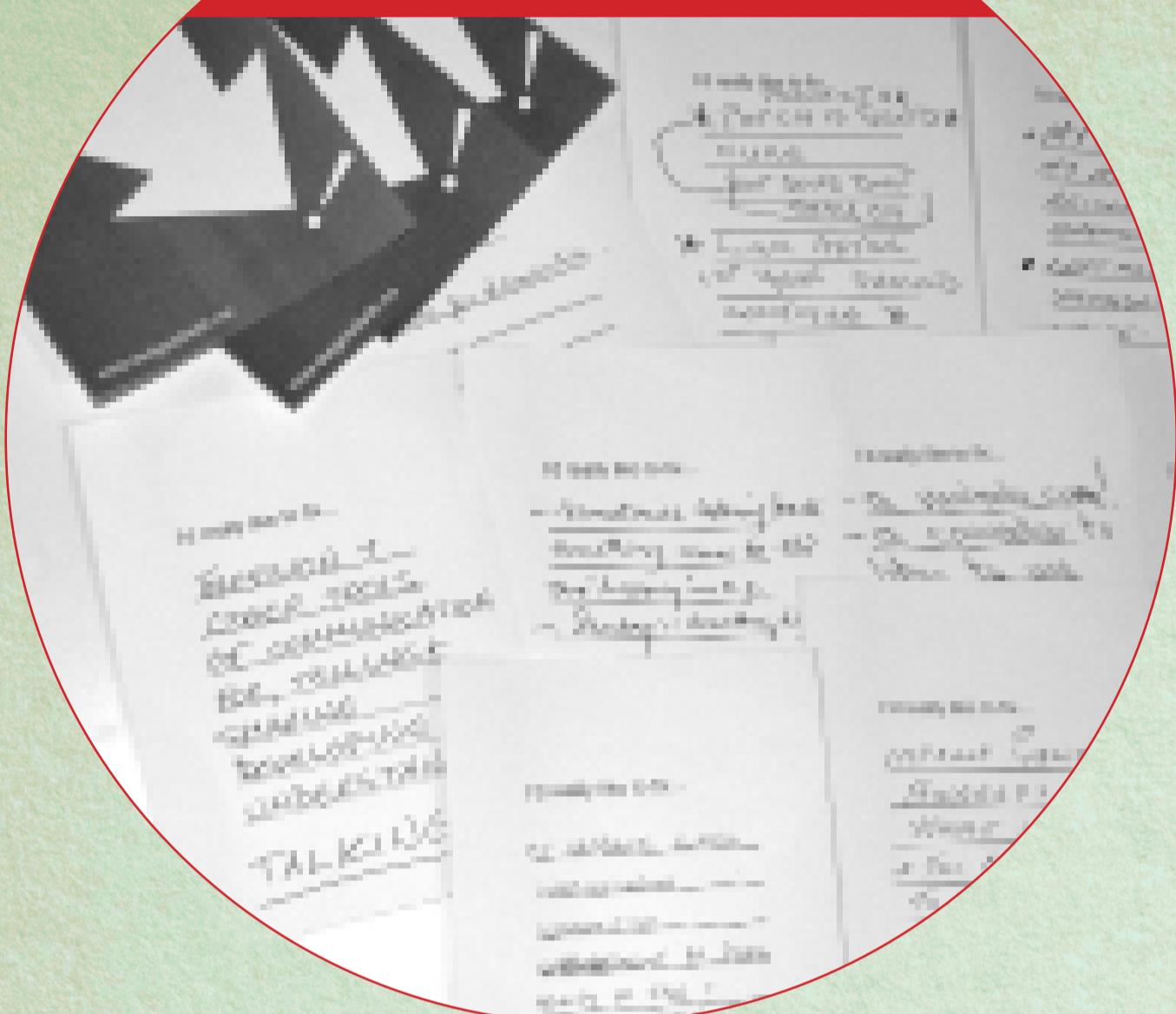
Sometimes looking back helps us design the future

bring-back

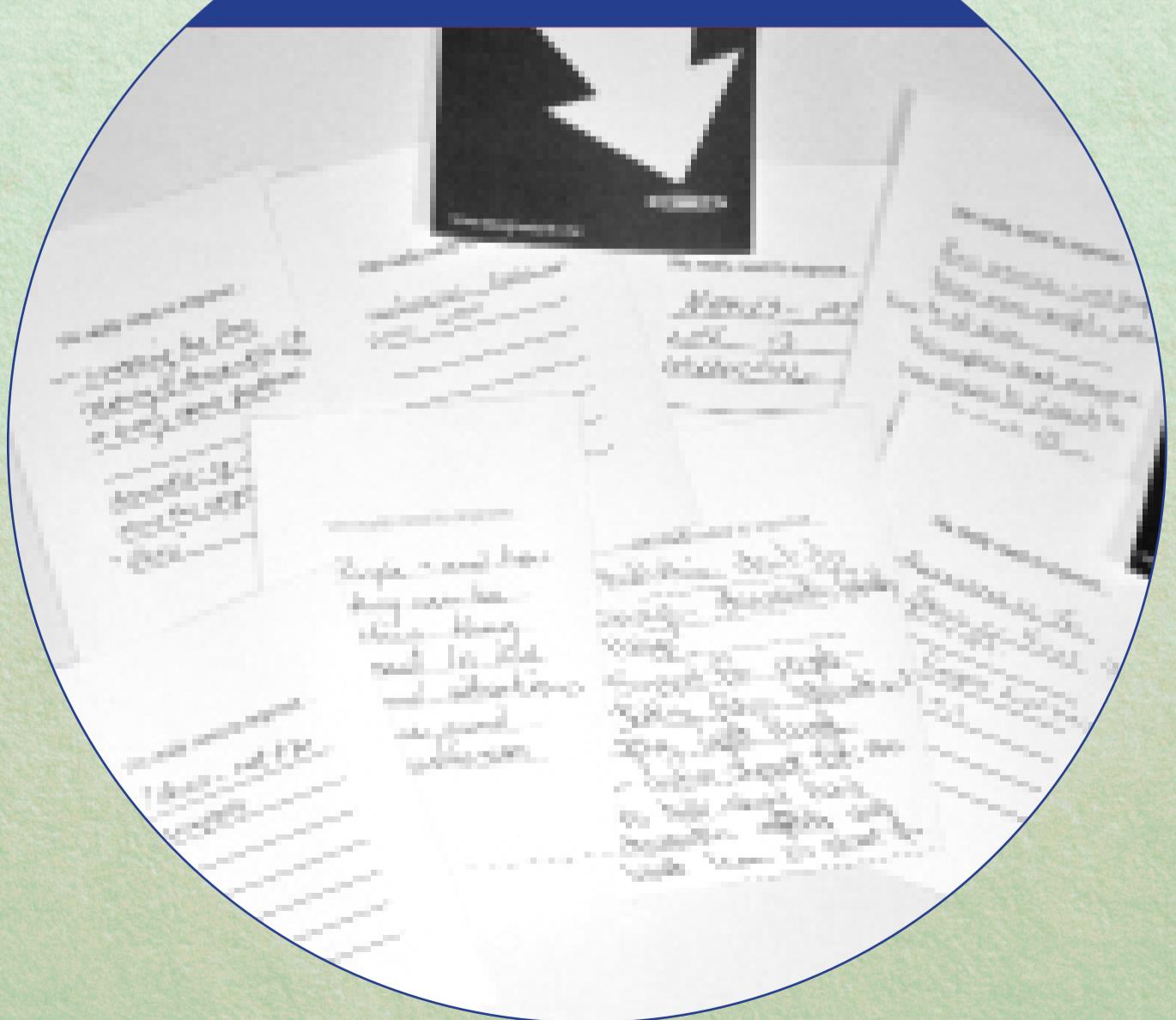
I would bring-back...

[www.designedwith.me](http://www.designedwith.me)

# fix



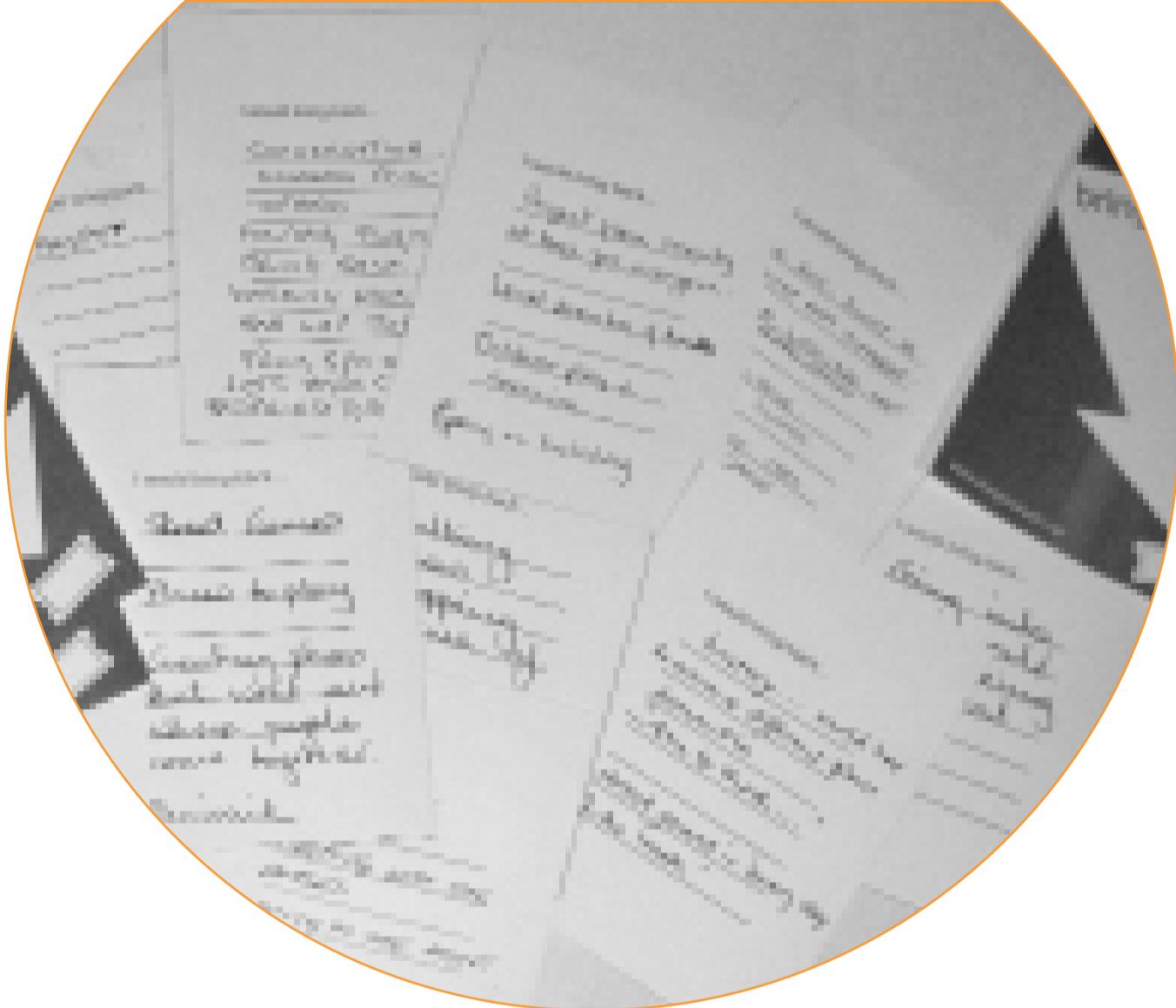
# improve



*“You made us think more than we are usually asked to do and its good for us to have to think.”*

Workshop Participant

## bring-back



### Workshop 1 - Experience Feedback and Findings

From the initial workshop, of 29th November 2016, a number of themes began to emerge that would influence the second workshop. The approach allowed for participants to register thoughts and considerations, however, they did not necessarily pick up all of the details discussed. As such the approach was supported through field notes and reflections taken during and directly after the event. The noted comments and the cards that were filled in were analysed to look at the common themes, thoughts, wants and desires.

The key themes that emerged were:

- Communication and respect
- New banking
- Street play
- Suitable social space
- Less cars
- Less technology
- More quiet space and time
- Strong desire to make Sunday a special day

The key themes were then arranged into a proposition for the next workshop: Redesign Sundays to make them special again, where human centred fun can occur and that supports respect and communication.

One particularly powerful, post workshop, piece of feedback that was offered over lunch was that: *“You made us think more than we are usually asked to do and its good for us to have to think.”* Workshop Participant

Also during the lunch, that followed, it was also noted that the carers or partners of the individuals involved wanted to know more and to understand what had happened during the session. They were interested in the activity and the discussion offering their own insights as the discussion continued. In relation to the carers, they particularly expressed a desire to be involved in any future event.

## Workshop 2: What does a collective response to the brief look like?

On 20th January 2017, a follow-up session was run for *Edinburgh, Mid and East Lothian Dementia Action Network* where the results of the first workshop were put forward. Following which an invitation to develop thinking around the brief, which had been generated at the first workshop, was proposed. In this session both carers and people with a diagnosis of dementia were invited to collage, scribble and chat about their views on what a redesigned Sunday might look like.

The second workshop was an opportunity to extend the practice of the first workshop acting as a route to examine its findings. The first workshop outcomes were developed through participation of only people who have a diagnosis of dementia and are members of *Edinburgh, Mid and East Lothian Dementia Action Network* as a result. Their discussions and views had led to key points of great interest to the individual participants and them as a collective. The key points identified were:

- Communication and Respect
- New Banking
- Street Play
- Suitable Social Space
- Less Cars
- Less Technology
- More Quiet Space and Time
- Strong Desire to Make Sunday a Special Day

Ultimately the ideas centred on opportunities to make time and space for social inclusion, understanding, personal esteem and personal empowerment to be nurtured and supported.

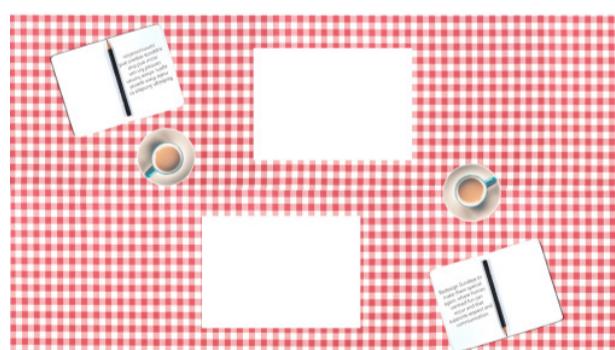
The resultant brief was formed upon the cards supplied for activities in Workshop 1 along with noted conversations that occurred. The outcome of which was:

***Redesign Sundays to make them special again, where human centred fun can occur and that supports respect and communication.***

With the brief set, the second workshop differed from the first as it brought together both carers and people with a diagnosis of dementia to expand upon and think around the brief. The involvement of the carers was arrived at following discussions at the last meeting where carers expressed their desire to know and understand what the group of people who have dementia were doing by way of activities. They were intrigued to know the results of their participation in Workshop 1 including the thoughtful responses given to the posed questions.

Workshop 1 formed a project agenda (generation of a brief) that had been independently set by people who have a diagnosis of dementia making them central to the process, as such, Workshop 2 was an opportune time for the involvement of carers or partners. The wider group allowed for greater involvement, understanding and thinking of the concerned parties supporting a sense of togetherness in discussion and action. The group of participants numbered 28 who were split into tables of 5 or 6.

The Workshop 2 process involved scribbling and collaging. The participants were invited to make marks, scribble details and stick images down to encourage discussion and communication of the discussion and emerging ideas.



Original Tablecloth Design

The day had been organised as a Dementia Cafe day and as such the idea of sketching on a tablecloth was used both as a scene setter and as a tool for generating insight and ideas. The initial proposition was to use a structured printed tablecloth that would restrict the area in which imagery could be stuck down, however, technical difficulties resulted in a slightly alternative approach. Tablecloths were still utilised but these were unstructured and as such offered open space for visual

communication. The participants were given pens and a range of materials that had been pre-cut for the event. The images that were pre-cut were based upon previous discussions incorporating people, activities and environments. The content was arranged by the group through scribbling of notes and ideas and by the selecting and sticking down of self selected imagery. To try to convey the visual representation of the 'research tablecloths' post-production has been used. The result is a cohesive collective image that responds to the brief for each group, which is supported by the original artefacts and notes.

The materials helped to stimulate an hour of action and discussion supported by the creation of tablecloths that depicted ideas and notes on what a better Sunday might look like.

Below are summary points of important discussion that occurred during the session. Please note that the following points were observed or the result of direct discussions that occurred as the research was conducted:

- The importance of Sunday being something different not necessarily special; gate marking a point in the week for something that stands out from everyday activities.

### **Insuring that Sunday's become inclusive for all parties.**

• One carer identified her struggle to feel included especially, after her husband went into full time care, creating a sense that support was limited. It was noted that for her Sunday could often feel like the loneliest day of the week; that it is a day still seen as special and so people suggest it is for and about family, and therefore friends take second place. Equally it was suggested that people don't actually do anything special and it is just another day but one that people appear to set aside for something mentally rather than practically. Since her husband went into care she has found it particularly troublesome.

- Another married couple discussed the problem of families not being close at hand and the because of the movement of people a lesser family connection is possible, which they associated as being something particular to the expectancy of a Sunday.

**The opportunity to mingle with children and younger generations.** Concerns were raised about partners who had dementia talking to children and wanting to talk to children and how society is not attuned to a person doing so. The common discussion in this area communicated by both carers and people with dementia was that there is a real want to connect with younger people and children a desire to talk to them that suggested something of uncomplicated discussion and/or understanding. The discussion noted the need for opportunities for people with dementia to watch and talk to children and younger people.

### Boats and the Sea

One participant noted his long relationship with sailing boats and that he still owned a boat that was now in dry dock. He is no longer able to sail but is still particularly interested in sailing and would like to discuss sailing with people who are interested. He particularly liked the idea of sharing what he knew with younger people who may have no knowledge or understanding of the sea and sailing.

### Sunday as pay-day

One participant suggested that every Sunday should become pay-day identifying it as a special day each week and supporting social activities during the day.

In Workshop 1 a heavy emphasis was placed on the importance of social interaction and play as a means for doing so. In the second workshop the emphasis was on activities that were inclusive, outside, food oriented, involved social connectivity, and developed around places or organisations capable of delivering, supporting or undertaking much more imaginative inclusive approaches.

Through both workshops it has been clear that the need for connectivity and the appropriate places to enable it are key. In many ways the discussion appears to propose openness of places that encourage understanding and reduce stigma or fear. Ultimately maintaining a societal inclusion through cross-generational togetherness. The next challenge will be how to develop such thinking through actions and activities for all.

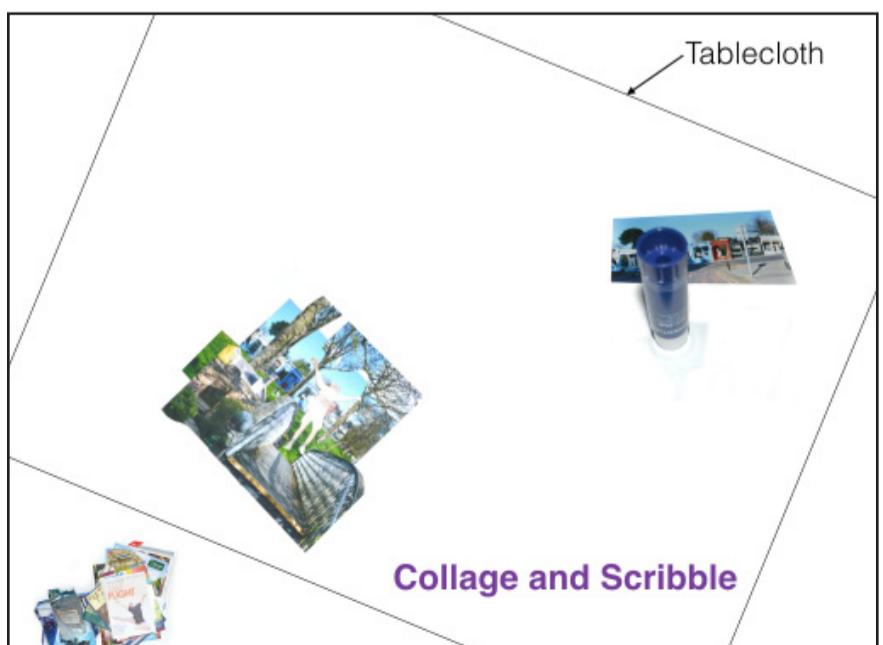


Communication and Respect  
New Banking  
Street Play  
Suitable Social Space  
Less Cars  
Less Technology  
More Quiet Space and Time  
Strong Desire to Make Sunday a Special Day



Communication and Respect  
Street Play / Suitable Social Space  
Strong Desire to Make Sunday a Special Day

**Redesign Sundays to make them special again, where human centred fun can occur and that supports respect and communication**



Collage and Scribble

IN  
MAY  
GREAT  
START

a plan for change

try things out

Smell the  
flowers

plan



Redesign  
Sundays to make  
them special  
again, where  
human centred  
fun can occur  
and that supports  
respect and  
communication

**Table 1 - Not  
about special but  
different**

Family Day; Time/Fun; Lunch –  
Not Different; Fresh Juice; Special  
Breakfast Full Cooked; Church - More  
Outreach - Exchange Ideas; Shut  
All the Shops; Different Activities;  
Read Papers; Plan for Monday; Radio  
Hymns Sing Along 8.10am; Save  
Money; Special Food; Slower Pace;  
Members of Family All Bring Food;  
Wine at Any Given Time; Cooking  
for Others; Gym trackers; No Phones;  
No Internet; Walking; Sport More  
Sport; 2 Hours Reading Books; Smell  
the Flowers; Get Out into Garden,  
Cuppa Listen to Birds; Very Relaxing  
Slow Start; Trips; Visiting – People  
in Homes or Hospitals; 4 Day Week;  
Go Out; Talking to Others Able  
to Talk About Condition Without  
Embarrassment; Make Sunday Payday

**THANKS  
FOR YOUR  
PATIENCE.**



Redesign  
Sundays to make  
them special  
again, where  
human centred  
fun can occur  
and that supports  
respect and  
communication

## Table 2 - More important than working

*Water / Boats – Skills and Knowledge  
(To be Shared); Outside Leisure;  
Upset if Not Getting Out; Welcome  
Intergenerational Conversation; Food;  
Family; More Important Than Working  
– All of Us Had To; Storytelling  
Sunday Mornings; Sunday Family  
Lunch; Church; Going Outside; No I.T.*



Redesign  
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communication

**Table 3 -  
Speaking to  
younger people  
is a tonic**

Family; Gardening to Meet Neighbours  
and Chat; Speaking to Younger People  
is a Tonic; Relaxation; Roast; Fun; Bus  
trip to the seaside – North Berwick;  
Pie and Pint; Wine for the ladies; Pub;  
Park and Ice Cream; Afternoon Tea;  
Picnic in the Park; Brunch; Walks.



Redesign  
Sundays to make  
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#### **Table 4 - Local communities as well as big events**

Social Events that are on the Doorstep  
– Easy Access; Local communities  
as Well as Big Events, Further Away;  
Lots of chat and a drink, I am allowed;  
B.B.El. (local charity) Beyond  
Boundaries East Lothian Special Day  
for My Husband (Cycling); Groups  
organising Events to Consider Holding  
them on a Sunday Afternoon – Make  
them Suitable for All Age Groups for  
Sunday Family Get-together.; Family  
Time; Sun; Cafe; Grannies Heiland  
(House); Embo; Cuddy (Horse); Clyne  
Gleneish.

EMBRACE

opportunities

YOU  
matter.



Redesign  
Sundays to make  
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human centred  
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and that supports  
respect and  
communication

**Table 5 -**  
**Encourage**  
**interaction**  
**accept it as**  
**normal**



Beagle walks!; Communities of Interest; Beach Party; Exercise – Feel Good!; Always Finish the Cake; Children and Dogs [and] Older People Playing Together; Shut the Shops; Churches be Less “Churchy” and More Embracing of Communities. Like Eric Liddel Centre; Have Great Big Picnic; Close Roads to Traffic. Pedestrain Events -> Pedestrain Parties Street; Don’t Pull Children Away Encourage Interaction Accept it as Normal or Reduce the Fear or Reaction; Safety/Engagement; Music – Sunday Concert!; Fresh Air.

# More Important Than Working

## structure

Inclusive Sunday

Social Events that are on the Doorstep – Easy Access

Local communities as Well as Big Events, Further Away

Churches be Less "Churchy" and More Embracing of Communities. Like Eric Liddel Centre

B.B.E.L. (local charity) Beyond Boundaries East Lothian Special Day for My Husband (Cycling)

Communities of Interest

Family

Church

Church - More Outreach - Exchange Ideas

Groups organising Events to Consider Holding them on a Sunday Afternoon – Make them Suitable for All Age Groups for Sunday Family Get-together

Visiting – People in Homes or Hospitals

## rules

No I.T.

No Internet

No Phones

Go Out

Safety/Engagement

Slower Pace

Shut All the Shops

Don't Pull Children Away Encourage Interaction Accept it as Normal or Reduce the Fear or Reaction

Lines of Togetherness

## activity

Close Roads to Traffic. Pedestrian Events -> Pedestrian Parties Street

Beach Party

Different Activities

Trips

2hrs Reading Books

Children and Dogs [and] Older People Playing Together

Storytelling Sunday Mornings

Bus trip to the seaside – North Berwick

Cuppa Listen to Birds

Music – Sunday Concert

Radio Hymns Sing Along 8.10am

Read Papers

Gardening to Meet Neighbours and Chat

Picnic in the Park

Get Out into Garden

Smell the Flowers

Cuddy

Have Great Big Picnic

Very Relaxing Slow Start

Make space by removing distractions

## Workshop 2: What was noted?

The content from Workshop 2 was redeveloped to form the visual communications of what was recorded on the previous pages. The content was also mapped to look at the language and to look again at developing themes.

## interact

Speaking to Younger People is a Tonic

Talking to Others Able to Talk About Condition Without Embarrassment

Skills and Knowledge (To be Shared)

Conversation, sharing and caring

## active

- Outside Leisure
- Walking and Walks
- Beagle walks
- Gym trackers
- Sport More Sport
- Going Outside
- Fresh Air
- Relaxation
- Excercise – Feel Good!

Themes of outdoor leisure and wellbeing

Opportunities for conversation

## consume

Lots of chat and a drink, I am allowed

Intergenerational Food

Brunch

Lunch – Not Different

Members of Family All Bring Food

Sunday Family Lunch

Cafe

Park and Ice Cream

Afternoon Tea

Special Breakfast Full Cooked

Wine at Any Given Time

Always Finish the Cake

Pie and Pint

Wine for the ladies

Roast

Pub

Special Food

Cooking for Others

food central to a relaxed welcoming atmosphere

How can hosting and serving work?

Time and Fun

Make it inclusive  
and enriching for all

- Introduce play
- Build on skills
- Break down barriers
- Find fun ways to overcome stigma or fears

Where and how?  
Should this happen?

Scheduled  
events?

Making and doing  
zone

Indoors or  
outside?

Relaxing  
environment  
for everybody  
a space for  
people

Hobbies  
and interests

Develop shared  
interests

Play should be for  
adults too.

## Games and Play Space

Cards  
ceremony  
play a role -  
like afternoon  
like tea?

Should people attending need to  
bring something - 'What will you bring to the party  
?'

## Reading and Storytelling area

Mixture  
of rest  
and play

Bring a story,  
tale or favourite  
book to a new  
audience by reading  
to a group or by  
listening to someone

Redesign Sundays to make them special again, where human centred fun can occur and that supports respect and communication **Let's do something that offers inclusive cativities and invites openness, caring, fun support and sharing...**

## Our Big Picnic

(Option 1)

**Our Big Picnic** - getting people in one place is made easy by the big picnic idea. It allows people of all ages and backgrounds to collect in an organised event where those who attend supply all their own food and drinks, and make the entertainment. Strawberries, sandwiches, pie and childish joy is required in a real big picnic experience.

Our Big Picnic is therefore simple in its conception. However, Our Big Picnic will be slightly more carnivalesque or fete like, closer aligned to traditional big picnic events. Indoors or outdoors the idea will be to incorporate themes of play, interests and hobbies and yarn telling in the open air (or dependant on Scotland's weather - indoors). Groups can be encouraged to put on a show and whatever ways that can be thought up to generate interaction between everyone involved will be heartily encouraged.

Time and open space out in the fresh air (preferably) will see a temporary community emerge for the day, where people make new friends and learn a little more about each other.

Dependant on the wishes of the Co-design team a theme may be sought.

## Open Street

(Option 2)

**Open Street** - Let's open our streets again to become a local social hub for play, talk and local understanding. The Scottish Government and Local Authorities have recently made the process to 'reclaim the streets' easier opening up the potential to ban cars and block off a street for a special event much easier. On this Sunday event the intention will be to make a chosen street more like streets from yester-year in that they become about people and the residents living in them again. By removing cars and creating a community focus for one day the street can be claimed for; kids to play in and for adults to meet in, and for adults and kids to meet and play in. A place for neighbours to; sit on their front door step, or to welcome people into their front gardens, or even to meet in the middle of the road to have a natter. Skipping, kerbie and tennis football are all encouraged, if you want to run about like superman just do it.

Encouraging neighbourly behaviour and making people feel part of something on their doorstep will allow us to think again about the places in which we live and the people around us. Share a cup of tea on someone's lawn or even find something to do after the day is done.

If a true spirit of neighbourliness is fostered than you might find a problem to fix or be offered help from the very people that live around you.

## D:caf

(Option 3)

**D:caf** is a dementia service with a difference. Here people living with dementia deliver a hospitable place for fun, conversation, innovation, play and companionship in an equalitarian environment.

Time and space are commodities that very few people recognise in modern lifestyles. Insular activities and the pressure of the cyber-social world have lead to a situation where people are becoming less sociable. In a real world setting and with real people to engage with D:caf will offer a place to invest in yourself and others through the acts of tea and a chat, gameplay and cake eating, hot chocolate and storytelling.

If you can't remember the last time you played a board game, cards or dominos and the idea of listening to someone tell a tale sounds reassuring and cosy then this will be the place for you.

Duration: A one off a 3 day Pop-up Cafe/ Eent Space operating from Friday to Sunday. Organised as a Social Enterprise.

### Pop-up (cafe/event space)

*adjective* • used to describe a shop, restaurant, etc. that operates temporarily or for a short period when it is likely to get a lot of customers.

### Social Enterprises

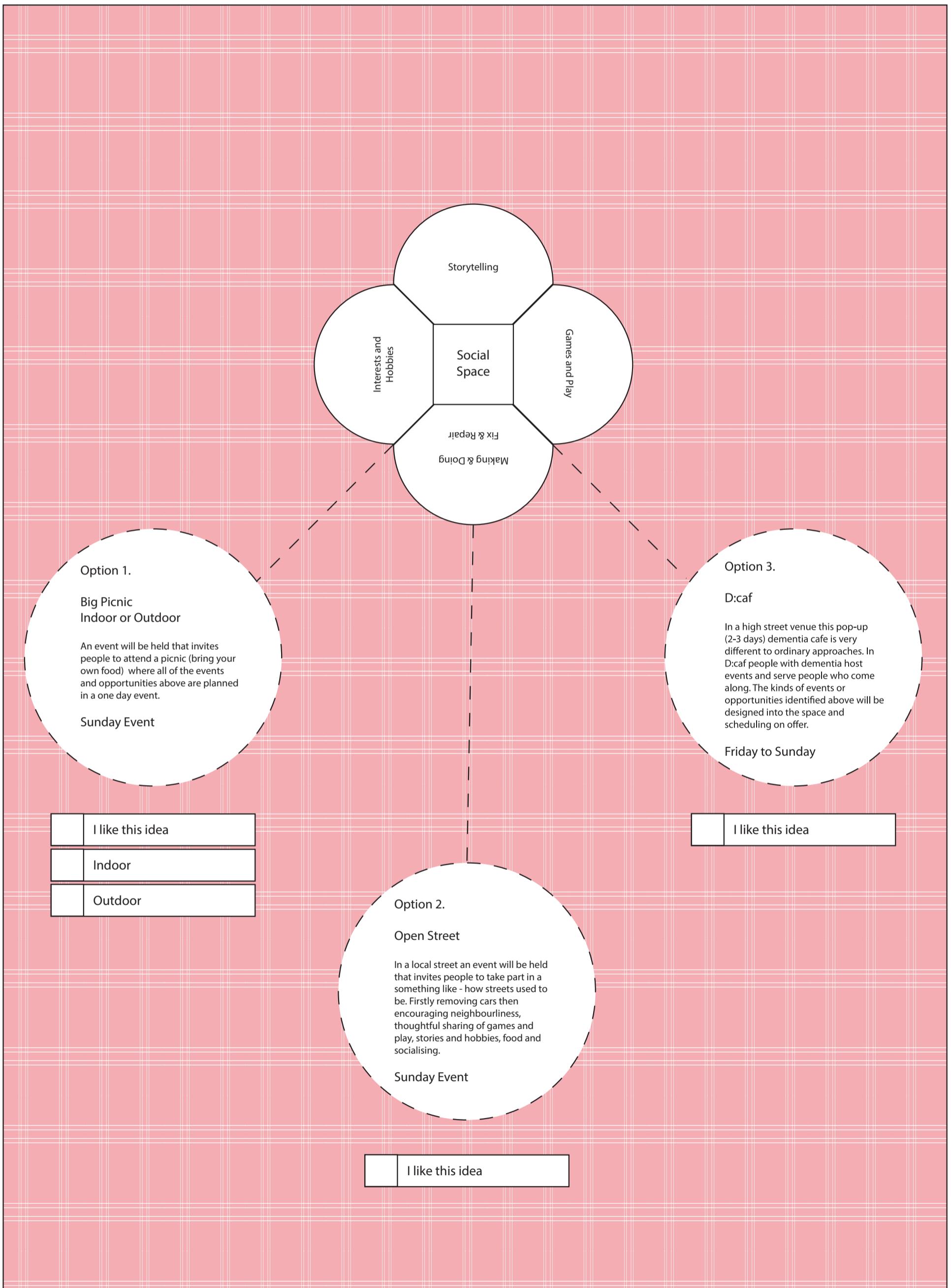
Social enterprises treat to tackle social problems, improve communities, people's life chances, or the environment. They make their money from selling goods and services in the open market, but they reinvest their profits back into the business or the local community. And so when they profit, society profits.

[socialenterprise.org.uk](http://socialenterprise.org.uk)

Examples:

**Social Bite**, where 1 in 4 staff are formerly homeless and where each store serves 30 homeless people gifted food and coffee each day. <http://social-bite.co.uk>

**The Grassmarket Café**, 'The café encourages vulnerable adults to volunteer and gives them the opportunity to reconnect with society and move into employment.' <http://grassmarket.org/cafe>





Let's - Redesign Sundays to make them special again, where human centred fun can occur and that supports respect and communication **Let's do something that offers inclusive activities and invites openness, caring, fun support and sharing...**

## Count me in

The aim is to make something happen this summer. To develop the winning idea (tick a box on the previous page) a further workshop will be held at the Eric Liddell Centre in Edinburgh in mid May. If you would like to be involved please fill in your:

Name(s):

Email:

Phone Number:

Please return this completed form in the supplied addressed and stamped envelope with your answers.

Many thanks for your support, co-operation and participation in the project *Designed With Me*. Keep up to date with the project at: [www.designedwith.me](http://www.designedwith.me)

Yours sincerely

Euan Winton

## I would love to... I think I could...

Please tick your preferences or note your answers:

Hear a tale

Tell a tale

Read a book to people

Hear a book being read

Play music

Listen to music

My favourite music is \_\_\_\_\_

I'd love to hear \_\_\_\_\_

My favourite game is \_\_\_\_\_

I'd like to play \_\_\_\_\_

I could show you how to \_\_\_\_\_

I'd like to learn how to \_\_\_\_\_

I'd like something fixed \_\_\_\_\_

I could help fix things \_\_\_\_\_

You may have skills and knowledge that would be very helpful in making this happen or that could be made use of during an event. You might be great at making. You might have skills in fixing things. Are you brilliant at cooking? Do you tell a great tale? Do you remember what playing should be like? You might be a great artist. Or you might just make a very good cup of tea.

Tell me how you might add something special or what kind of thing you would like to do.

I have always been good at...

I think I could use this to...

I've always been interested in...

I could share my skills in...

I would be happy to...

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