Creating an Active Multisensory Environment for People Living with Dementia (AMuSED)

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This thesis is submitted for the degree of

Doctor of Philosophy

November 2022

Dedication

This PhD is dedicated to my parents Folusho Olorunda, Esq. and Mrs. Lola Olorunda, without whom this would not have been possible.

Declaration

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

- Esther Olorunda

Acknowledgement

I would like to express my gratitude to both of my supervisors Prof Rachel McCrindle and Prof Simon Sherratt for their continuous support throughout the PhD. Dear Rachel, I am thankful for your encouragement, motivation, and for all the times you pointed me in the right direction and connected me with the right people. Your excellent guidance and insightful comments during the writing of this thesis were invaluable and highly instrumental in my growth as a researcher.

Thankful to Michelle Berry, Kim Franks, Matt Strevens, Philip Keohane, Tracey Esteve, Terry Spencer, and the Dementia Friendly Reading Steering Group for their immense support and for providing me with a platform to conduct my evaluations. Thank you to the Royal Berkshire Hospital Care Crew and also to Phillippa Heath of The MERL who was an absolute delight to work with and never let me leave The MERL without having some cake. Special thank you to Fred McCrindle for the lovely car rides and tours of Reading and Newbury whist helping me to deliver the AMuSED boxes to the evaluation sites.

Finally, I am grateful to my parents who always provided me with a safe space to vent my thoughts, continuously cheered me on and showered me with love and unwavering support. Special thanks to the rest of my amazing support system Olubunmi, Oluwaseun, Felicia, and Ifeoluwa for always being there, consistently reminding me to rest and for allowing me to constantly bombard them with Snaps of progress updates. My sincere appreciation also goes to Harry Richardson who constantly checked on me, never failed to ask how my PhD was going and always ensured that I had all the flexibility I needed in my schedule.

Abstract

There are over 50 million people with dementia worldwide including 900,000 people in the UK. Dementia is a health condition that can affect the memory, thinking capability, mood, behaviour, orientation, and lifestyle of a person living with it. It is an overall term used to represent a range of progressive disorders that cause damage to the brain. To maintain wellbeing, reduce apathy, and encourage participation in activities outside of a person with dementia's daily routine, it is important to provide opportunities for engagement in activities such as art, exercise, music, aromatherapy, and reminiscence. There are many very useful interventions, kits and activities on the market that help meet this goal ranging from simple jigsaws and colouring books to highly technical sensory rooms and interactive games. However, whilst each intervention contributes known benefits, there are also some downsides variously attached to them such as: high cost per unit, primary focus on only one element, inability to engage users for a long time, lack of challenges in games and activities, inability to cater to people across different stages of dementia, lack of adaptability as a person's dementia progresses, and inability to be personalised based on users' interests. Through working with a group of experts in dementia care and adopting a user-centric Design Thinking approach to the research, this PhD has developed a multisensory toolkit, AMuSED (**A**ctive **Mu**lti-**S**ensory **E**nvironment for People Living with **D**ementia) that brings together different aspects of dementia therapy into a single portable box for use by carers, care teams and dementia activity coordinators with people living with dementia to engage and stimulate them physically, mentally, and socially through a combination of sensory elements and themed activities. As well as defining the AMuSED Concept and creating the AMuSED Framework as a way of specifying different AMuSED toolkit themes, four differently themed AMuSED toolkits (Countryside, Seaside, Christmas, and Entertainment) were developed and evaluated in six different care environments during the PhD.

Table of Contents

Table of Figures

List of Tables

Chapter 1: Introduction

1.1 Introduction to dementia

Dementia is a health condition that can affect the memory, thinking capability, mood, behaviour, orientation, and lifestyle of a person living with it. It is an overall term used to represent a range of progressive disorders that cause damage to the brain, the most common of which is Alzheimer's, which accounts for 60-70% of cases (World Health Organization, 2018). The symptoms of dementia present differently in each person living with the condition as its manifestation is dependent on the affected parts of the brain and the underlying illness causing it. The progressive nature of the disease also means that these symptoms tend to worsen over time and although there is no cure for dementia, there are medical interventions and non-pharmacological methods available that aim to maintain quality of life, increase life expectancy, and prolong the independence of a person living with dementia for as long as possible post diagnosis.

Even though dementia is not a normal part of the aging process, it predominantly affects older people (LoGiuduce and Watson, 2014), therefore as the world's population ages, the number of people living with dementia has been projected to continue to increase, especially in low- and middle-income countries (Prince, Guerchet and Prina, 2013). Of the many types of dementia including Alzheimer's disease (AD), vascular dementia (VaD), frontotemporal dementia (FTD) and dementia with Lewy bodies (DLB) (Goodman et al., 2017), Alzheimer's disease has been recorded as the most common type of the dementia globally (Marfany et al., 2018).

The number of people living with dementia globally has been projected to increase from 58 million people in 2020 to 82 million by 2030 and 152 million people by 2050 (Alzheimer's Disease International, 2020). Of this number, Alzheimer's disease accounts for 50-75% of all global cases, vascular dementia for approximately 17%, dementia with Lewy bodies for 10%, and frontotemporal dementia, which is a less common form of dementia, for about 2% of remaining global dementia cases (Alzheimer's Disease International, 2020). More specifically, in the United Kingdom, there are approximately 900,000 people living with dementia, a number projected to rise to 1.6 million by 2040. In a similar trend to the global population, Alzheimer's disease accounts for 50-75% of UK cases, with vascular dementia accounting for up to 20%, dementia with Lewy bodies about 10% and frontotemporal dementia approximately 2% of UK cases (Alzheimer's Society, 2021).

The progression of dementia comes with a decline in a person's cognitive functions such that a person with dementia begins to lose their ability to reason, recall, understand and communicate. As a way of describing the progression of the disease, dementia is often categorised into three stages: mild (early stage), moderate (middle stage), and severe (late stage) dementia (Wittenberg et al., 2019; Alzheimer's Society, 2021). The proportions of severity among dementia cases in the UK are recorded as 55.4% for mild dementia, 32.1% for moderate dementia, and 12.5% for severe dementia (Alzheimer's Society, 2014).

People who are diagnosed with dementia usually require varying levels of post diagnosis support depending on the severity of the diagnosis and the speed of progression of the disease. This form of support can range from support groups (Mason, Clare and Pistrang, 2005) and dementia cafes (Takechi et al., 2019) to assistive technologies (Gibson et al., 2016) and other forms of non-pharmacological therapy (Meyer and O'Keefe, 2020). The large numbers of people affected mean that very significant amounts of money are spent globally on direct medical, social care and informal care costs with the total costs expected to surpass $2.8 trillion in 2030 (World Health Organisation, 2021). In the UK the total cost of care for people with dementia is £34.7 billion, a figure that is set to rise sharply to £94.1 billion by 2040. This includes the cost of social care for people with dementia, which is set to nearly triple by 2040, increasing from £15.7 billion to £45.4 billion (Alzheimers Society, 2019).

1.2 Rationale for engagement

Dementia not only causes cognitive decline in people living with the disease, but also reduces their capacity to perform daily tasks (Takeda, Tanaka, Okochi and Kazui, 2012). Many older people living with dementia also develop behavioural issues such as agitation, aggression, delusion and wandering (Finkel, Burns and Cohen, 2000), and a further manifestation of dementia especially in its advanced stages is passivity or the exhibition of passive behaviours which are defined as diminution of behaviours such as a decline in motor skills as well as apathy and a lack of interaction with the environment (Colling, 2000). Passivity has been shown to be even more of a problem than aggression (Stewart, 2004) causing disruption in activities of daily living (Vernooij-Dassen, 2007) as well as a decline in physical and social functions (Harwood, Barker, Ownby, & Ducra, 2000). Although agitation and passivity seem like opposites, their causes may both be attributed to a lack of stimulation from the physical and social environment (Kolanowski, Litaker and Buettner, 2005).

To reduce the occurrence of behavioural issues and promote wellbeing among people living with dementia, there is a need to provide meaningful activities in both formal and informal settings (Nyman and Szymczynska, 2016). Informal interventions can be in the form of support groups or dementia cafes (Bannan and Montgomery-Smith, 2008) while more formal approaches like psychological and reminiscence therapies (Guss et al., 2014) can also be incorporated. Pleasurable activities such as exposure to art (Camic and Chatterjee, 2013), plants and green spaces (Ashton, 2015), and therapies such as music, food and light therapies have been shown to help people living with dementia who are under-stimulated by reducing their functional decline, improving their physical function, relieving stress and enhancing their behaviour (Buettner and Ferrario, 1998). These therapies and activities are usually administered by their caregivers who may be professional care workers when in community settings, but who are often members of the family that take on the care role informally (Roland and Chappell, 2017) as many people continue to live in their homes post diagnosis (Banerjee et al., 2003). This focus on activities not only benefits people with dementia but can also help to strengthen the bond between them and their caregivers and reduce caregiver stress (Carbonneau, Caron and Desrosiers, 2011).

1.3 Carer givers and dementia activity coordinators

People living with dementia usually require some form of care in different aspects of their daily lives. Due to the behavioural issues they normally face, the provision of meaningful activities for them is important to their caregivers regardless of their living arrangement or care setting (Skrajner and Camp, 2007). In care homes and hospital settings, activities are generally organised by care crew (Brooke and Herring, 2016) or activity co-ordinators (Guzmán et al., 2017) who deliver both active and passive activities and experiences that aim to promote the health and wellbeing of those they are caring for (Evans et al., 2019). This can range from music, reminiscence, art, puzzles, and games to more passive approaches like watching movies (Rybacka, Brooke and Wright, 2017) with successful delivery of activities usually involving teamwork and collaboration between the activity coordinators and care staff (Guzmán et al., 2017). Activity coordinators are also sometimes employed in personal homes through local or government funded programmes to provide support and deliver pleasant activities to people with dementia living in their homes (Lord et al., 2020). However, in many instances, unpaid family members provide most of the dementia care (Perti et al., 2019) and also have the added responsibility of keeping the person they care for entertained and occupied (James et al., 2014; Roland and Chappell, 2017).

1.4 Meaningful activities to promote engagement and stimulation

There are a very wide range of excellent and appropriate activities available on the market designed to engage and stimulate people living with dementia including specialist multisensory rooms and environments such as the Snoezelen (Duchi et al., 2019; Lorusso and Bosch, 2018), projected interactive gaming systems such as the Tovertafel (Anderiesen, 2017) 'magic table'; robotic pets such as Paro the robotic seal (Shibata et al., 2001) and NeCoRo the robotic cat (Libin and Cohen-Mansfeild, 2004); reminiscence kits and memory boxes (Schweitzer and Bruce, 2008); sensory kits and CDs (Higgs et al., 2020) and jigsaws and colouring books designed for adults with dementia. However, upon review of the many products available on the market, whilst each is beneficial and therapeutic in one or more ways there is currently no single product that has all the qualities of being low-cost, portable, and adaptable to different stages of dementia, and which combines sensory and activity elements with physical and media artifacts through a strong reminiscence theme.

1.5 Aim of the research

The aim of this PhD is to develop an **A**ctive **Mu**lti-**S**ensory **E**nvironment for People Living with **D**ementia (AMuSED) that that brings together, in a single toolkit, different aspects of dementia therapy that are contained in a single portable box for use by caregivers, care teams and dementia activity coordinators to engage and stimulate people living with dementia physically, mentally, and socially through a combination of sensory elements and themed activities.

1.6 Covid statement and scoping statement

Prior to stating the objectives of the research it is important to state that this PhD was undertaken during the 2-year COVID period which meant that whilst the PhD has followed a robust research process, has produced innovative outcomes, and whose value was not compromised in any way, COVID did necessitate a number of changes to (1) the original focus of the PhD; (2) the way in which the research process could be conducted; (3) the way in which it was possible to interact with the collaborators and participants involved in the project; and (4) the type of data that could be collected.

1.6.1 COVID-19 impact statement

Covid-19 impacted on the PhD in the following ways:

PhD focus: the initial aim of this PhD was to investigate, from a metrics driven viewpoint, whether the Tovertafel (an expensive and non-portable interactive games table developed in the

Netherlands for people with dementia) recently installed in the Royal Berkshire Hospital could be used to support patients with dementia and assess whether it could be successfully used to (1) engage and stimulate patients with dementia who were apathetic, and (2) engage and calm patients who were demonstrating aggressive behaviours; and (3) to compare how its use in a hospital setting would differ from it more normal installation in care home environments. However, in March 2020, the Covid-19 pandemic led to lockdowns, bans on people visiting hospitals and care homes, and additional pressures of covid on NHS staff which made it impossible to continue with this direction for the PhD. Building on the initial primary and secondary research undertaken prior to March 2020, the aim of the PhD was subsequently altered to the development of a novel non-pharmacological intervention, AMuSED, to assist activity coordinators to engage and stimulate people with dementia.

Involvement of users during design and development of the intervention: After COVID lockdowns curtailed plans to work inside hospitals and care homes, strong collaborations were established with dementia care experts via the Reading Dementia Friends Steering Group which has been set up to discuss and ensure best practice dementia care in Reading and the surrounding area. This Steering Group, which moved to being an online during COVID, enabled the co-design and co-development of AMuSED intervention with experts, but it did mean that the project could not directly involve people with dementia or their caregivers in the design process as would normally be done in a user-centric design process.

Evaluation process: Recurrent lockdowns imposed by the UK government also caused disruptions to the evaluation of this research including (1) Inability to be present during the evaluations at some of the evaluation sites due to the UK wide restrictions which prevented people other than care home staff from being on site; (2) Prevention of planned AMuSED activity sessions from taking place for as long as three or more weeks due to covid outbreaks at different care homes; (3) Cancelled community engagement activities such as chatty cafes for a significant period; (4) Illness or isolation of care home managers, care home staff and activity coordinators due to covid causing staff shortages and a focus away from engagement activities to basic care resulting in fewer evaluation sessions than planned, and a less consistent approach to data collection than planned as not all evaluations could take place in the timescale of the PhD; (5) The inability to set up longer-period hypothesis driven trials with control groups within the care homes (something now discussed for future work)

1.6.2 Scoping statement

As a result of the impact of COVID-19 documented in Section 1.6.1 it should be noted that this PhD has been focused on developing a novel intervention, the AMuSED toolkit as well as the development of the AMuSED Model/Framework to ensure that the work has a legacy in the dementia community. It has involved a range of stakeholders at different stages of the research process and the AMuSED Toolkit has been evaluated from the perspective of caregivers and activity coordinators in multiple care locations over a period of time despite the very challenging circumstanced described in Section 1.6.1. Given the circumstances however it was not possible to undertake any clinical or other forms of metric measurement/experiments to assess the benefits of using AMuSED on either activity coordinators or people living with dementia within the scope of the PhD, but how this could be undertaken is described in Section 9.4 Further work.

1.7 Key research objectives

As stated in section 1.5, the aim of this PhD is to develop an **A**ctive **Mu**lti-**S**ensory **E**nvironment for People Living with **D**ementia (AMuSED) for use by caregivers, care teams and dementia activity coordinators to engage and stimulate people living with dementia through a combination of sensory elements and themed activities. In order to achieve this the objectives of this research were to:

1. Work alongside dementia experts to co-create the requirements for a multisensory and multi-activity environment for people living with dementia.

2. Translate the co-created requirements into a series of prototypes that increasingly define the form of an **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) as an affordable, adaptable and portable toolkit that can be used by caregivers and activity coordinators to provide engaging and stimulating multi-sensory and multi-activity sessions to people living with dementia in a range of care provisions.

3. Based on the series of AMuSED prototype toolkits created, develop an AMuSED framework and model that enable different AMuSED toolkits to be defined for individuals, themes, and/or places of care including for example, individual homes, community settings, care homes and hospitals.

4. Evaluate a range of AMuSED toolkits with care teams and activity co-ordinators in community and care facilities in Reading and Newbury.

1.8 Research approach

The foundation of this research is the Design Thinking methodology (Brown, 2008). This method was selected for use in this PhD due to its ability to provide a series of processes that can be used in the identification of problems and creation of useful solutions. At its core, design thinking is based on the principle that development should always start by building an understanding of the group of people a solution is being created for and what their needs are (Bell, 2008; Ahmed, Dannhauser and Philip, 2018). As such, it is a person-centred innovation process that places emphasis on observation, collaboration, fast learning, idea visualisation, prototyping and business analysis (Lockwood, 2010) and it was used throughout this research to identify gaps in literature and practice for providing engagement to people living with dementia, and to develop meaningful solutions to address these gaps. The Design Thinking methodology and its justification for use, is discussed further in Chapter 4.

There are three key beneficiaries to this work: (1) carers/activity coordinators who need to provide meaningful activities; (2) people living with dementia who will engage in these activities, and (3) families or care home/hospital managers who need to fund such interventions. The initial idea for the AMuSED toolkit stemmed from discussions with the dementia nurses and a volunteering session with the Care Crew at a hospital in Reading, however, COVID lockdowns curtailed our plans to work inside hospitals and care homes. Instead, we established collaborations with dementia care experts via the Reading Dementia Friends Steering Group, which discusses and provides best practice dementia care in Reading and the surrounding area. This group included dementia experts working across different contexts of dementia care, support and advice and who as a collective possessed a wealth of expertise relating to dementia activity provision and who were ideally placed to co-design and critique the AMuSED concept and its various prototypes. This process was approved by the University of Reading's Ethics Committee with the inclusion criteria being that each of the experts must have a position of responsibility associated with dementia as well as access to an online video conferencing platform such as Zoom or Microsoft Teams. Prototypes formed an important part of the discussion process throughout the process with expert feedback and ideas being incorporated into the new versions of the AMuSED toolkit after each meeting. At the end of the design process four themed AMuSED toolkits were evaluated in community or care homes settings in Reading and Newbury.

1.9 Novelty of the research

There are four key contributions to the field from this research:

1. The concept of an affordable, portable and adaptable **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) toolkit, based on analysis of current state-of-the-art research and state-of-the-practice therapy, for use by caregivers and activity coordinators to provide engaging and stimulating multi-sensory and multi-activity sessions for people with dementia (detailed in Chapter 4)

2. The AMuSED Box and Toolkit, a multi-sensory and multi-activity toolkit that implements the AMuSED concept so that it can be used by caregivers and activity coordinators in different care settings such as individual homes, community spaces, care homes and hospitals to stimulate the physical, mental and social wellbeing of people living with dementia (detailed in Chapter 5). The AMuSED box refers to the printed reminiscence panels that form the box sides; and the AMuSED toolkit refers to the contents of the box – but both terms are generally interchangeable and are used as such throughout this thesis as they form part of the same AMuSED entity.

3. The AMuSED Framework and Model – a framework that formalised the ideas incorporated in the AMuSED Concept and AMuSED Toolkit Prototypes in order that AMuSED Boxes can be specified and built based on individuals' preferences, requested themes, and/or places of care including for example, individual homes, community settings, care homes and hospitals. This framework forms the basis for the continuation of the AMuSED work and its translation from research into mainstream social care provision (Chapter 6).

4. The application of Design Thinking to the creation of non-pharmacological intervention design for people living with dementia (Chapter 8)

1.10 Structure of the thesis

This thesis highlights the roadmap of the research from conception to the final contributions. The chapters examine the journey taken from the introduction of the research to the key recommendations for future research.

Chapter two introduces the main types of dementia and the impact that the condition has on people living with it and those caring for them. It then focuses on the underpinning research that has been done to date on multisensory activities for people living with dementia as well as considering how other non-pharmacological interventions such as those involving art, music, and reminiscence can help people living with dementia.

Chapter three explores a range of existing technologies and products currently available for providing activities to people living with dementia such as reminiscence boxes, fiddle muffs, the Tovertafel interactive table, and sensory rooms etc. and their use in engaging people living with dementia.

Chapter four focuses on the research design and requirements co-creation process. It details the design thinking methodology, user-centred design concepts, and the range of observational, discussion and design activities undertaken with different dementia experts from community, care home and hospital environments. It then combines the outcomes of these design concepts and expert opinions with findings from the literature in Chapters 2 and 3 and defines the key requirements for an active multisensory environment that will help caregivers and activity coordinators provide engaging and stimulating activity sessions for people living with dementia. This stage represents the first novel output from the PhD – the AMuSED (**A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia) concept.

Chapter five describes the practical development of the AMuSED toolkit, the second novel output of this research. This chapter shows how the design thinking methodology and user-centred design were translated into the development of the AMuSED toolkit. It details the different forms of stimulation offered by the toolkit and explains their relevance to providing engagement for people living with dementia. It also highlights the elements and activities in the toolkit as well as the prompt sheets and activity booklets created to help support the caregivers and activity coordinators.

Chapter six introduces the AMuSED framework and model, the third novel output of the research. This chapter describes the AMuSED model including each of its layers and how they have been influenced by the processes described in chapters 2 to 5. It also describes the toolkit library, its relevance to the AMuSED toolkit, and to the different AMuSED box themes. The AMuSED framework acts as a tool for defining and creating further AMuSED boxes based on caregiver or activity coordinator requirements for the people in their care.

Chapter seven details the evaluation of the AMuSED concept and the resulting AMuSED boxes. It examines the evaluation and data collection process from the various evaluation sites and the results of the evaluations.

Chapter eight discusses the results of the evaluation and the ways in which the different AMuSED toolkits were used by activity coordinators to engage people with dementia in the different care settings. This chapter focuses on the results of the evaluation in relation to the existing literature, the effect of themes on the AMuSED toolkits and shows the importance of providing engagement through an active multisensory environment for people living with dementia.

Finally, the thesis concludes with chapter nine by summarising the work undertaken, discussing the strengths and limitations of the research and highlighting the PhD's contribution to the field of non-pharmacological dementia care. It also makes key recommendations for future research

1.11 Summary

This chapter provided an introduction into dementia care and the importance of having activities available to caregivers and activity coordinators that will provide stimulation and engagement to people living with dementia. The chapter also describes the research approach undertaken and summarised the aims and objectives of the research as well as the contributions to the field which will be described in more details in the forthcoming chapters.

Chapter 1

Background on dementia

Chapter 2

Underpinning research on multisensory activities

Chapter 3

Non-pharmacological interventions in practice

Chapter 4

Requirements co-creation with dementia experts

The AMuSED Concept

Chapter 7

Evaluation of AMuSED

Chapter 5

The AMuSED Toolkit

Chapter 8

Use of AMuSED with people living with dementia

Chapter 6
The AMuSED Framework

Chapter 9

Summary and suggestions for future work

The AMuSED Model

Novel contributions of the PhD

Chapter 2: Multisensory activities for people living with dementia

2.1 Introduction

To identify a key problem, understand user needs related to this problem and determine the research objectives of this PhD to solve the problem, this chapter explores dementia, its different forms and the effect it has on people living with the condition. It also explores the behavioural and psychological symptoms of dementia such as apathy, passivity, agitation, and ways in which they can be managed through non-pharmacological interventions. It reviews the different forms of therapies and activities used in the provision of engagement for people living with dementia such as art therapy, music therapy, reminiscence therapy, and multisensory stimulation and highlights their key benefits as reported in the literature.

2.2 Common forms of dementia

There are different forms of dementia, including Alzheimer's disease (AD), vascular dementia, mixed dementia, dementia with Lewy bodies, frontotemporal dementia, and others (Bruun et al., 2018). Although various forms of treatment might lead to an improvement in dementia symptoms, many dementia causing diseases are incurable (Alzheimer's society, 2018). To treat the symptoms of dementia either pharmacologically or non-pharmacologically and maintain quality of life for as long as possible, it is important for patients to receive as early a diagnosis as possible. Most people with dementia present first to their family physicians for diagnosis (National Institute of Health and Clinical Excellence, 2011), as primary care physicians are usually the first to observe patients with possible dementia symptoms and are often the ones to make the diagnosis (Van Hout, Vernooji-Dassen and Stalman, 2007). One of the challenges of dementia diagnosis is a person's denial of changes in their cognitive ability (Lampson, 2021), mood, behaviour (Brijnath et al., 2021) and functional ability especially as these are often masked by coping strategies adopted by dementia patients (Woods et al., 2003). Family physicians take any present risk factors such as older age, female sex, family history into account before the performance of any diagnostic tests. Factors such as patient history, family input and physical examination should also be considered as they are vital to the diagnosis of dementia (Galvin and Sadowsky, 2012).

Alzheimer's disease is the most common form of dementia and is classified as a neurodegenerative disorder as it is associated with tangles in the brain, inflammation, loss of connections and the eventual death of brain cells (Rizzi, Rosset and Roriz-Cruz, 2014). It is characterised by a progressive impairment of behavioural and cognitive functions including comprehension, reasoning, language, judgement and attention (Kumar et al., 2018) which can affect their quality of life (Lök et al., 2019) and ability to perform activities of daily living (Cuevas et al., 2020). Advancing age has been identified as the most significant risk factor of Alzheimer's, with incidence doubling every five years after the age of 65 (Hazan, 2020). Alzheimer's is typically classified into three stages: mild, moderate and severe, with the symptoms varying depending on the level of progression (Zvērová, 2019). Mild dementia is characterised by mild impairments in memory, communication patterns, executive ability, and depression (Wattmo, Wallin and Minthon, 2013), while the common symptoms of the moderate stage are disorientation of place and time, decreased judgement, dyspraxia and decreased skills regarding activities of daily living (Wattmo, Minthon and Walin, 2016). The severe stage is characterised by a marked impairment of short-term memories and the inability to perform most instrumental activities of daily living, often resulting in institutionalisation (Galasko et al., 2005).

Vascular dementia is regarded as the second most common form of dementia (Kalaria, 2018) and is defined as a loss of cognitive function resulting from hypoperfusive or haemorrhagic brain lesions due to cerebrovascular disease (Román, 2003), it is also characterised by a loss in rationality, judgement and cognitive performance (Wang et al., 2020), and affects multiple cognitive domains including language and communicative function (Banovic, Zunic and Sinanovic, 2018). People living with vascular dementia often experience behavioural and psychological symptoms, with emphasis on mood disorders such as delusions, depression, irritability, euphoria, distress and disinhibitions (Majer et al., 2019). Vascular dementia has also been linked to stroke, and the prevention of recurrent stroke and control of cardiovascular risk factors has been highlighted as a cornerstone in limiting vascular dementia (Wolters and Ikram, 2019). Cognitive stimulation therapy has also been recommended as the best non—pharmacological intervention for managing mild to moderate vascular dementia (Soedirman and Laksmidewi, 2021).

Alzheimer's disease and vascular dementia have generally been recognised as the two most prevalent forms of dementia, but less attention has been paid to their co-occurrence in a diagnosis often referred to as mixed dementia (MD) (Zekry, Hauw and Gold, 2002). This form of dementia occurs in patients who suffer from a neurodegenerative disorder such as Alzheimer's disease or

dementia with Lewy bodies in addition to a cerebrovascular disease such as vascular dementia (Custodio et al., 2017). Often, a person will have a greater amount of one type of dementia than another, this is usually known as the predominant type. Some authors believe that mixed dementia may be the most common form of dementia (Javanshiri et al., 2018) because neuropathological and epidemiological studies have pointed to the very common association between Alzheimer's disease and vascular dementia pathologies (Riley, Snowdon and Markesbery, 2002).

Dementia with Lewy bodies is often closely associated with Parkinson's disease (Aarsland, Londos and Ballard, 2009) due to their similar clinical features. This form of dementia is diagnosed by the presence of memory impairment, executive dysfunction and visuoperceptual ability, mild language impairment, attention deficit, fluctuating cognition and recurrent visual hallucinations (Jellinger and Korczyn, 2018). These hallucinations may occur spontaneously without the presence of perceptional impairment (Cagnin et al., 2013) and are possibly related to the presence of Lewy bodies in the temporal lobe (Harding, Broe and Halliday, 2002). People diagnosed with dementia with Lewy bodies usually develop parkinsonism over the years (Kim, Kågedal and Halliday, 2014) with over 85% of cases exhibiting parkinsonian features such as rigidity and bradykinesia (Postuma at al., 2015).

Frontotemporal dementia is the most common neurodegenerative disorder in individuals under the age of 60 (Nguyen et al., 2018) and is the second most common form of dementia in people under 65 years old after Alzheimer's disease (Ratnavalli, Brayne, Dawson and Hodges, 2002). It refers to a group of rapidly progressive neurodegenerative disorders that have an array of clinical, genetic and pathological manifestations (Bright et al., 2019). It is usually characterised by changes in personality, language and behaviour with involvement of the frontal and temporal regions of the brain (Deleon and Miller, 2018). People diagnosed with this disease may develop concomitant parkinsonism or motor neuron disease, leading to a broad clinical phenotype ranging from amyotrophic lateral sclerosis (ALS) to progressive supranuclear palsy (PSP) and corticobasal syndrome (CBS) (Meeter, Kaat, Rohrer and Van Swieten, 2017). Approximately 40% of people diagnosed with frontotemporal dementia have an affected relative (Goldman et al., 2005), which suggests that the disease has a genetic cause.

2.3 Behavioural and psychological symptoms of dementia (BPSD)

Behavioural and psychological symptoms of dementia (BPSD) is a term used to describe a range of behaviours and symptoms that affect most people living with dementia (Cloak and Al Khalili, 2019)

at some point in their illness (Savva et al., 2009). These symptoms often cause distress to the patients and their caregivers (Kim, Noh and Kim, 2021) and can sometimes lead to institutionalisation (Ikeda et al., 2004) or longer in-patient hospital stays (Wancata et al., 2003). BPSD includes symptoms such as aggression, agitation, depression, apathy, wandering and sleep disturbance (Jennings et al., 2018).

People can experience behavioural symptoms of dementia (Emblad and Mukaetova-Ladinska, 2021) such as agitation or withdrawal for reasons ranging from overstimulation from loud noises, crowds, or television to understimulation from boredom or isolation (Van Dan Bossche and Vandenbulcke, 2021). The prevention of boredom is very essential, as boredom often leads to disturbing behaviour (Cohen-Mansfield, Marx and Rosenthal, 1989). Although prescription medication and drug therapy (Calsolaro et al., 2021) are the main forms of treatment for behavioural symptoms despite insufficient evidence of their effectiveness (Teri et al., 2000), non-pharmacological interventions have been suggested as the first line of treatment (Huda, 2021).

2.3.1 Agitation

Agitation refers to a range of behaviours including pacing, repetitive vocalisations, restlessness and verbal or physical aggression (Cohen-Mansfield, 1997) and is a symptom of distress in people living with dementia (Cummings, 2015). It is the most common neuropsychiatric symptom (Okura et al., 2010) and accounts for about 12% of the health and social care costs for people living with dementia (Morris et al., 2015). Agitation affects up to 70% of people with dementia (Jakobson, Avari and Kalayam, 2015) and is said to be as a result of a person being unable to identify, communicate and respond to their own needs (Livingston, 2017).

In care homes, agitation in one resident may trigger agitation in other residents (Ridder, 2013) which can increase caregiver burden and lead to caregiver burnout (Gitlin, Kales and Lyketsos,2012). It can also result in violence between residents or violence from residents to care home staff (Khan et al., 2018). The recommended management approach for dementia related agitation is comprised of non-pharmacological interventions. However, when non-pharmacological interventions are not feasible especially in emergency situations where the safety of the patient is at stake, drug therapy is the recommended option (Ljaopo, 2017).

2.3.2 Apathy

Apathy is a clinically problematic and disabling non-cognitive symptom of dementia (Radakovic et al., 2021) that affects people living with dementia at some point during the course of their illness (Van Reekum, 2005). It is defined as the absence of feeling, interest, concern, emotion or motivation not attributable to a reduced level of consciousness, cognitive impairment, or emotional distress (Theleritis et al., 2018). It may manifest differently in the different forms of dementia (Quaranta et al., 2012) and its symptoms may change during the course of the disease (Brodaty et al., 2015).

Apathy in people living with dementia is linked to functional decline, increased levels of caretaker burden and increased rate of patient mortality (Massimo et al., 2015). The loss of motivation that comes with apathy severely inhibits a person's ability to function independently especially when carrying out activities of daily living such as hygiene, feeding and maintaining social relationships (Lanctôt et al., 2017). The ABC model of apathy (Kumfor et al., 2018) recognises three different aspects of apathy with varying clinical manifestations.

(A) Affective-emotional apathy: an inability to guide behaviour using emotional context which leads to emotional diminution and changed social interactions.

(B) Behavioural apathy: a deficiency in initiating and maintaining spontaneous patterns of motor movement.

(C) Cognitive apathy: a lack of motivation to participate in goal-oriented behaviour.

Apathy is associated with negative outcomes such as poor treatment response, faster cognitive decline, increased reliance on caregivers and earlier institutionalisation (Vilalta-Franch et al., 2013). Psychoactive drugs (Azhar et al., 2022) often prescribed to care home residents offer a sedative effect and have been linked to the exhibition of withdrawal behaviour and apathy (Voelkl, Fries and Galecki, 1995). This is a source of concern as a lack of physical ability in older adults not only leads to the decline of their physical and cognitive capabilities (Colcombe and Kramer, 2003), but also reduces their physical flexibility (Febriyona, Biahimo and Lihu, 2022), strength and coordination (Warburton, Nicol and Bredin, 2006).

A sign of a good care home is the level at which the residents are engaged in stimulating and meaningful activities (Smith et al., 2018). Unfortunately, many care home residents spend their days unoccupied and are often found sitting for long periods of time or taking extended naps (Bates-jensen et al., 2004). People living with dementia, especially in the later stages have a limited

availability of sensory engagement (Wang, Albayrak and Van der Cammen, 2019) as they often only receive passive care without the opportunity to engage in meaningful activity (Marques et al., 2012) even though they are at risk of sensory deprivation due to their reduced perception of sound, smell, taste and sight (Haigh and Mytton, 2016).

Multisensory activities are recommended for people living with dementia (Mileski et al., 2018) because people living with dementia show greater wellbeing (Leszko and Bugajska, 2018) and are known to have lower rates of depression and mortality when they are positively engaged than their unengaged counterparts (Lemke and Moos, 1986). Tailoring these activities to the interests, physical and cognitive functions of individuals increases their positive engagement and reduces apathy (Deeken and Rapp, 2022) to a greater extent than when the activities are only tailored to one of these factors. This tailoring method translates to meeting the individual needs of each person in order to reduce the occurrence of behavioural symptoms (Kolanowski et al., 2006).

2.4 Non-pharmacological interventions for engagement

Non-pharmacological interventions are safe, non-invasive ways of treating some of the behavioural and psychological symptoms of dementia (Poulos et al., 2017). They are aimed at maintaining the function and participation of people living with dementia for as long as possible as the disease progresses, thereby reducing disability and improving both patient and caregiver quality of life (Zucchella et al., 2018). The use of non-pharmacological interventions is usually recommended as the first line of treatment for people living with dementia (Dyer et al., 2016) as it may also improve their function and independence (World health Organization, 2001). Non-pharmacological avenues for engagement include interventions such as art therapy, exercise programmes, music therapy, aromatherapy, cognitive stimulation, multisensory stimulation and reminiscence therapy (Dyer et al., 2018).

2.4.1 Art Therapy

Art therapy is defined as a form of psychotherapy that uses art media as its primary mode of communication. In this context, art is not used as a diagnostic tool, but as a method of addressing emotional issues, confusion and distress. People who engage in art therapy also do not need to have previous experience or skill in art, as aesthetic is not the primary aim of this intervention (British Association of Art Therapists, 2013). Rather, it is aimed at managing the manifestations of dementia, as this form of therapy may help to slow down cognitive decline, address symptoms

related to psychosocially challenging behaviours and improve quality of life (Deshmukh, Holmes and Cardno, 2018).

Art therapy mainly includes painting, collage and looking at images (Seifert, Spottke and Fliessbach, 2017) and it acts as a form of sensory stimulus, as the creativity and art making process targets cognitive, motor, emotional and interpersonal skills. Although cognitive abilities decline during the progression of dementia, studies show that people with advanced dementia are still able to complete self-portraits when asked (Beard, 2012).

Art therapy can be greatly beneficial for people in their old age and particularly so for people living with dementia (Powlen, 2021) because sadly, their notion of aging is often accompanied by the concept of loss such as loss of mobility, loss of cognitive function, loss of friends and family and loss of health. This form of thinking often prevents people from experiencing the enjoyable and creative experiences that come with old age and the chance to enter a new phase of life that can be used for self-rediscovery, to enjoy new activities or relationships and to participate in activities that they previously never had the time for (Stewart, 2004).

Figure 2.1: Art therapy for people living with dementia

Source: (Joanna Jaaniste, 2021)

Over the last two decades, art therapy has been increasingly used for support and therapeutic care in different care settings (Ehresman, 2014) and the process of making art has been described as an avenue for non-verbal communication that provides people living with dementia with the means

to be understood and to have their emotions validated by others (Camartin, 2012). The potential benefits of art therapy are being recognised by medical professionals who work with people with dementia such as family physicians, neurologists and geriatricians (Popa et al., 2021). Health care and educational programmes also provide people living with dementia with opportunities for art making, especially those in long-term and healthcare institutions (Guseva, 2019).

Art therapy has not only been identified as one of the avenues by which people can express themselves even in old age, but also an avenue through which the progression of a person's dementia can be observed and evaluated from studying the persons artwork over time (Khan-Denis, 1997). Wald (1986) explained that the graphic indicators of Alzheimer's dementia include regression, simplification, fragmentation, disorganisation, overlapping configurations, confused perspective, short scattered headlines, omission of essential details and cramped appearance among others. These indicators are usually seen in cases where people with dementia initially start off with clear handwriting and detailed images but regress to less detailed images and the use of less paper space and fewer colours as the disease progresses.

The benefits of art therapy have been recorded, especially in dealing with agitation and anxiety, with agitated dementia patients shown to become calm after being presented with and engaging in art materials (Laranjeira, 2020). However, despite the increasing level of interest in the use of art therapy as a non-pharmacological tool in the management of the behavioural symptoms of dementia, current evidence in research still inhibits the translation from science to practice as only a few studies have been published that formally investigate the effect of art therapy on people living with dementia (Maujean, Pepping and Kendall, 2014). Compared to some forms of non-pharmacological interventions like multisensory environments, art therapy is very cost effective which is seen as an added benefit because due to the rising cost of healthcare and institutionalisation of people with dementia, it is important that more cost-effective programs are developed and implemented (Cheng et al., 2020).

2.4.2 Music Therapy

Music and activities involving music are an integral part of human existence. Music in older people can contribute to positive self-esteem, independence (Natividad, 2021), feelings of competence, as well as reduced feelings of isolation (Hays and Minichiello, 2005). With regards to people living with dementia, music can also promote social interaction and well-being, as well as avenues for reminiscing and evoking memories (Unbehaun et al., 2021). People with Alzheimer's disease

respond to music as they have been seen to remember, sing and dance to songs despite their memory loss and aphasia (Brotons, 2000). Furthermore, people living with dementia who had musical abilities prior to the onset of the disease appear to retain those abilities, indicating that musical abilities might not always be affected by the progression of dementia (Cuddy and Duffin, 2005).

Residents of care homes have expressed their appreciation for exposure to music and music related activities in their daily lives (Melhuish, Grady and Holland, 2019) and have revealed how music has enabled them to participate in interesting activities that have improved their daily living (Holmes et al., 2006).

The introduction of background music or singing (Cho, 2018) into activities also contributes to the improvement of the interactions between people living with dementia and their caregivers (Götell, Brown and Ekman, 2009). Sixsmith and Gibson (2007) suggest that the benefits of music therapy fall into four categories: enhanced feelings of well-being, encouragement of valued activities, social interaction and an increase in sense of empowerment and control.

Figure 2.2: Music therapy for people living with dementia

Source: (Greg, 2018)

Hearing a piece of music can evoke memories which can lead to reminiscence and conversations about past experiences (Bando, Yoshioka and Nishikiori, 2019). Singing and enjoying music in

groups is also one of the most widespread forms of active musical participation (Clift et al., 2010) and has been shown to be enjoyable for people living with dementia (Lee, O'Neill and Moss, 2020) as well as have the potential to improve their quality of life (Barnish and Barran, 2020) and the wellbeing of their caregivers (Bannan and Montgomery-Smith, 2008).

A positive feature of music therapy and singing interventions is that they are low risk (Redding, 2020), they do not need to be provided by a music therapist and can be used without any special equipment. However, although music therapy has been shown to have many positive outcomes (Ray and Götell, 2018) including presenting a framework for meaningful activities, improving participation in activities, boosting social interaction, managing behavioural problems such as agitation and improving feeding during mealtimes (Biley, 2000), encounters with music are not always positive (Hanser et al., 2020) as some people can experience problems associated with music and musical activities such as an inability to express musical preference as well as loss of hearing and other forms of impairments (Ragneskog et al., 1996).

2.4.3 Reminiscence therapy

Reminiscence therapy is one of the most popular psychological interventions for people living with dementia. It is described as the discussion of past events, activities and experiences (Redulla, 2020), usually with the aid of useful prompts from the past such as music, photographs or familiar objects (O'Philbin et al., 2018). It is widely used as a non-pharmacological intervention for people living with dementia (Woods et al., 2016) and was developed by Butler (1963) as a form of treatment for dementia through the process of "Life Review" which involves using various forms of memory triggers such as objects from a past period, household items, music, and photos (Woods et al., 2012).

Reminiscence therapy may be organised individually or in groups. For individual reminiscence therapy, topics that tend to provide positive influence are considered for use and one-to-one therapy sessions are conducted to help people recall memories of their past (Ching-Teng, 2020). It is important for the social worker or therapy conductor to understand the psychological conditions, social conditions, cultural backgrounds and life experiences of the participant before providing reminiscence therapy as this form of therapy requires the use of skills such as listening, communication, empathy, timely reaffirmation and positive feedback (Chao et al., 2008).

Figure 2.3: Reminiscence therapy for people living with dementia

Source: (Stickley, 2020)

Group based reminiscence therapy is widely used as it allows participants to stimulate one another through communication and increases their attention span (Park et al., 2019). This form of reminiscence therapy normally involves topics that are seen as non-threatening and has been found to have positive effects on older people with depressed moods (Pinquart, Duberstein and Lyness, 2007) including those living in long term care environments. This style of reminiscence therapy can take many forms and have different components, and the use of themes and family members are sometimes incorporated into sessions (Macleod et al., 2021).

The conductors of group-based reminiscence therapy sessions (Lee, 2020) focus on maintaining an atmosphere of harmony within the group throughout the sessions to prevent unnecessary loss of energy by the attendees (Pittiglio, 2000). These conductors observe the interactions among participants in order to ensure that the goal of group reminiscence is achieved (Li et al., 2020). They also guide the reminiscence process through the use of open questions, supplementary items, questioning and timely in-depth clarification (Thomas and Sezgin, 2021) to assist the group in expanding and deepening their recollection. Sometimes, focus is placed on each phase of life experience in order to steer the participants into a comprehensive recollection (Jones, 2003).

Reminiscence therapy can be beneficial for people living with dementia (Pérez-Sáez et al., 2021) as it places an emphasis on long-term memories, which are usually remembered more often than short-term or recent memories (Morris, 1994) and the psychological improvement induced by this form of therapy can be beneficial to both people living with dementia and their caregivers (Hilgeman et al., 2014). It is a strengths-based approach that can provide person-centred care (Francis et al., 2020) because it draws on peoples' past memories which are often preserved in dementia (Woods et al., 2018).

Reminiscence therapy may be different from some of the other forms of non-pharmacological interventions and therapies as the person leading the reminiscence therapy sessions should be trained and the items used as memory triggers must be prepared, therefore reminiscence therapy might not always be cost-effective (Lazar, Thompson and Demiris, 2014).

2.4.4 Multisensory stimulation

Multisensory stimulation, also known as Snoezelen involves the stimulation of the senses through the exploration of a multisensory environment (Cusic et al., 2022), following a non-directive and facilitative approach (López-Almela and Gómez-Conesa, 2011). It is the combination of lights, sounds, smells, tactile objects and sometimes taste to stimulate the different senses and provide a stimulating, relaxing and stress-free environment (Sánchez et al., 2013). This form of stimulation is traditionally offered in a multisensory or Snoezelen room (Pinto et al., 2020) and can be carried out using aromas, music, fibreoptic sprays, bubble tubes and projected images (O'Connor et al., 2009) or by incorporating sensory stimulation into daily care routines (Van Weert et al., 2005).

Snoezelen originated from the Netherlands in the 1970s and the term "Snoezelen" is a contraction of two Dutch words translated in English as "sniffing" and "dozing" (Hulsegge and Verheul, 2005). It was initially introduced as a non-pharmacological intervention for people with learning difficulties (Burns, Cox and Plant, 2000), but has since been adopted for use in the treatment of the behavioural and psychological symptoms of dementia (Cerga Pashoja et al., 2018). It has been demonstrated to be effective in the short-term management of behaviour and mood as well as encouraging communication and interaction especially in people suffering from moderate to severe dementia (Maseda et al., 2018). The use of Snoezelen also improves the rapport between people living with dementia and staff in care homes (Tsai and Hong, 2019).

A unique approach to multisensory stimulation is the development of thematic multisensory stimulation (Verkaik et al., 2019). This form of multisensory stimulation involves simultaneously stimulating multiple senses using stimuli related to positive themes that could awaken positive feelings and memories in people living with dementia. This approach is based on the premise that positive memories are preserved better than neutral memories and are therefore recalled more easily. Thematic multisensory stimulation is observed in a study by (Goto et al., 2014) which compared the effects of a Japanese garden room to the effects of stimuli from a generic Snoezelen room. The results of this study showed reduced stress levels and positive behavioural changes in the participants who visited the Japanese garden room while there was little to no effect in the participants who visited the Snoezelen room. This study concluded that thematic multisensory stimulation might lead to improvements in psychological and behavioural outcomes (Goto et al., 2017).

A distinguishing element of multisensory stimulation is the adoption of a non-directive approach that encourages the participants to explore and engage with the sensory stimuli of their choice (Zaree, 2020). This makes this form of stimulation compatible with person-centred care and places emphasis on the acknowledgement of the personhood of the person living with dementia (Norberg, 2019), the personalisation of their care and the shared decision-making process which prioritises the relationship between the person living with dementia and their caregiver (Edvardsson, Winblad and Sandman, 2008). This focus on choice of engagement with different sensory elements is also important as people living with dementia often experience sensory deprivation or an imbalance in the pacing of sensory stimulating or sensory calming activities (Kovach, 2000). This can lead to agitated behaviours or other behavioural and psychological symptoms (Sánchez et al., 2013). Although changes in basic auditory and visual processing such as a reduction in visual acuity and peripheral auditory processes also occur with age, it is important to explore multisensory integration in aging, as it is one of the few contexts in which reduced inhibitory control and enhanced binding across coincident stimuli can confer additional benefits to older adults (Campbell et al., 2010).

(Diaconescu, Hasher and McIntosh, 2013) report that multisensory responses are more pronounced with age, especially in older adults due to the enhanced responses observed in the posterior parietal and medial prefrontal regions of the brains of older adults when different forms of stimuli are introduced. The advantage of multisensory stimulation over other forms of therapies and stimulation is that people can engage with elements that stimulate their different senses: visual,

audio, olfactory, gustatory, as well as cognitive functions. The stimulation of each of these senses offers unique benefits to people living with dementia and the combination of these different forms of stimulation can produce positive effects on the mood and wellbeing of a person living with dementia. It is also known however that some sensory stimulations, for example, visual stimulation can exert dominance over other sensory stimulations, for example, olfactory stimulation which might enhance or deter the way in which people with dementia perceive stimulations (Batic and Gabassi, 1987).

Visual stimulation: Visual stimulation using images is common, especially in reminiscence therapy because of the ability for images to evoke long-term memories as well as emotions in people living with dementia (Wu et al., 2020). It is a key factor in multisensory stimulation and can be administered both individually and in group sessions. The sense of vision has been identified as the most likely of the senses to be stimulated within a multisensory environment and has shown positive effects on anxiety and other dementia related behavioural and psychological symptoms (Maseda et al., 2018). This is due in large part to visual dominance which is the tendency for visual stimuli to dominate awareness when presented simultaneously with other forms of stimuli, leading to visual stimulation provoking the first response in humans when several stimuli from various sensory modalities are present (Cooper, 1998). This overpowering ascendency of visual cues over other sensory cues and the belief that visual sensory dominance effects are stronger during late adulthood is why visual stimulation is a key factor in the delivery of multisensory stimulation to older adults (Diaconescu, Hasher and McIntosh, 2013).

It has also been reported that older adults show a more pronounced visual dominance effect compared to young adults due to the difficulties they face when performing listening tasks that require temporal processing (Schneider et al., 1998). Therefore, the introduction of visual cues and elements into multisensory stimulation and reminiscence therapy can not only serve as tools for engagement, but also as sensory elicitors and has been recorded as being successful in the retrieval of autobiographic memories for people living with dementia (Cotelli, Manenti and Zanetti, 2012). However, people living with dementia can easily become overstimulated when interacting with visually stimulating environments (Dixon and Lazar, 2020). Therefore, it is important to eliminate possible sources of overstimulation such as cluttered photos, webpages, bright colours and lighting, and large blocks of text when providing visual stimulation to this group of people.

Audio stimulation: sensory stimulation has been used for many years to provide engagement to people living with dementia, especially those in their later stages (Cohen-Mansfield et al., 2010) and the provision of audio stimulation has been shown to increase their focus and comprehension as well as help them concentrate on a task (Dixon and Lazar, 2020). Audio stimulation is sometimes combined with other forms of stimulation such as visual stimulation. This combination strengthens the overall experience of the participants in a session and is especially useful for people who might have other forms of impairments.

Olfactory stimulation: olfactory stimulation such as aromatherapy and the use of smells and fragrances has gained popularity in the engagement of people living with dementia. This form of stimulation has been known to cause an improvement in cognitive impairment due to the stimulation of the limbic system and hypothalamus by olfactory stimuli (Takahashi et al., 2020). Odour memory, or memory from smells are unique in that they are different from other modalities of memory, independent of other types of memory, long lasting, and resistant to decay over long intervals, which is why they are excellent in the formation and retrieval of significant autobiographical experiences (Schab, 1991). Studies have also shown that smells have the capacity to serve as context cues, which is the underlying factor in the formation of content dependent smell-evoked autobiographical memories (Vermetten and Bremner, 2003).

The use of smells and aromatherapy is one of the main complementary forms of therapy used by healthcare professionals in hospitals and care homes (Buckle, 2014), and this form of stimulation is usually administered to people living with dementia through the use of scent capsules, diffusers or vaporisers and usually results in a positive response stemming from the pleasant aromas (Watson, Hatcher and Good, 2019). The use of olfactory stimulation, especially in reminiscence therapy has shown positive results as autobiographical memories recalled through using olfactory cues are reported as stronger, clearer and more emotional than those recalled by verbal cues (Chu and Downes, 2002). Olfactory stimuli tailored to themes have also been found to be successful in the alleviation of depression and the retrieval of memories in older adults and people living with dementia (Hanaoka et al., 2018). The use of this form of stimuli has also been reported to produce the strongest emotional sensations with the feeling of relieving past experiences when compared to other cues (Herz, 2004).

The primary aim of reminiscence therapy with people living with dementia is the remembrance of positive long-term memories, therefore olfactory stimulation is deemed as appropriate for this

group of people as it has been shown to evoke even older memories – some as old as from before the age of 10 years – when compared with visual stimulation (Willander and Larsson, 2006) – even though vision has been shown to be the dominant stimuli in other situations. A study which used magnetic resonance imaging to examine the brain activity of the participants at the point where they recalled autobiographical memories through the use of smell cues, showed that the emotional regions of the brain such as the amygdala are more activated by smell cues (Arshamian et al., 2013).

Gustatory stimulation: the implementation and administration of multisensory environments to people living with dementia is often focused on visual and tactile stimulation with little to no consideration given to gustatory stimulation or elements that stimulate the sense of taste (Collier and Jakob, 2017). Although dementia, especially Alzheimer's dementia is categorised by massive neuronal loss in the brain, including the taste cortex meaning that people living with dementia often experience a reduced sense of taste (Ogawa et al., 2017), the gustatory sensory systems can still be activated even in the advanced stages of the condition (Prins et al., 2020). Non-pharmacological interventions such as food therapy are often used in the management of the behavioural and psychological symptoms of dementia and involve the preparation, tasting and eating of food by people living with dementia, usually with the aid or supervision of their family members or caregivers. When combined with other non-pharmacological interventions, gustatory stimulation through food therapy has been shown to promote positive mood and engagement in people living with dementia (Quail et al., 2020).

Tactile Stimulation: the use of items that provide tactile stimulation is very popular in dementia care especially in the implementation of sensory rooms (Jakob and Collier, 2017). Tactile stimulation has been proven to promote relaxation, calm and contribute to a sense of trust in people living with dementia. It is also known to lead to a reduction in anxiety and an increase in cognition (Chang, 2020). Studies have shown that when people living with dementia are offered opportunities to experience different touch sensations, it results in a positive impact on their physical, emotional and social lives (Bray et al., 2021).

The combination of these different forms of stimulation can be termed as multisensory stimulation, which is suitable for people living with dementia, especially those with severe dementia, and in particular, those with limited verbal communication because it does not rely on cognitive abilities (Finnema et al., 2000) and is able to provide stimulation without the need for intellectual activity while also creating an atmosphere of trust and relaxation (Burns, Cox and Plant, 2000). However, a

drawback of multisensory or Snoezelen rooms is that although the equipment required in their creation may be easily acquired, they are expensive (Lancioni, Cuvo and O'reilly, 2002) and therefore might not be the most cost-effective form of stimulation for people living with dementia.

2.4.5 Cognitive stimulation

Cognitive stimulation is one of the most popular forms of non-pharmacological intervention for people living with dementia and has been shown to delay functional impairments and improve quality of life (Orrell et al., 2005). This form of stimulation preserves cognitive function in people living with dementia by protecting against cognitive decline through the provision of avenues for the maintenance of mental and brain activity (Kim et al., 2017). Cognitive stimulation is provided to people living with dementia through the administration of various forms of activities such as physical games, quizzes, word association games, puzzles, object categorisation, orientation using maps etc. (Bertrand et al., 2019) and is based on implicit learning, executive functioning and stimulating language, as the activities involved are focused on reminiscence, development and exploration of new ideas and thoughts, orientation and association in order to promote a sense of community during the sessions (Aguirre et al., 2013).

Cognitive stimulation has different effects on multiple areas of cognitive function for people living with dementia. Spector et al. (2010) explain that the verbal and visual episodic learning, verbal short memory, recall and recognition, comprehension of syntax and orientation domains appear to be the cognitive domains most impacted by the implementation of cognitive stimulation therapy. The combination of cognitive stimulation and reminiscence therapy also has positive effects on the level of cognition and quality of life of people living with dementia (Lin et al., 2018) with the effects of Cognitive Stimulation Therapy lasting up to 3 months after being administered (Woods et al., 2012). The aim of cognitive stimulation in people living with dementia is to create an environment of fun and learning in order to strengthen the abilities and social relationship among this group of people.

2.4.6 Other existing interventions

Apart from those listed above, there are other forms of non-pharmacological interventions used in the management of the behavioural and psychological symptoms of dementia both in literature and in practice (Scales, Zimmerman and Miller, 2018; Cammisuli et al., 2016), such as:

Aromatherapy: the use of scented oils and balms to improve a person's mood (Behrman, Chouliaras and Ebmeier, 2014). This form of therapy can be administered in different ways such as through

the use of diffusers, creams, sachets, patches etc. (Strøm, Ytrehus and Grov, 2016). There have been mixed results on the use of aromatherapy for people living with dementia. While the use of oils in the olfactory system is associated with positive outcomes irrespective of the type of oil or duration of treatment (Press-Sandler et al., 2016), it has also been found to be ineffective for the management of agitation (Livingston et al, 2014).

Massage therapy: the use of tactile stimulation (Zhao, Gu and Zhang, 2020) such as rubbing, kneading, non-contact therapeutic touch or acupressure on different parts of the body such as shoulders, back, neck, hands, legs and feet (Hansen, Jørgensen and ørtenblad, 2006). This form of therapy is effective in reducing anxiety, agitation, stress and depression (Randall and Clissett, 2016) and can help a person living with dementia feel comforted and cared about especially in care environments (Gleeson and Timmins, 2004).

Light therapy: the use of light fixtures or natural bright light to promote the synchronization of the circadian rhythm with environmental light-dark cycles (Behrman et al., 2014). This form of therapy is used in the treatment of sleep disturbances and other forms of behavioural symptoms such as agitation in people living with dementia (Forbes et al., 2014). Evidence for the efficiency of light therapy shows mixed results as some studies report positive impact on agitation and sleep (Cabrera et al., 2015), while others report little to no evidence of success in the management of sleep and agitation (Brasure et al., 2016).

Animal-assisted therapy: mostly involving dogs, this form of therapy is aimed at promoting socialisation and providing emotional support, sensory stimulation and an enhanced wellbeing to people living with dementia (Bernabei et al., 2013). In small studies, the use of pets has been shown to improve social interaction and reduce agitation, passivity and disruptive behaviour (Brodaty and Burns, 2012). Studies involving the use of robotic pets have also been shown to improve mood and reduce agitation (Petersen et al., 2017).

2.5 Summary

This literature review chapter has given an insight into dementia, its different forms and their resulting symptoms. It explored some of the behavioural and psychological symptoms of the condition such as apathy and agitation and investigated the non-pharmacological interventions that have been proven beneficial in the mitigation of these symptoms for people living with dementia. From undertaking this study of the literature, it has become clear that therapies such as art, music,

reminiscence, aromatherapy and multisensory stimulation are important when considering multisensory environments for the engagement and stimulation of people living with dementia. These therapies, activities and sensory environments are also used in practice and their use is discussed in chapter 3.

Chapter 3: Delivering activities to people living with dementia in practice

People living with dementia have a low rate of participation in activities outside of their daily routine because of their declined physical and cognitive capabilities (Baker et al., 2001). However, delivering activities and therapies to them can help them live better lives and keep their minds active to better cope with the consequences of the disease (Milte et al., 2016). It is important for these activities to be tailored to suit the interests of the participants as this enhances their feelings of involvement and connection and classifies the activity as meaningful (Kharel, 2019). Such activities also help prevent social isolation, problematic behaviours and decline in functionality (Buettner and Fitzsimmons, 2003).

Chapter 2 reviewed a range of non-pharmacological therapies and activities that have been proven to help engage people living with dementia. This chapter extends this review to look at how these therapies are delivered in practice and who is responsible for delivering them in different care settings. The chapter also reviews some of the products that are currently available on the market to assist the delivery of therapeutic activities in order to identify gaps in the field.

3.1 Who delivers the activities?

Alzheimer's disease and other forms of dementia affect approximately 5.5 million individuals annually, many of whom are non-institutionalised and are receiving ongoing care from family members in their homes (James et al., 2014). In these instances, unpaid family members provide most of the dementia care (Perti et al., 2019) and have the added responsibility of keeping the person living with dementia entertained and occupied. However, in hospitals and care institutions, the delivery of meaningful activities to people living with dementia is often carried out by activity coordinators (Hobson, 2019) whose aim is to support patients with complex needs, enhance their experience and develop a therapeutic environment using activities and distraction therapies (Brooke and Herring, 2016). Activity coordinators are also sometimes employed in personal homes through local or government funded programmes to provide support and deliver pleasant activities to people living with dementia living in their homes (Lord et al., 2020).

In care homes and hospitals, the successful delivery of activities usually involves teamwork and collaboration between the activity coordinators, nurses, and care staff (Guzmán et al., 2017). The role of the activity coordinators in these settings is very essential as the coordinator ensures that

activities are carried out, especially when the nurses and care staff are caught up in care activities. The role variously involves prompting the residents or patients to eat by organising social dining initiatives or supporting conversation though the creation of meaningful activities, therapies, and one-to-one time (Handley, Bunn and Goodman, 2017). The involvement of activity coordinators in dementia care has been shown to have a positive influence in supporting patients' needs and the collaboration with nurses and care staff also provides a more person-centred approach to dementia care and allows for the integration of activities into a person's care plan (Clifford and Doody, 2018).

The presence of activity coordinators has been linked to the adherence of people living with dementia to their activity sessions. This is because the knowledgeability and competence of the activity coordinators lead to the development of trust between them and their session attendees (Vseteckova at al., 2018). In some locations, the activity coordinator is combined with a social therapist who focuses specifically on engaging the people in socialisation activities, encouraging communication among them, and paying attention to their needs and emotional aspects (Moyle, 2010).

Although the benefits of providing activities to people living with dementia have been clearly expressed in literature, members of staff in the different care settings in which people living with dementia are situated often prioritise their response to the needs of those in their care, ranking basic needs over the need for engagement, activities, and interaction due to pressure of time (Rapaport et al., 2018). Therefore, the role of the activity coordinator, formal and informal, is very crucial to the engagement, stimulation and wellbeing of people living with dementia (Novelli et al., 2018) in these various care locations.

3.2 Models of care

People living with dementia can be cared for in different locations ranging from personal homes to hospitals for various reasons. Regardless of the location, the need for care is paramount to their wellbeing and the quality of care received in these different locations can have a direct impact on their quality of life.

3.2.1 Personal home support

People living with dementia often want to continue living at home rather than in care facilities. Living at home has also been linked to physical, social, emotional, economic, and cognitive benefits in older people (Freilich et al., 2014) such as proximity to family and social groups, preservation of

physical and mental health, and maintenance of some levels of independence and autonomy (Stoop et al., 2019). However, most of the dementia care at home is provided by informal caregivers such as family, neighbours and friends (Sriram, Jenkinson and Peters, 2019), and this group of people often report physical, social, emotional and psychological strain on themselves due to their caregiving activities, which can affect their health and ability to provide care to their care recipient with dementia (Melhuish, Grady and Holland, 2019).

Oftentimes, services of nursing staff are employed to provide care and support to people living with dementia in their personal homes (Bolt et al., 2020). This form of care can either be paid for by the family or funded through government programmes and usually includes domestic assistance such as cleaning, cooking and personal hygiene (Carter et al., 2021) as well as providing support to family caregivers by reducing their stress and providing them with respite (Goh et al., 2022). Personal home support may also provide companionship and promote social engagement using games and other activities (Barrett et al., 2019). In some cases, social engagement is provided by the community for people living with dementia in their personal homes through avenues such as dementia cafés which provide spaces for them and their caregivers to partake in group activities with others from their community. This form of social engagement has been reported to foster peer support, social inclusion and friendship among people living with dementia (Innes, 2021).

3.2.2 Care home facilities

People living with dementia often have to relocate from their personal homes to care homes as the disease progresses, and this is reported to be one of the most difficult decisions faced by family caregivers (Cole, Samsi and Manthorpe, 2018). The reasons for this relocation vary and range from worsening symptoms (Lord et al., 2016) to increased medical care needs, especially following a hospital admission (Ashton, Roe and Jack, 2016). Studies also show that people with low levels of social support and engagement in social activities are more likely to move into a care home (Hanratty et al., 2018).

The provision of specialist care is a primary focus of the care home sector (Windle et al., 2020) as people living with dementia in care homes are often heavily reliant on nursing staff for their care needs (Maarse and Jeurissen, 2016). The quality of care provided also has a lasting impact on the quality of life of the residents (Anderson and Blair, 2021), therefore most care homes place emphasis on person centred care by prioritising comfort, inclusion, identity, attachment, and engagement in activities just as much as physical or medical needs (Goodall, 2021).

3.2.3 Sheltered housing

Sheltered housing is aimed at meeting the care and support needs of older people while also maintaining their independence (Darton, 2021). Although there are different forms a sheltered housing facility might take, the primary features of most sheltered housing locations include a self-contained living accommodation with the availability of 24-hour care and communal spaces where the residents can engage in social activities (LaingBuisson, 2016). Some evidence suggest that this model of care can improve the quality of life, promote independence and autonomy, and reduce social isolation and hospitalisations for people living with dementia (Twyford, 2016). A flexible approach to person-centred care is adopted in sheltered housing locations to maintain the independence of the residents (Cameron, Johnson and Evans, 2020). However, to reduce feelings of isolation, social activities such as outdoor walking, bingo, mindfulness, music, and art are often organised for the residents (Smith et al., 2021).

3.2.4 Hospitals

Hospital environments can be challenging for people living with dementia, as hospitalisation can cause significant distress due to the unfamiliar environment and enforced dependency (White et al., 2017). Therefore, quality care is imperative in this location (Tay et al., 2018). Research suggests that quality care can be achieved through the adoption of person-centred care and the prioritisation of the wellbeing of people living with dementia (Ross, Tod and Clarke, 2015). A critical challenge of dementia care in hospitals is the overuse of antipsychotic drugs, which has been linked to an increased risk of falls, longer length of stays and deteriorating physical and mental health (Dewing and Dijk, 2016). Non-pharmacological interventions such as music and art therapy are often used in hospital for people living with dementia and have been linked to several benefits such as an enhanced quality of life (Daykin, 2016), mitigation of behavioural symptoms such as anxiety and agitation (Ray and Mittleman, 2017), and the enhancement of communication and connection with others (Gross et al., 2015).

3.3 Best practices for delivering activities

Regardless of the location, the delivery of activities in a meaningful way is very crucial in dementia care as it can help manage the psychological and social needs of people living with dementia (Harmer and Orrell, 2008). It is important to ensure that the therapies, activities, and interventions developed are able to improve a person's quality of life because the method of delivery of activities can have a great impact on how an individual experiences them (Smit et al, 2016). Providing the

appropriate level of training to the activity coordinators or caregivers is also beneficial in the successful delivery of these activity sessions (Baker et al., 2019).

Minor details such as seating positions, methods of communication and the appropriate use of staff can greatly affect how an activity is received by an individual or a group. Organising activity sessions in a calm, welcoming and fun environment can also help each member of the group feel included as well as encourage people who initially did not want to participate in the session to join (Burke et al., 2021). The use of objects for visual orientation in activities is also recommended, as well as the use of prompts to steer the conversation among a group of people (MacRae, Macrae and Carlin, 2020).

Paying attention to people's emotions during any activity session is essential as sometimes, people living with dementia communicate with their actions rather than their words, therefore it is important to understand what each person is trying to communicate through their actions. Cues such as sudden outbursts and displays of discomfort can indicate that a person is not enjoying an activity and taking note of this can help activity coordinators to adjust the activities to better fit the needs of the people involved or to deliver the activity in a different way (Dixon and Lazar, 2020).

Building a good rapport with the attendees can also improve the session outcome as well as create a positive atmosphere during the session. It is recommended to allow attendees choice and control over interventions as this results in an improved level of enjoyment of the attendees (Watchman et al., 2021). Finally, personalised activity sessions where contents of the activity are personalised with objects and artefacts relevant to the individuals and their social circle can make the sessions more engaging and improve meaningful communication, social relationships as well as contribute to the enhancement of person-centred care (Branco, Quental and Ribeiro, 2017).

3.4 Reminiscence activities

Reminiscence activities are widely used in the production of memory triggers for people living with dementia to evoke autobiographical memories (Cohen-Mansfield, Parpura-Gill and Golander, 2006). They primarily make use of non-digital clues such as music, pictures, and household equipment from the past, mostly the formative years of self-identity (Conway et al., 2005). Huber, Prebler and Hurtienne (2018) employed the use of drawers filled with generic and tangible memory triggers such as postcards with local photographs, everyday objects, and animal figurines for use in their reminiscence intervention in two care facilities. They also incorporated themes into the

drawers, such as nature, farm, sports, and household. The results of this study showed that the residents enjoyed and were able to interact with the drawers. However, it was noted that even though the residents engaged with the drawers (see Figure 1), they did not freely explore them unless invited to do so by the caregivers.

Figure 3.1: The interactive drawers for reminiscence therapy

Source: (Huber, Prebler and Hurtienne, 2018)

Another medium often used for reminiscence therapy and activities is the reminiscence or memory box. A memory box is a time capsule that connects an individual or group of people with the past through the items that the box contains (UK Dementia Directory, 2018). It is usually in the form of a rectangular, wall mounted box with a wooden case and a glass insert, built to hold personal memorabilia of the person or group of people for which it is to be used. However, some memory boxes take a different form and are portable enough to be moved around. Memory boxes are typically acquired in different forms through different means, they can either be homemade with personalised items, purchased from a vendor or acquired through a subscription service.

Memory boxes can be used in both individual or group settings and usually contain images and objects that capture key aspects of the life of the person or people living with dementia (Schweitzer and Bruce, 2008). These boxes may be placed in a person's room within a care home setting or have their place in the community (Subramaniam and Woods, 2010).

Regardless of the success of memory boxes in reminiscence therapy, sometimes using the word "reminiscence" can put pressure on people living with dementia to think back and remember. Therefore, replacing "reminiscence" with "sensory boxes" removes this pressure and helps people focus (Robinson, 2020). Memory boxes are significant in dementia care locations as they address key therapeutic goals in dementia care such as maximising awareness and orientation and establishing links to the healthy and familiar (Cohen and Weisman, 1991). They are also helpful in establishing personal identity and acting as tools for reminiscence (Gulwadi, 2013).

Figure 3.2: Memory boxes

Source: (TechSilver, 2021; Davidson 2019).

One of the challenges of translating reminiscence therapy from research to the wellbeing of patients is the need for a therapist to deliver the therapy in practice. Some reminiscence interventions aim to overcome this challenge with the use of mobile multimedia and gaming platforms (Hamel, 2016). In some cases, technology such as iPads or the use of apps are incorporated into reminiscence activities as tools to evoke memory triggers (Alm et al., 2005) such as Memory Matters, an iPad reminiscence app developed to engage people living with dementia in interactive activities aimed at evoking their long-term memories (Blake, 2013). Currently, the few technology-enabled platforms that have been developed have been successful and have shown positive effects on mood and interaction (Zhang and Ho, 2017).

Some reminiscence interventions also make use of music due to its ability to evoke positive memories (Kulibert, 2019) especially in the case of individualised music listening (Gaviola et al., 2020), a study by (Gaviola et al., 2021) created personalised playlists including classical, religious, rock, country and western music for each participant and their family member on an iPod shuffle. This individualised musical playlist was curated according to the person's preferences and the results of the study showed transcendental reminiscing by the participants from beyond the moment of the intervention to times past.

The use of prompts in reminiscence therapy for people living with dementia has been shown to promote recall, stimulate response and enrich the overall reminiscence experience (Kelly and Ahessy, 2021). Prompt questions usually assume a specific, known answer relating to people, places or events and usually have a dynamic selection process based on the replies of the participants in the reminiscence session (Asprino et al., 2017). In the conduction of reminiscence sessions, it is important to focus on positive memories and avoid putting pressure on the participants to provide correct answers or recollections as this could awaken feelings of distress or lead to the remembrance of unpleasant memories (Lazar, Thompson and Demiris, 2018). Therefore, the use of prompt questions has gained popularity due to their have success in allowing for the avoidance of the occurrence of these frustrations especially when people living with dementia have trouble recognising personal items (Astell et al., 2010).

3.5 Twiddle muffs

A twiddle muff is a double thickness hand muff with various items attached inside and out to provide tactile stimulation. It was created to provide a stimulation activity for the restless hands of people living with dementia (Chinedu, Raki and Eghosa, 2016). Twiddle muffs usually contain strands of textured ribbons, buttons, zips, knotted flowers beads and various fabrics to provide a range of stimulation. The rationale behind the use of twiddle muffs is that the idea of being able to grasp, hold, finger or fiddle with an item can provide a sense of security to people living with dementia, especially in the late stages. Therefore, twiddle muffs and personalised textiles are often used to refocus attention and soothe agitation (Treadaway et al., 2016). They are also sometimes used to occupy people with dementia in hospital with the hopes of providing a distraction or alternative to fiddling with and pulling out their cannulas (Burgess, 2018). It is important to note that just like in the case of some reminiscence interventions, people with dementia often need encouragement or even help to engage with twiddle muffs, especially those with advanced dementia.

Figure 3.3: A twiddle muff

Source: (Careforyou,2021).

3.6 PARO

The practice of animal assisted therapy has led to the development of socially assistive robots and automated pets like Sony's robotic dog Aibo (Fujita, 2004), the NeCoRo robotic cat (Libin and Cohen-Mansfeild, 2004) and PARO the robotic seal. Automated pets are often seen as a preferable option to regular pets due to some of the drawbacks associated with animal assisted therapy using live animals, including human injury, allergic reactions, and the risk of grief if the animal dies. The use of robotic pets has shown many benefits to people living with dementia such as an improvement in their relationships, mood, and quality of life (Lane et al., 2016). They have also been reported to improve immune system response, decrease feelings of loneliness, enhance communication and lower stress levels (Shibata and Wada, 2011) as well as reduce acute pain associated with care procedures in people living with dementia (Demange, 2019).

The most widely studied socially assistive robot for elderly care is PARO. Designed by (Shibata et al., 2001), PARO is a pet-type socially assistive robot with the appearance of a baby harp seal. Equipped with sensors including light, temperature, tactile, posture, touch sensitive whiskers, sound, and voice recognition, blinking eyes and a flexible head that mimics paying attention, PARO is able to respond to a number of stimuli and sensations including touching and holding. The combination of all these technologies creates the illusion that the seal is responding to its environment and to peoples' interaction with it.

Figure 3.4: The PARO seal

Source: (Shibata et al., 2001)

PARO was not developed to be a replacement for social interaction with live animals, but a facilitator of it. It was developed for use in group settings rather than in isolation, to facilitate communication, social interaction, serve as a stress reliever for calming agitated people and to get reactions from unresponsive patients. People living with dementia have been shown to prefer real and cuddly animals to non-furry animals (Tamura et al., 2004) and therefore have a good time with PARO which has hypoallergenic fur that does not shed making it the ideal pet for those who might want a pet but may not be able to bear the burden of having one.

Although there is mounting evidence highlighting the benefits of PARO and other similar technologies (Abdi et al., 2018), the replacement of live animals with robots has sparked some ethical debates (Chiberska, 2021), with issues such as "are robots replacing people?" being raised, as well as the worry of what might be lost in human contact and interaction if the use of robots is adopted on a larger scale or in situations where human interaction is usually required and paramount (Barcousky, 2010). There is concern regarding the use of PARO as it simulates life and can be seen as deceptive to people living with dementia (Calo et al., 2011). However, if PARO and other robotic pets are used as tools for encouraging communication and socialisation among people with a common interest in them, they can ultimately play a vital role in the improvement of the quality of life of people living with dementia (Hung et al., 2019).

3.7 Tovertafel

Meaning "magic table" in Dutch, the Tovertafel is a technology that serves to stimulate the brains of people living with dementia and improve their social interaction. This technology is made up of

a projector, infrared sensors, speakers, and a central processing unit that all work together to project light in the form of interactive games to stimulate physical, mental and social activity in people with later stage dementia (Anderiesen, 2017). This product was co-created with people with moderate to severe dementia to reduce the apathy usually identified in this group due to the progression of their dementia.

The Tovertafel qualifies as an exergame, a concept used to describe motion-based gaming systems that integrates innovative technologies such as movement tracking, motion sensors and virtual realities (Unbehaun et al., 2020). The initial development of the Tovertafel consisted of six games – Little Fishes, Fluttering Butterflies, Sweeping Leaves, Throw that Ball, Amazed by Flowers and Guess the Sayings – which respond to hand and arm movements, and which were shown to produce a significant improvement in the physical activity, social interaction and happiness of people living with late stage dementia in care homes as well as reduce their fear, anger and grief (Talman and Gustafsson, 2020).

Figure 3.5: The Tovertafel games

Source: (Eaton, 2018; Tover, 2021)

The use of the Tovertafel keeps residents of care homes occupied and has been shown to have a positive effect on the quality of visits from the residents' families as well as improve the mood of the caregivers (Good et al., 2019). Bruil, Adriaansen, Groothuis and Bossema (2018) performed an exploratory, quasi-experimental study on the quality of life of 34 nursing home residents with dementia before, during and after playing with the Tovertafel. The result of the study showed improvements in the quality of life of the residents with moderate to severe dementia for up to a week after playing with the Tovertafel. Not only has the Tovertafel been recorded as being successful for physical, mental, and social stimulation while also creating a purpose for the day, it

has also been shown to alert caregivers to the declining conditions of their care patients through the observation of the changes in their interaction with the table (Lennartson, 2018).

3.8 Multisensory Environments

People living with dementia are usually at risk of sensory deprivation due to their limited access to meaningful and suitable activities. They can also sometimes be exposed to overstimulation especially in care home facilities due to the noise and busy areas. Both conditions pose a challenge to their overall health as they can lead to the development of aggravating behavioural symptoms (Jakob, Treadaway and Manchester, 2017). In addition, older people often experience a reduced acuity of vision, hearing, taste, and smell which puts them at risk of sensory deprivation. Therefore, the provision of multisensory activities is essential to enable them to remain active (Pulsford and Thompson, 2019).

Sensory deprivation in people living with dementia usually presents itself as a great reduction of stimulation to the senses and ultimately leads to a significant decrease in health and wellbeing (Kovach, 2000). The symptoms of sensory deprivation are similar to symptoms common in people with late-stage dementia, they usually include confusion, irritability, depression, apathy, hallucination, and disorientation (Zubek, 1974). A major reason for sensory deprivation in people living with dementia especially in its late stages is their limited ability to process sensory stimuli due to reduced acuity of senses, cognitive decline, loss of social skills and environmental restriction (MacDonald, 2002). Sensory deprivation is also caused by exposure to overstimulation from busy areas especially in care homes, which could create confusion and cause a person living with dementia to shut down due to an inability to properly process their surroundings (Bowlby, 1993).

Although dementia is usually linked to a decline in cognitive function and capability, the sensory and emotional processing areas of the brain remain relatively intact in people living with dementia. Therefore, appropriate sensory stimulation has the potential to impact these areas of the brain and produce a calming effect to mitigate some of the dementia characteristics (Collier et al., 2010). Hence, the creation of multisensory experiences by using multisensory environments is highly essential in dementia care in order to address the sensory needs of people living with dementia (Jakob, Collier and Ivanova, 2019).

The concept of multisensory environments also known as Snoezelen was initially created as a leisure-based activity for people with learning disabilities (Hulsegge and Verheul, 1987), but has

since evolved into a therapeutic intervention aimed at enhancing feelings of comfort and wellbeing, relieving stress, and maximising a person's potential to focus. The benefits of multisensory environments to people living with dementia include reduced agitation and disruptive behaviour (Maseda et al., 2014), reduced apathy, improvement on mood, communication, and social engagement (Goris, Ansel and Schutte, 2016). Sensory rooms provide visual, olfactory, auditory, vestibular, and tactile stimulation that are offered through the use of engagement equipment such as fibreoptic cables, coloured lights, bubble tube columns and projectors, and this multisensory stimulation can also promote several functions such as relaxation, self-confidence, leisure, attention span, self-control, and the exploration of creative activities (Duchi et al., 2019).

Figure 3.6: Multisensory rooms

Source: Snoezelen.info

Sensory equilibrium may be accomplished within a multisensory environment through controlled visual, auditory, olfactory, and tactile stimulation designed to mitigate overactive behaviours such as anxiety, agitation or aggressiveness as well as underactive behaviours such as apathy and depression. This process may include the use of interactive LED lighting elements that can be controlled by the participant, vibracoustic furniture that allow the participant to feel musical vibrations, and aromatherapy (Lorusso and Bosch, 2018).

Despite the popularity of multisensory environments and Snoezelen rooms in literature, their use in practice has been limited and inconsistent as there have been reports of the underutilisation of existing spaces and the lack of well-designed sensory sessions (Andrews, 2020). Sensory rooms have been reported to be underused and often locked up especially in care homes due to a lack of proper consideration of their design and use within the establishment. This failed design and poor

facilitation often results in the discouragement of staff and underutilisation of the sensory rooms as they are perceived as having little value (Dalke, 2010).

Whilst the impact of sensory rooms is well demonstrated, a study of existing research and commercial platforms reveals high installation costs and a lack of portability as some of their deficiencies because Snoezelen/sensory rooms generally require elements to be fixed or setup in dedicated rooms. There is also an insufficient amount of research considering the design of multisensory environments, including whether the current design is the most appropriate for people living with dementia and whether the way sensory rooms are set up could have an effect on residents and staff of care facilities, and on the perceived outcomes of the experience provided (Jakob and Collier, 2017).

A solution to some of these issues is the use of the Snoezelen mini cart. This cart contains the elements normally used in multisensory rooms such as bubble tubes, fiberoptic sprays, projectors, aromatherapy diffusers and elements for tactile stimulation. Although, the use of the Snoezelen mini cart does not solve the issue of the high cost of Snoezelen as it incorporates the same elements used in Snoezelen, it provides a portable means of implementing Snoezelen as the cart can usually be moved around on wheels and used in different locations.

Figure 3.7: Snoezelen mini carts

Source: Flaghouse (n.d)

3.9 Games and Activities

The introduction of games and leisure activities to people living with dementia can improve their quality of life and help manage some of the behavioural and psychological symptoms associated with the disease (Astell, 2013). This non-pharmacological approach has been shown to be effective in improving performance in activities of daily living, increasing positive emotions, improving wellbeing, and fostering positive attitudes towards caregivers (Barton et al., 2016). The primary aim of the use of activity kits with people living with dementia is to complement a person's abilities and to work on their sense of self to provide person centred care rather than resulting to pharmacological and environmental control of the disease (Halek et al., 2013). However, mainstream games and leisure products are often unsuitable for people living with dementia because they do not take their diminished physical and cognitive capabilities into consideration. Therefore, providing suitable activities can sometimes be a challenge as people living with dementia and their relatives often find the use of young children's toys too childish and stigmatising (Lucero et al., 2000) and therefore do not engage with them.

However, activity kits that are developed from a careful selection of tactile, auditory, olfactory, and visual items are known to provide solace, opportunities for emotional expression, relief from boredom and loneliness, cognitive integration, neuromuscular strength, and perceptual processing (Conedera and Mitchell, 2007). Those tailored to people living with dementia usually include a wide range of items that are commonly used to provide diversion such as games, arts and crafts, physical activities such as exercise, audiotapes, cognitive stimulating activities, music, and entertainment, sorting activities such as puzzles, sensory activities, domestic or homemaking activities and reminiscence activities (Regier, Hodgson and Gitlin, 2017). Items such as key and lock boards, pieces of textured fabric and clothes to fold are usually added to provide stimulation to people with severe dementia. To promote sensory stimulation in hospitals, nurses also sometimes introduce activity kits such as sewing cards, adult colouring books, and puzzles to distract patients with dementia from how busy and noisy hospital environments often are (Zonsius, Cothran and Miller, 2020). Often, outdoor activities such as gardening are incorporated into activity kits, as participation in sensory outdoor activities have been shown to reduce agitation due to less distractions (Collins et al., 2020).

Although there is evidence to suggest that the use of activity kits is safe and appropriate for people living with dementia in acute and residential care settings as well as in hospital (Higgs et al., 2020), people living with dementia still experience fewer opportunities to engage in activities with other

people due to the lack of objects and activities specifically designed for them (Treadaway, Kenning and Coleman, 2014). Therefore, the appropriate selection of games and activities is essential to avoid overstimulation. The items selected in the development of an activity kit should reflect the preferences, physical abilities and cognitive capabilities of the user or group of users. It is also crucial that all items included do not infantilise, insult, or threaten the self-image of the users.

In practice, there are various options of activity kits available to people living with dementia, ranging from already made kits sold as a unit, or instructional materials for the development of DIY (Do It Yourself) kits. These available kits vary in content, size and cost and are provided by different organisations. One of such activity kits is the Relish activity pack. This pack contains different collections of paper-based activities such as painting and varying puzzle types and caters to different stages of dementia. Although there are many benefits of this kit, it does not cater to the different human senses and does not provide any form of multisensory stimulation.

Figure 3.8: Relish Mid-Late stage special activity pack

Source: Relish (n.d)

While some activity kits can just be bought off the shelf as a one-off purchase, other activity kits are developed to be run on a subscription basis. One of such kits is the subscription activity box by S&B Sensory Ltd (Zen S&B Sensory, 2021). This activity box is offered on a bi-monthly subscription basis with each member receiving a personalised box once every two months. It contains sensory stimulating items such as elements for reminiscence and tactile stimulation which are advertised as being able to support emotion regulation, encourage muscle growth and build a positive therapeutic wellbeing. The advantage of a subscription box is that the user has the option to get

new sensory elements regularly which will provide the element of variety. However, the bimonthly payments for this box may be too expensive for people, especially if purchased by an individual and may not be sustainable long term.

Figure 3.9: The S&B subscription box

Source: Zen S&B Sensory

Some commercial platforms do not provide already made activity or sensory kits but rather provide resources or manuals to be used in their creation. One notable resource for the development of sensory boxes is offered by (Constantia Care Admin, 2018) and describes the use of sensory boxes as well as examples and pictures of elements that can be incorporated into the development of a sensory box. Although this resource offers advice on the creation of a box that provides only tactile stimulation, it also offers advice for personalisation which is usually recommended for activity kits that would be used in the personal homes of people living with dementia. This option is very low cost as not only is the manual free, but it also allows the caregiver or family to create the box based on their personal budget. In addition, this resource also offers the option to incorporate different themes into the sensory box.

Figure 3.10: Constantia care sensory box

Source: (Constantia Care Admin, 2018)

Table 3.1 compares some of the sensory and activity interventions described above that are representative of products available to people living with dementia in practice and in doing so it shows that none of these products available commercially offer all the features listed on the table.

Table 3.1: Dementia Product Functionality Matrix

Feature	Portable	Low Cost	Integrates elements of technology	Combines activities and sensory room elements	Caters to multiple senses	Incorporates the use of themes
Memory boxes	✓	✓	X	X	✓	✓
PARO	✓	X	✓	X	✓	X
Twiddle muffs	✓	✓	X	X	✓	X
Tovertafel	X	X	✓	X	✓	X
Sensory rooms	X	X	✓	X	✓	X
Snoezelen Mini cart	✓	X	✓	X	✓	X
Relish special activity pack	✓	✓	X	X	X	X
S&B subscription box	✓	✓	X	X	✓	X
Constantia Care Memory Box	✓	✓	X	X	✓	✓

3.10 Summary

This chapter has explored the non-pharmacological interventions available for providing engagement to people living with dementia in practice such as memory boxes, twiddle muffs, the Tovertafel, PARO and multisensory rooms. Upon doing this review, it is clear that although there are many beneficial interventions that offer a range of elements, there is no single provision that has all the qualities of (1) being low-cost, (2) combining sensory and activity elements, (3) integrating elements of technology, (4) catering to multiple senses, and (5) incorporating the use of themes. This combination of qualities would result in an activity kit that is affordable, adaptable to different stages of dementia and can be personalised. Therefore, this PhD aims to fill this gap by creating a multisensory and multiactivity intervention that is not only suitable for use with people living with dementia but also combines all the qualities highlighted. Chapter 4 details the methodology used in the creation of this intervention and the research design.

Chapter 4: Design research and approaches for requirements co-creation

This chapter provides details of the research into the design processes used in this PhD. After presenting several different design methods it gives an overview of the methodological approaches selected for this research and details the justification for these choices. It then explores the design thinking approach and details the importance of the literature review and how it led to identifying the overall aim for the PhD and an understanding of user needs to identify the requirements for an active multisensory environment for people living with dementia. It also examines user-centred design and explains the choice of user personas created for this intervention. The chapter provides an account of the observation performed at a hospital in Reading and the process of working with the Dementia Steering Group and its experts which helped with gathering requirements from a practical point of view. It also delves into the process of the co-creation of the AMuSED toolkit with the Museum of English Rural Life and the training of the hospital activity staff on the use of the AMuSED toolkit. Finally, this chapter examines prototyping, the importance of prototyping in the design process and the use of iterative prototyping in this research.

4.1 Design Methods

Design research is described as the development of interventions as a solution to complex problems while also systematically studying the development of these interventions and the context in which they emerge (Schoenfeld, 2014). In order to create these solutions or make improvements, the problems must be investigated and diagnosed to inform the design of novel technologies and interventions (Bilandzic and Venable, 2011). Following the development of these new technologies, they should be evaluated to provide evidence that they have utility with respect to solving the relevant problem or making the desired improvement. In design research, a researcher can use both classical research methods such as quantitative or qualitative methods, and design methods such as action research (Yee, 2010). Quantitative methods involve objective and systematic data collection and analysis using tools such as structural testing, statistical analysis, written surveys, and anthropometry (Roth, 1999), while qualitative methods are aimed at making sense of or interpreting phenomena in terms of the meanings people ascribe to them. They can include observation, personal interviews, diaries, self-reporting, focus groups and ethnography (Denzin and Lincoln, 2011). Both quantitative and qualitative methods are often combined in research,

especially in user centred research methods such as action research (McNiff, 2008) or design thinking (Brown, 2008).

Action Research

According to (Kemmis and McTaggart and Nixon, 2014), action research is a form of collective, self-reflective inquiry that practitioners in social situations take to improve the rationality and justice of their own social practices, as well as their understanding of these practices and the situations in which they carry out these practices. These practitioners can be any group with a shared concern and the motivation to address the concern, such as teachers, parents, students, community members and social activists. The approach qualifies as action research only when it is collaborative and achieved through the critically examined action of individual group members.

Action research is aimed at changing the practitioners' practices, their understanding of their practices, and the conditions in which they practice (Kemmis, 2009). (McNiff, 2016) describes the basic steps to action research as:

1. Reviewing current practice.
2. Identifying an aspect to be improved.
3. Imagining a way forward.
4. Testing out the way forward and taking stock of what happened.
5. Modifying the plan in light of the resulting findings and modifying the action.
6. Evaluating the modified action.
7. Reiterating the process until satisfaction is achieved.

The true nature of action research is not about aiming for behavioural outcomes like in the case of traditional research, but about generating new and interesting questions that open up new possibilities (McNiff, 2008). This often results in a partnership between investigators and participants (members of the community) with respect to planning and interpreting research, and subsequent partnering in the development, implementation, and evaluation of any resulting interventions (Minkler and Wallerstein, 2003). Based on this partnership, interviews, conversations, past records, group discussions etc. are often incorporated into the research to promote the examination of the multiple contexts surrounding the communities, practices, and practitioners (Averill, 2002). Action research also frequently incorporates ethnography in the form of ethnographic participant observation in a bid to deeply understand the practitioners within the community (Tacchi, Slater and Hearn, 2003).

Ethnography

Ethnography is the study of people in naturally occurring settings or "fields" using methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the settings and/or activities in order to collect data in a systemic manner without meaning being imposed on them externally (Miller and Brewer, 2003). This method typically involves going out into the field for data collection and includes the use of techniques such as observations and interviews while also sometimes incorporating visual recordings, document analysis and diaries (Singer, 2009). Ethnography seeks to answer key anthropological questions concerning the ways of life of human beings, and its roots in cross-cultural understanding has delivered the possibility for it to be used to understand more about the process of modern design (Bucciarelli and Bucciarelli, 1994).

Ethnography can therefore be employed as a design research method to investigate life and culture as a context for innovation and creativity, and this form of research has been shown to encourage innovation and mitigate risk (Wakeford, 2004). However, traditional ethnography has been redefined for design research under the concept of Rapid Ethnography (Norman, 1998), which is reported as a more effective way of achieving a deep understanding of people's habits, meanings and rituals around relevant activities and artefacts. This is also similar to the "lightweight" ethnography concept presented by (Hughes et al., 1994) which was reported to be more fitted to commercial designers than the traditional slower paced form of ethnography. Rapid ethnography is reportedly based on three key ideas including narrowing the focus of the field before entering and zooming in on the key members of the group, using multiple interactive observation techniques to increase the likelihood of discovering exceptional and relevant user behaviour, and making use of collaborative and computerised iterative data analysis methods. This process has been reported as a highly flexible form of ethnography and one more suitable to accommodate the rapid expansion and development in the product design field (Rodgers and Anusas, 2008).

4.2 Design Thinking

Design Thinking methodology (Brown, 2008) is a series of processes used in the identification of problems and creation of useful solutions and in doing so it combines an iterative yet structured development process, important in engineered solutions, with consideration of user needs. The design thinking methodology is an approach to problem solving that produces relevant solutions

through ideation (Black et al., 2019). At its core, it is based on the principle that development should always start by building an understanding of the group of people a solution is being created for (Bell, 2008). Various techniques are used to empathize with the users to gain insights into human behaviour to come to a clear understanding of who the user of the solution is and what their needs are (Ahmed, Dannhauser and Philip, 2018). This method of problem solving is described as a person-centred innovation process that places emphasis on observation, collaboration, fast learning, idea visualisation, prototyping and business analysis (Lockwood, 2010).

While the concept of design thinking is considered to be relatively new (Vasilieva, 2018), the concept of product design has been of interest to business researchers for decades and has been explored by various theorists (Bloch, 2011). When all the individual elements of design thinking are combined and viewed as an end-to-end system, design thinking emerges as a distinctive practice and a collection of tools, approaches, and attitudes (Buhl, 2019). It provides a combined approach that brings together both analytic and creative methods of reasoning as well as a process and set of techniques and tools (Orilkowski, 2010). The design thinking methodology places emphasis on the development of possibilities rather than the satisfaction of constraints and is an enablement methodology that is focused on envisioning what is possible (Neumeier, 2009). This method serves as a catalyst for collaboration, innovation, and enablement. It promotes visualisation, observation and concept prototyping and reveals an output that proves as a tool to bring products, experiences and services to the market (Welsh and Dehler, 2013).

With the intention of facilitating brainstorming, design thinking presents itself as an iterative approach used in the support of divergent thinking. Comprised of various stages including empathy, ideation, prototyping and testing, it provides a framework for the identification of problems and how they can be approached (Johansson-Sköldberg, Woodilla and Çetinkaya, 2013).
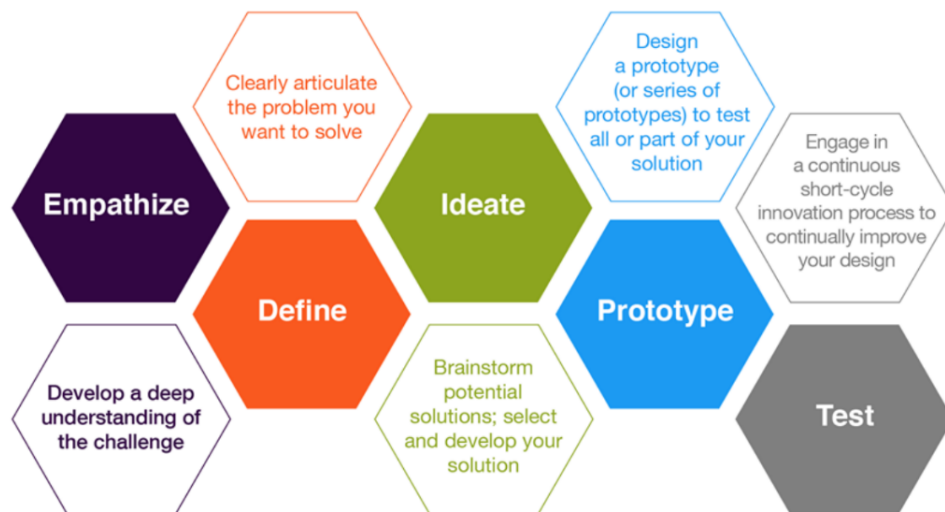
Figure 4.1: The Design Thinking methodology

Source: University of Illinois, adopted from (Plattner, 2009)

The uniqueness of the design thinking methodology lies in its ability to be richly adopted and implemented across various concepts and disciplines (Li et al., 2019; Micheli et al., 2019). To take advantage of the creative, problem finding approaches offered by design thinking, it is best to think of this approach less as a monolithic, fixed practice and more as a flexible practice framed by a deep responsibility to audiences, designs and compositions (Teal, 2010). This manner of thinking requires empathy and must be attentive to the critical, ideological, and cultural variables that shape the work done and the teams involved in doing the work (Gasparini, 2015). In doing so, design thinking will not only be adaptable to different audiences and situations, but also be applicable as a playbook through which people can draw from a useful set of tools to help in their work (Greenwood et al., 2019).

4.2.1 Justification for design thinking in current research

Compared to other research methods such as action research (Brydon-Miller et al., 2003) and ethnography (Gobo and Marciniak, 2011), the design thinking methodology not only seeks to understand the way of life of a particular group of people, but is also deeply rooted in understanding the needs of the group as well as how to develop useful solutions to fill such needs through a unique combination of human centred design and a strong foundation in innovation (Chasanidou, Gasparini, and Lee, 2015). Whereas action research while sharing some similarities

with design thinking, is not aimed at generating design principles and interventions, but rather at the study and improvement of existing practices (Denscombe, 2021). More recently, there has been a need to put more "human" in human-centred design, and design thinking, once adopted, offers a specific approach to problem solving and allows for a more reflective stance in the design process (Friedland and Yamauchi, 2011) by not only providing multiple points of view, but also an avenue to continuously revise the solution (Bowen and Petrelli, 2011).

The human-centredness of this methodology as well as its provision of an iterative set of steps to innovation provides the justification for its use in the design process and at many stages in this research. The design thinking methodology has many variations in the stages, proposed by many existing models such as the Empathise, Define, Ideate, Prototype and Test model developed by the Institute of Design at Stanford (Plattner, 2009) and the Inspiration, Ideation and Implementation model created by IDEO (Brown, 2008). However, the different improvement cycles represented in the different available models permeate all the stages through repetition, including the identification of a problem and the rapid exploration of ideas and possible solutions (Pereira and de FSM Russo, 2018).

4.2.2 Design Thinking and Engineering Design

Engineering design is described as the purposeful integration of scientific knowledge to create something that fulfils a need (Berge et al., 2014). The role of design in engineering is linked to problem solving and the confrontation of a problem with what is already known in order to foster new and creative solutions (Pahl and Beitz, 1988). In engineering design, design thinking has been used to add a strong focus to the users' needs, integrate a flexible procedure for solving complex problems, and provide a guideline to foster creativity for development teams (Pereira et al., 2021). This has encouraged interdisciplinary teamwork and interactive learning cycles especially in the early stages of the development process (Brown, 2008). One of the challenges faced by engineers in the design process is that of discovering and satisfying the volatile requirements of the stakeholders (Hehn et al., 2019). Vetterli et al (2013) suggests that the human-centred attribute of design thinking addresses this challenge and fosters innovative design especially through methods such as rapid prototyping.

Design thinking builds on rich qualitative and quantitative tools across all phases of the design process such as needs assessment, design principles, creative design, and prototyping in order to create a rich human-centred product or service (Roschuni et al., 2011). A model of design thinking

reframed for Development Engineering created by (Beckman and Barry, 2010) illustrates that the design thinking process typically begins with design research and immersive user needs assessment using qualitative tools such as interviews and observations, which would be analysed to provide insights for framing the problem and developing imperatives that would be used for concept development and prototyping. The resulting prototype is then tested in the field with users for rapid improvement and redesign where required.

Figure 4.2: Design thinking in development engineering

(Levine, Agogino and Lesniewski, 2016)

Another model of design thinking – The design thinking process model – developed for Method Engineering by (Plattner, Meinel and Weinberg, 2009) consists of six consecutive loops – Understand, Observe, Point of View, Ideate, Prototype and Test – with suggested iterative loops between the steps to illustrate the possibility of back-and-forth movement between different phases of the methodology according to the requirements of each step's outcome.
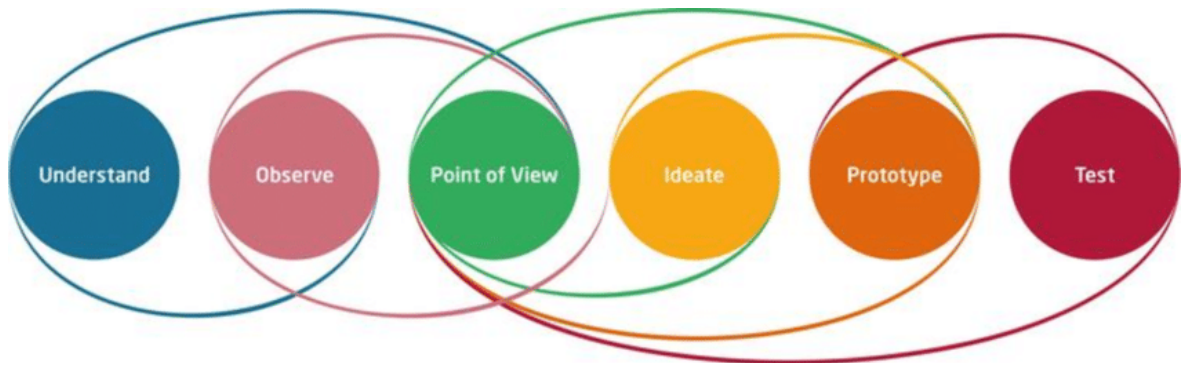
Figure 4.3: The Design Thinking Process Model

(Plattner, Meinel and Weinberg, 2009)

This model further expanded by (Thoring and Müller, 2011) describes the steps in the design thinking methodology as follows:

1. Understand: collecting existing information and becoming an expert through research.
2. Observe: gathering insights about users' needs through interviews or observations.
3. Point of View: developing a micro theory about users' needs by searching for analogies and metaphors.
4. Ideate: generating ideas for possible solution to the defined problem of needs through brainstorming, brainwriting etc.
5. Prototype: developing a representation of the concept through prototyping, model making, roleplaying etc.
6. Test: gathering feedback from users and stakeholders about concept and prototype by showing the prototype to potential users and stakeholders, letting them work with it and receiving positive or negative feedback through tools such as questionnaires.
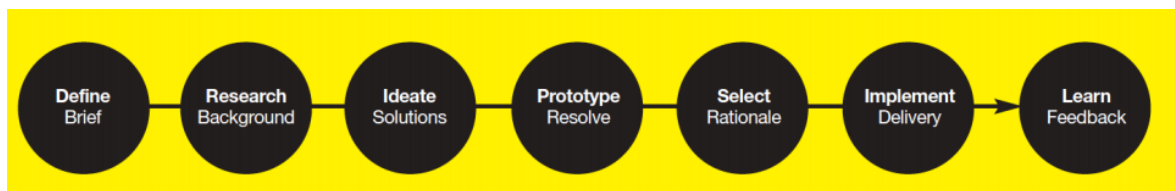
Figure 4.4: 7-stage Model of Design Thinking

(Ambrose and Harris, 2009)

(Ambrose and Harris, 2009) developed a 7-stage model of design thinking which takes into consideration the feedback and learning process that often follow the implementation of

interventions of innovative products and designs. In addition to define, ideate, and protype, their model of design thinking includes the following steps:

- Research: collecting background information such as history of the design problem through primary and secondary research sources.
- Select: reviewing all the proposed solutions against the design objective in order to choose the best one for development based on the key decision criterion of fitness for purpose.
- Implement: confirming design specifications, ensuring end result meets specifications and ending with the final delivery of the finished product.
- Learning: Obtaining feedback to determine whether the solution meets the goals of the brief. Rooms for improvements can also be identified during this stage.

In software engineering, the use of design thinking fosters human-centred solutions more effectively by turning problems and user needs into possible solutions (Hehn and Uebernickel, 2018). The design thinking methodology was adopted by (Valentim et al., 2017) for the design of mobile applications as a way to transition from technology-centred design to human-centred design. This model, adapted from (Brown, 2008) explains that in the development for human-centred design, iteration plays a significant role (Zoltowski et al., 2012) and therefore describes design thinking as a process of three iterative stages namely: Inspiration, Ideation, and Implementation. The inspiration stage in this model of design thinking represents situations generated through interactions with stakeholders which motivate the search of solutions. The ideation stage is described as the process of generating, developing, and testing different ideas that may lead to solutions, while the final stage in the design process – implementation – represents a path to develop and run the selected concept (Erzurumlu and Erzurumlu, 2015). Finally, this model suggests the use of tools and techniques such as personas, co-creation and brainstorming during the different stages of the design thinking process.
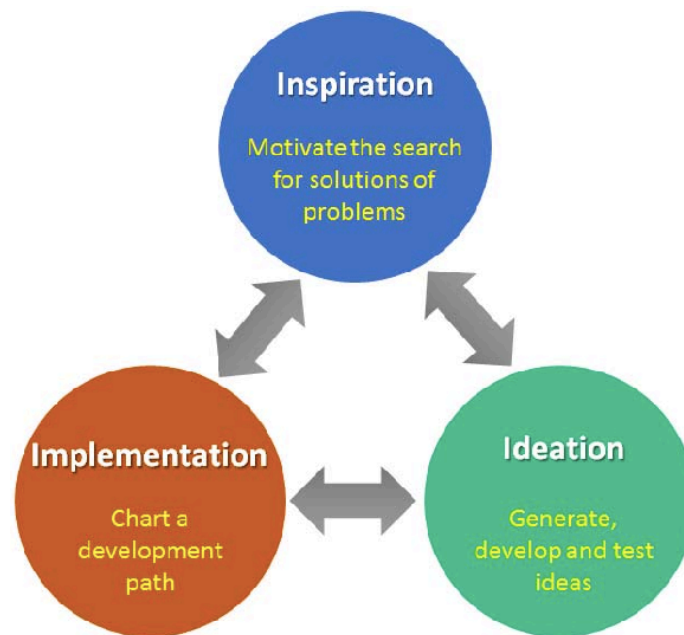
Figure 4.5: Three stages of the design thinking process

(Valentim et al., 2017)

4.2.3 Design Thinking and Innovation

The use of design thinking promotes exploring, analysing, and developing various outcomes and possibilities to create the most suitable solutions that lead to innovations (Vu, 2017). The design thinking principles of working with users, prototyping, testing, and iterating, result in the development of products and services that are not only fit for purpose, but are also adaptable enough to be tailored for businesses in different sectors (Ward, Runcie, and Morris, 2009). According to (Hobday, 1998), the innovation process continues long after implementation as products often involve a series of phases such as maintenance, upgrades, and performance modifications.

It is also important to note that although the design thinking methodology is successful as an avenue for innovation (Carlgren, 2013), there is often the challenge of capturing value from innovation, as product developers sometime aim to earn profits through commercialisation to promote further research and development of the product (Pisano and Teece, 2007). In considering commercialisation of innovative products, it is important to examine factors such as novelty and intellectual property to ensure that not only is the design protected, but also that it does not infringe other existing IPs (Hitchcock, 2022).

4.2.3.1 Commercialisation

Commercialisation can be described as the process of bringing new products and services to market, generally crossing from the development stage to the market entry and then to growth (Boni, 2018). According to (Kurokawa, 2013). Ideas and products generated from the design thinking approach have been commercialised and adopted in the form of ventures and start-ups, as well as by existing companies. However, a lot of technologies resulting from student research focus more on "invention" rather than "innovation". Due to this, they usually do not go further than the lab and unfortunately do not create social goods or generate revenue.

(Wang et al., 2019) proposed the HRIpreneur Thinking innovation Pipeline, a Lean Human-Robot Interaction (HRI) research innovation pipeline that incorporates commercialisation into the early stages of the design process. This model suggests that market-oriented and consumer need-driven insights be injected into the early stages of the design thinking approach in order to develop minimum valuable testbeds or prototypes with the end users and stakeholders involved. This study also categorised innovation into two types:

1. Technology-Push innovations: these are the innovations or research findings which do not have immediate problems to solve, or apparent market needs but possess the potential to reshape customer behaviour through new user cases and futuristic user experiences.
2. Market-Pull innovations: these innovations have clear market needs and are designed to solve specific market problems following in-depth customer research.

Wang et al. (2019) state that regardless of the innovation type, products developed from university research can be commercialised by taking advantage of funding opportunities such as Venture Capitalist investments especially in the early stages of research like product prototyping and Intellectual Property solidifications.

Tan (2013) further expanded the commercialisation process of design thinking inventions to include the following steps:
1. Production: this includes process planning, studying regulatory requirements, procurement of components, production control and management, assembly, quality assurance, logistics management and packaging.
2. Marketing and Sales: includes preparation of marketing plan, sales and promotion, product pricing, delivery, and customer support.

3. Market Feedback: gathering and analysing customer, retailer and distributor feedback and making appropriate recommendations.

4. New Model Planning: incorporating market reports and all information in the product development process into the preparation and development of subsequent models.

According to (Tan, 2013), an invention typically occurs in the prototype development phase of the design process. Therefore, to protect the Intellectual Property, a patent search should be conducted before the production phase begins, and a patent filed to protect the novelty of the product. Collaborations can then be sought out by partnering with the appropriate organisations to develop the product further for commercialisation.

4.2.3.2 Intellectual property ownership

The heritage of product design is largely built upon the ability to generate a market by developing new concepts and creating customer desirability. Novelty and uniqueness have also been proposed as a great way to achieve market domination after the development of new concepts and products (Des Follett, Marra and Conran, 2015). However, while design thinking is largely used in the development of novel solutions, Intellectual Property (IP) is not always considered during the ideation stage of the design process, which can lead to the infringement of other existing patents and intellectual properties (Chulvi et al., 2013). It is therefore essential to conduct Intellectual Property infringement checks throughout the different stages of solution design to not only avoid reinventing past solutions, but to also draw inspiration from past designs, especially if commercialisation is to be considered. This refers to the continuous checking of IP infringements throughout the entire design process (Koh, 2013).

The cost of conducting frequent and thorough Intellectual Property infringement checks can be challenging, especially for new technology start-ups and entrepreneurs with limited resources. Therefore, (Zeng et al., 2012) suggests the adoption of data mining systems as an affordable and effective means of retrieving relevant Intellectual Property information throughout the design process. The efficiency of such data mining systems however depends largely on the ability to handle the vast number of existing patents and being able to extract design information from the Intellectual Property documents (Liang et al., 2009).

4.2.3.3 Product support and maintenance

Most physical products experience wear, tear, and deterioration with age and use, which begs the need for product support and maintenance. The role of maintenance and product support can be perceived as a part of the innovation process that compensates for deficiencies in design, as well as human error, statutory requirements, accidents etc. (Markeset and Kumar, 2003). Product support and maintenance needs are often decided during the design and development phase, and the scope has broadened over the last few decades to include aspects such as installation, supply of spare parts, maintenance and repair, logistics, product upgrade, warranty, modifications, and telephone support (Blanchard, 2009). Periodic maintenance has also been shown to increase the service life of products, generate low waste, and reduce resource use (Sousa-Zomer et al., 2019).

(Gebauer et al., 2008) combined product support and maintenance under the umbrella of product related services and classified product related services into two different categories based on the product innovation process. The first category, defined as integrated service, is service which was considered and developed as part of the innovation process, where both the new product and service are introduced simultaneously to the users. The second category known as separated service, is described as service offered when the product has already been developed and introduced. The ideas for service in this stage are based on service ideas discovered during product usage, unlike with integrated service where the ideas for service innovation stem from the functionality of the product. This categorisation of product related services show that product support and maintenance can be offered as a part of product functionality or can be derived through new customer needs observed during the usage of the product.

4.2.4 Design thinking and this PhD

As commercialisation of AMuSED is outside of the scope of this PhD, and whilst it is reflected on in Chapter 9, the work within the PhD was carried out using the five-step model version of design thinking methodology created by (Plattner, 2009) due to its multidisciplinary capabilities (Lin et al., 2020) and success in delivering innovative and human-centred solutions (Naiman, 2019). The initial stages of this model are divergent and seek to foster idea generation and design exploration through empathy generation and problem definition, while in the later stages, convergence occurs as the idea generated in the earlier stages are refined and developed into tangible products through prototyping. In using the above mentioned five-step model, the PhD followed the steps below (and Figure 4.1) in an iterative manner:

1. Empathize: this step focused on gaining an understanding of people with dementia and of those that provide care to them as well as the problems they face. Existing literature was reviewed to develop a deep understanding of the challenges associated with providing engaging and stimulating activities to people living with dementia. As well as the different therapy types discussed in Chapter 2, this chapter reviews further as part of the user-centred design approach the important concepts of portability, affordability, usability, adaptability, accessibility, and personalisation in non-pharmacological interventions for people living with dementia.

2. Define: this step focused on defining in more detail the problems to be solved and what others have done to solve the problem. By reviewing products currently available on the market in Chapters 3, gaps were identified in the non-pharmacological interventions used in practice to stimulate people living with dementia, enabling the aim and objectives of this PhD to be defined to address these deficiencies. (See section 4.3 below).

3. Ideate: this step focused on defining a range of solution ideas and then choosing the best ideas to meet the requirements of the caregivers and activity coordinators for a non-pharmacological product that can engage and stimulate people living with dementia. By working with care teams and dementia experts as described in this chapter, the concept of bringing together different aspects of dementia therapy into a single portable box for use by carers, care teams and dementia activity coordinators with people living with dementia to engage and stimulate them physically, mentally, and socially through a combination of sensory elements and themed activities was conceived and defined. This took the form of AMuSED, **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia, realised as a multisensory and multi-activity toolkit (described in Chapter 5) and a framework (described in Chapter 6) for people living with dementia.

4. Prototype: this stage focused on creating a series of prototypes (as described in Section 4.9). The co-created requirements were translated into an iterative series of prototype designs that defined the form of the **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) as an affordable, adaptable, accessible, usable, and portable toolkit that can be personalised, and used by caregivers and activity coordinators to provide engagement and stimulation through multisensory and multi-activity sessions in a range of care provisions.

5. Test: this stage focused on testing the prototypes in order to get feedback from caregivers and activity coordinators on the AMuSED concept and design alongside suggestions for how

the design can be improved or extended. The final AMuSED toolkit editions (as described in Chapter 5) were evaluated (as described in Chapter 7) by care staff and activity coordinators in community and care facilities in Reading and the Thames Valley area.
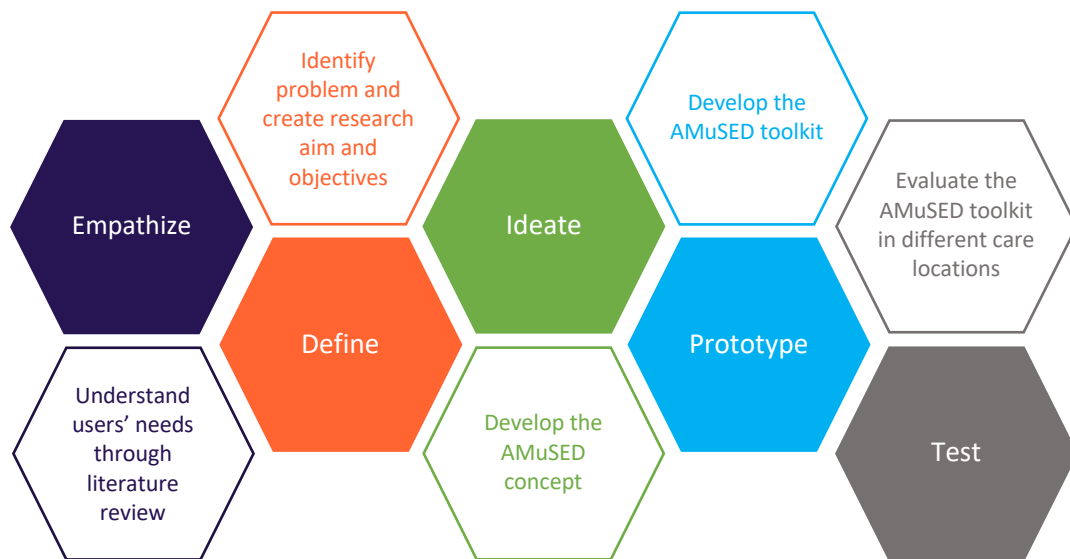
Figure 4.6: Design thinking diagram reflecting the PhD stages

Using the design thinking methodology for this research allowed for a deeper understanding of the challenges associated with providing engagement to people living with dementia and provided a structured approach that resulted in the creation of the AMuSED toolkit as a solution. The remainder of this chapter describes how the literature review conducted in chapters 2 and 3 led to the creation of the requirements for an active multisensory environment and shows how this research incorporated user centred design into the design thinking approach through the creation of multiple user personas. Finally, it describes the observation with the care crew, the challenges identified after the observation and how the AMuSED toolkit was developed through collaboration with dementia experts using various prototypes.

4.3 Importance of the literature review

In the use of the design thinking methodology for this research, the first stage – empathize – involved identifying the needs of people living with dementia by recognising the gaps in literature

and practice through the medium of a literature review. The rationale behind undertaking a literature review was to gain a proper understanding of the problem (Hart, 2018) in order to produce innovative results (Liedtka, 2018). The importance of conducting a literature review in research cannot be overemphasized because to understand what needs to be done in new research, there is a need to understand what has been done before as well as the strengths and limitations of the existing studies (Asmussen and Møller, 2019). The literature review is the foundation of any research project (Boote and Beile, 2005) as it provides the broad context of the study and separates what is from what is not. It provides information on what has been studied and accomplished as well as identifies what still needs to be accomplished.

Apart from the provision of prior knowledge in the field, conducting a literature review helps to delimit the research problem, avoid the use of fruitless approaches, seek new lines of inquiry, recognise recommendations for further research and seek support for grounded theory (Gall, Borg and Gall, 1996). It can also serve to create a framework in which new findings can be attached to previous findings (Booth et al., 2021) because without the establishment of the state of the previous research, it is impossible to establish how the new research serves to advance what has been previously done (Randolph, 2009).

The main question that should be asked in the design phase of a literature review is why the review should be conducted (Snyder, 2019). The literature review done in this research was conducted as a way of understanding dementia, people living with dementia and the non-pharmacological interventions currently available to people living with dementia. In doing this review, dementia and its various forms were revealed, as well as the different stages of dementia such as mild, moderate and severe dementia. This literature review included search terms such as "dementia", "types of dementia", "dementia and activity", "behavioural issues", "apathy and dementia", "agitation and dementia", "dementia therapies", "non-pharmacological intervention", "multisensory stimulation", "activity coordinator", "dementia care and engagement" etc and was achieved using academic databases (Google Scholar; PubMed; ResearchGate).

(Snyder, 2019) argues that for a literature review to count as well conducted, it must engender new ideas and directions within that particular field. The second chapter of this thesis reviewed non-pharmacological interventions available for stimulating and engaging people living with dementia and while doing this, the behavioural issues and challenges faced by people living with dementia such as apathy and agitation were revealed in literature. Existing research and literature also

revealed the need to provide meaningful forms of multisensory stimulation to mitigate the effects of these behavioural issues. In reviewing the different forms of therapies available to people living with dementia such as art, music, reminiscence and multisensory and their benefits, the idea for a solution that combines these various forms of therapy in one entity emerged. A gap was identified that revealed that although the available solutions for providing activities to people living with dementia such as painting, games, and puzzles, were beneficial, none of them were combined with the additional benefit of multisensory stimulation or Snoezelen.

The identification of this gap led to the third chapter of this thesis which explored the actual technologies available for providing engagement to people living with dementia in practice. It investigated the use of the Tovertafel, sensory rooms, twiddle muffs and other non-pharmacological interventions available in practice and identified both their benefits and deficiencies. This process led to the development of the AMuSED concept as a solution to bridge this gap in literature and practice.

4.4 Aim and objectives of the PhD

The aim of this PhD is to develop an **A**ctive **Mu**lti-**S**ensory **E**nvironment for People Living with **D**ementia (AMuSED) that that brings together, in a single toolkit, different aspects of dementia therapy into a single portable box for use by caregivers, care teams and dementia activity coordinators to engage and stimulate people living with dementia physically, mentally, and socially through a combination of sensory elements and themed activities.

To achieve this aim, the key objectives specified are:
1. Work alongside dementia experts to co-create the requirements for a multisensory and multi-activity environment for people living with dementia.
2. Translate the co-created requirements into a series of prototypes that increasingly define the form of an **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) as an affordable, adaptable and portable toolkit that can be used by caregivers and activity coordinators to provide engaging and stimulating multi-sensory and multi-activity sessions to people living with dementia in a range of care provisions.
3. Develop an AMuSED framework based on the prototypes created that enables different AMuSED toolkits to be defined for individuals, themes, and/or places of care including for example, individual homes, community settings, care homes and hospitals.

4. Evaluate a range of AMuSED toolkits with care teams and activity co-ordinators in community and care facilities in Reading and the Thames Valley.

4.5 Key requirements for using an active multisensory environment in practice

Apart from revealing the gaps in literature and practice for therapy interventions, the literature review also helped to identify several key requirements for making an active multisensory environment, not only engaging, and stimulating for people living with dementia, but also affordable and usable by managers in care homes and hospitals, activity coordinators and care teams, and individual caregivers. The identification of these requirements helped to shape the design process and focus on important attributes that have been highlighted in literature. These are discussed below and are referred to further in the user-centred design section.

4.5.1 Affordability

Although the use of technology can be adopted as part of dementia care, it is often expensive, and many individuals or care facilities are not able to afford specialist technological solutions and interventions. Therefore, the need for effective and affordable non-pharmacological interventions is vital as these are required to improve the quality of life of people living with dementia and their caregivers in different care settings (Ihara et al., 2019). This is even more imperative considering many people living with dementia are in low- and middle-income countries (Eggink et al., 2019) where affordability is a key consideration in the adoption of any intervention. This affordability criterion is often met by web-based interventions and solutions such as mobile and e-health applications rather than by non-web-based interventions because of the increasing global access to the internet (Global Digital Population, 2019), but online solutions cannot provide the full sensory experience. Therefore, there is a need for physical (digital or traditional) non-web based non-pharmacological interventions to also be affordable to ensure that people living with dementia and their caregivers can also have access to them.

4.5.2 Portability

The need for portability is essential in the design and development of interventions because portability has been shown to facilitate the uptake and adoption or implementation of an intervention by care home residents, families, and care staff (Irazoki et al., 2020; Barnett et al., 2017). It also leads to the development of solutions that contribute to meaningful engagement and interaction for people living with dementia, especially in care facilities (Neal, du Toit and Lovarini, 2020). Additionally, because people living with dementia are easily distracted and have a short

attention span, portability for this group of people also extends to the need for fast and easy set up interventions in order to avoid discomfort or loss of interest (Tabbaa et al., 2019).

4.5.3 Adaptability

Due to the progressive nature of dementia, it is imperative that interventions developed for people living with dementia are designed to adapt to different stages of the condition to remain relevant as a person's dementia progresses. People living with dementia experience functional, cognitive, and behavioural changes as the condition progresses. Therefore, technology and interventions designed for this group of people should be able to adapt to the changes in what a person is still able to do at each stage of their dementia progression (Hammink, Moor and Mohammadi, 2021). Ideally, adaptability in the design process should be focused not only on the progression of a person's dementia but also on the various changes in their individual needs and preferences that happen as a result of this progression (Ancient and Good, 2014), however this is often not considered and has led to the increasing requests for adaptability in the design of interventions for people living with dementia (Joddrell and Astell, 2016). Lessons could be learnt from how software-based interventions consider adaptability in their design process. For example, the ReACT app considers adaptability by enabling individualised default settings in many features of the app and providing the option to deactivate certain functions by selecting or deselecting functionalities of the app based on the needs and severity of dementia of the user (øksnebjerg, Woods and Waldemar, 2019).

4.5.4 Accessibility

When designing interventions for use with people living with dementia, it is important to include accessibility in the process. People living with dementia, especially in care facilities are often seen to suffer from other comorbidities (Chaurasia et al., 2016) that might lead to one or more forms of impairment and thereby influence adoption of the intervention. Users might for example experience impairments related to vision, hearing, or mobility etc. which translates to different individual needs. People living with dementia can also experience deficits in physical functioning such as motor control, balance, motor coordination, gait, and speed (Astell, Czarnuch and Dove, 2018). It is important to accommodate these varying needs to create interventions that are accessible to a large number and range of users. In the implementation of non-pharmacological interventions, it is also important to ensure that all the activities offered are physically accessible to allow for participation from people with a wide range of physical abilities (Benveniste, Jouvelot and Péquignot, 2010).

4.5.5 Personalisation

Personalisation in the implementation of non-pharmacological solutions for the treatment of behavioural and psychological symptoms of dementia has been shown to positively influence wellbeing, behaviour and social interaction and is recommended in the delivery of person-centred care (Koren, 2010). Personalisation has also been highlighted as a useful tool to calm agitated residents in care home facilities (Kuot et al., 2021). In some interventions such as music therapy, studies show that personalised music is more effective in eliciting memories than general music and it is hence recommended that time should be taken to identify musical preferences among participants (Schoenfelder and Gerdner, 2010). Similarly, the use of personalised elements such as personal photos, meaningful media items, familiar music and personal or familiar items in reminiscence therapy can trigger personal memories for both the person living with dementia and their family members as well as increase avenues and opportunities for interaction between them and their caregivers. Including personalisation as a design attribute has also been shown to promote the continuation of the positive effects of the intervention, even after the reminiscence sessions end (Evans, Garabedian and Bray, 2019).

4.5.6 Usability

The concept of usability is rooted in behavioural, social and design sciences, and is related to user experience (Inal et al., 2020). Usability refers to the satisfaction, effectiveness and efficiency with which users can reach their goals when using a new product, service, or system within a specified context (International Organisation for Standardization (ISO), 1998). The consideration of usability as an attribute in the design of technological tools and interventions is paramount to ensure effectiveness (Rodriguez et al., 2018). Usability can also consider the design or layout of the intervention, content, functionality, and assistance or help provided while the intervention or technology is being used (Ottaviani et al., 2021). Interventions that offer high levels of complexity are often criticised by users and have low success with user adoption (Pot, Blom and Willemese, 2015) and hence simplicity and ease of use is an important consideration when designing interventions for people with dementia and their caregivers.

4.6 User-centred design

A common theme among some of the interventions reviewed as well as a key part of the Design Thinking methodology is the adoption of a user-centred approach to the design process. User-

centred design is an approach that bases the design of an innovation on information around the people who will use the innovation with the aim of maximising usability in context of the application, system or product being developed (Dopp et al., 2019). This technique has been widely applied across different formats such as software, services, products, and training materials, and it can be applied to most evidence-based practices and implementation strategies in healthcare (Helker et al., 2016).

One of the reasons for implementation failures in technology usage is the lack of user-centred design (Vilimek and Keinath, 2018). Technologies or interventions that are not designed with the users in mind and the contexts in which they will be implemented often have limited reach and suboptimal engagement post implementation (Lyon and Koemer, 2016). In this case, reach refers to the number of people offered a service relative to the number of people eligible to receive the service, while engagement refers to the adherence to or uptake of a service (Graham et al., 2019). The concept of user-centred design emerged from the search of product designers for ways to understand the people using their products (Buley, 2013) with the main aim of the approach being to discover what users need and to create products, services and experiences that meet these needs (Chamberlain, Sharp and Maiden, 2006).

Greer and Harris (2018) argue that there are three important elements in user-centred design namely user research, iterative design, and collaboration. User research is the search for knowledge about the users and is usually integral to the design work and forms a key part of the design process (Hall and Stark, 2013). Iterative design is an ongoing and recursive form of design that requires the flexibility of a product (Wong and Park, 2010). Rather than the static and linear nature of the classic design process, iterative design is dynamic, open-ended and is based not on technical specifications but on context and a comprehensive report of user stories (Klein, 2016). Lastly, collaboration involves the coming together of the researcher, designer, and experts in real time (Bourelle et al., 2013).

User-centred design is thus a multidisciplinary approach to design that embraces the active search and incorporation of user feedback to ensure that products, services, and experiences are developed with a complete knowledge of the needs and requirements of the user (Sturm and Tscholl, 2019). In this process, it is important for the researcher to act as a translator between the users and the design by making use of their research skills to collect and interpret data collected about the users and their needs (Griffin et al., 2019). This data can either be collected primarily or

obtained through secondary sources and usually forms the basis of the design criteria which can then be interpreted through tool such as personas and scenarios, concept sketching (Sanders, 2002), and prototypes. Typically, in user-centred design, emphasis is placed on gathering user opinions and specifications through methods such as questionnaires, interviews, and demonstration to the intended users (Chun and Nam, 2019). Furthermore, combining user opinions with an in-depth study of similar products results in the incorporation of useful features that serve specific needs rather than the addition of features purely 'for fun' or 'gold plating' just because of the availability of the technology (Stinson et al., 2014).

User-centred design has been adopted in this research because of the need to understand people living with dementia, the behavioural and psychological issues they experience and the technologies and interventions available to caregivers and activity coordinators to help them mitigate these issues. Not only did the use of this approach provide insight into the users, but it also provided the opportunity to explore the current interventions available in the product space for use by caregivers and activity coordinators to engage people living with dementia in activities. Considering users from the start of the research process provided clarity regarding what may or may not be appropriate for people living with dementia in terms of non-pharmacological interventions for engagement and stimulation and led to the identification of deficiencies in some of the technologies and interventions reviewed such as the high cost per unit, lack of portability, and lack of adaptability. The user-centred approach thus provided the basis for the development of an intervention that meets user needs and addresses deficiencies identified in literature and/or in practice.

In considering design thinking and user-centred design, priority should be placed on how the key beneficiaries of this research, in this thesis, Activity Coordinators, people living with dementia, their families or care home/hospital managers, will interact with an active multisensory environment. The focus should be placed especially on the direct users of the intervention – the activity coordinators or caregivers who conduct activities – and how the design of the intervention would influence their ability to successfully deliver engaging and stimulating activity sessions to people living with dementia. According to (Clifford and Doody, 2018), the role of an activity coordinator is a supportive role taken on by the caregivers of people living with dementia and it is identified as a very vital role in person centred care. In relation to dementia care, the role of the activity coordinator can be represented in different forms especially based on the care location (Novelli et al., 2018), and can be undertaken by either formal caregivers such as care home staff and hospital

care crew, informal caregivers (family members or other close person not in a professional caregiver role), volunteers, or a professional activity coordinator.

Formal caregivers

More recently, care homes have been striving to create a balance between the provision of professional care services and the creation of a homely, living environment for their residents through person centred care (Lemos Dekker and Pols, 2020). In the delivery of this form of care, engagement of the care recipient is deemed essential and has been shown to provide many benefits to wellbeing and quality of life (Goodall et al., 2021). Formal caregivers are people hired to care for a person living with dementia in exchange for renumeration and are usually not family members or close acquaintances of their care recipient (Toribio-Diaz et al., 2013). They can provide care within different settings such as care homes, assisted living or sheltered housing facilities, and personal homes of their care recipients (Schneider et al., 2002). Furthermore, in addition to medication management and assisting with activities of daily living (D'Onofrio et al., 2017) – bathing, dressing, feeding – formal caregivers may also organise and coordinate activities for leisure and stimulation (Cohen-Mansfield, Gavendo and Blackburn, 2019).

Informal caregivers

According to (Family Caregiver Alliance, 2020), an informal caregiver is a person with a significant personal relationship with, and provides a broad range of assistance to, a person in need of care. In relation to dementia care, (Bourne, Camic and Crutch, 2021) also describe informal caregivers as those without formal healthcare education who are caring for people living with dementia, usually in an unpaid role. Informal care is often not a conscious choice but a gradual adaptation to changes in the condition of the care recipient, and this group of caregivers provide care because someone needs help, out of love, or out of a moral sense of duty (De Vugt and Verhey, 2013). Informal caregivers often provide years of extensive one-to-one care which is usually adapted to the continuously changing demands that arise as the dementia progresses (Quinn, Clare and Woods, 2010). They usually supervise or eventually take over activities of daily living, manage cognitive problems and behavioural changes, cope with relational and emotional consequences, and participate in care treatment and decisions such as transfer to care facilities (De Vugt and Verhey, 2013). In order to deal with these emotional and behavioural changes, informal caregivers normally adopt the use of different activities, therapies and non-pharmacological interventions (Cooper et al., 2012), and have been known to play an important role in therapies such as reminiscence therapy (Jo and Song, 2015).

Volunteers

Volunteering is the act of freely giving a person's time to perform an activity for which they are not paid, for the benefit of a person, group, or cause (Guerra et al., 2012). Volunteers in dementia care often assist care staff, caregivers and people living with dementia by helping to manage some of the behavioural and psychological symptoms of dementia (Hurst et al., 2019), particularly within hospital settings, care homes, and sheltered or assisted living facilities (Söderhamn et al., 2012). Volunteers also offer meaningful activities which are appropriate for their care recipients such as games, exercise, art, reminiscence therapy, music, and pet therapy (Kelsey and Laditka, 2006). In addition to the delivery of these activities, some volunteers also perform activities such as preparing food and transportation, one-on-one supervision, and motivational support (Arkin, 2003). Collaboration between professional caregivers and volunteers can result in mutual support and team strengthening (Pritchard and Dewing, 2001). However, it is important to provide education tailored to dementia care to volunteers (Robinson and Clemons, 1999).

Professional activity coordinators

The role of the activity coordinator in dementia care is described as a vital supportive role that caters to the management of behavioural symptoms and attends to the needs of the person with dementia (Clifford and Doody, 2018). Professional activity coordinators are usually employed to deliver multiple structured activities such as bingo, reminiscence therapy, music, beauty parlour activities, and van rides (Teri et al., 2009) to residents within the care location. They usually support the caregiver or care staff by taking responsibility for the delivery of activities, especially while the caregivers or care professionals are engaged in other care duties. This collaboration between caregivers and professional activity coordinators allows for a more person-centred approach and integration of activities into the care plan of the person with dementia (Pulsford, Duxbury and Hadi, 2011). The activity coordinator role in dementia care usually involves the activation of people living with dementia through avenues such as social interaction, cognitive stimulation, exercise, games, and multiple forms of therapies (Schultz et al., 2021). It is a vital role and is often recommended within dementia care. It is also advised that different types of caregivers – formal and informal – incorporate the delivery of pleasant activities into their dementia care plan as this has been shown to help in delivering better person-centred care (Teri et al., 2009).

In the development of interventions for activity coordinators, it is important to note the varying levels of expertise from professional activity coordinators to volunteers and informal caregivers. It

is therefore imperative that support be implemented either as a way of providing information on the intervention through guides and other materials, or to mitigate potential issues that might arise with the use of the intervention (Gilson et al., 2019). Also, due to issues such as staff shortage (King et al., 2013), it is important to develop interventions that support one-to-many as well as one-to-one care (Astell, 2015). Importance should also be placed on interventions which are easy to use and free of complexities, as these are more likely to be adopted especially by informal caregivers such as family members (Newton et al., 2016).

Furthermore, whether an intervention will be used at home with a person with dementia throughout the progression of their disease, or in care homes and hospitals with people with varying forms and levels of dementia, attributes such as adaptability and accessibility (Seymour et al., 2017) are vital in ensuring that the intervention is not only useful at one stage of dementia, but at different stages to provide constant support and remain relevant as the dementia progresses (Gowans et al., 2004). Also, receiving feedback from people living with dementia concerning an intervention may be difficult as they may have trouble evaluating an intervention and articulating the benefits and pitfalls of a design (Cohen-Mansfield, Gavendo and Blackburn, 2019) due to the symptoms of the disease. In this case, evaluations and feedback concerning the intervention can be collected from other means such as caregivers and care home staff, and activity coordinators (Tsunaka and Chung, 2012) using tools such as surveys and questionnaires.

4.6.1 Questionnaires

One of the ways of collecting data and receiving feedback on an intervention especially in user centred design is the use of questionnaires (Abras et al., 2004). Questionnaires deliver an objective means of collecting information about people's opinions, knowledge, and behaviour (Gilham, 2002) and are used to uncover answers to specific questions (Taherdoost, 2016). They are described as the heart of a survey and a critical instrument in the results of a survey. Questionnaire items may be open or close-ended and be presented in various formats such as statements with tick boxes, rating scales, visual analogue scales, and symbols such as smiley faces (Boynton and Greenhalgh, 2004).

One of the first decisions a researcher must make when designing a questionnaire is the use of open or closed ended questions. Open ended questions allow the respondents to answer in their own words, while closed questions require select an answer from a set of choices (Krosnick and Presser,

2018). The study undertaken in this research involved the use of questionnaires with both open and closed ended questions to allow respondents to record their first and final impressions of the intervention developed, as well as record important information regarding their activity sessions in which the intervention was used. The closed ended questions included in the questionnaires allowed respondents to pick an option that best suits their opinions on the new intervention, while the open-ended questions provided more freedom and allowed respondents to creatively answer questions in a more descriptive manner using their own words.

The questionnaires also incorporated multiple scaling techniques including graphic rating scales and Likert scales.

- Graphic rating scale: this is a visual analogue scale with descriptive terms placed at intervals for the measurement of mood and emotions (Scott and Huskisson, 1976). This research incorporated the use of the graphic rating scale in the Test stage of the design thinking method, where respondents were asked to describe the mood of their session attendees using a three-point smiley face scale – sad face, neutral face, and happy face – in order to record the general mood before, during and immediately after the activity sessions where the intervention was used.

- Likert scale: this is one of the most popular scaling methods and is a form of attitude scale where respondents indicate their degree of agreement or disagreement with a variety of statements about an object, attitude or event (Taherdoost, 2019). The Likert scale, developed by (Likert, 1932) is a psychometric tool in which respondents are asked to state their level of agreement to given statements from strongly disagree to strongly agree. Although the original Likert scale had five points, over the years, it has been used with different measurements ranging from two points to eleven points (Simms et al., 2019). This research used the 5-point Likert scale due to its ease of construction and its likelihood of producing reliable results (Chomeya, 2010). It has also been recorded as being easy to read and understand by respondents (Taherdoost, 2019).

4.6.2 User personas

As part of user-centred design for the development process, it is necessary to know who the ideal user will be (Miller, 2020). User personas were introduced by Alan Cooper as a tool for focusing on end users and their needs (Cooper et al., 2014). He proposed personas as fictitious characters based on composite archetypes and epitomising behavioural data extracted from empirical analysis and studies. He further explained that although personas are not real people, they are based on the

behaviours and motivations of real people that have been observed and represented throughout the design process (Cooper, Reimann and Cronin, 2007). The creation of user personas is very valid in the design process as it helps to describe the users of the technology or intervention as well as their relevant characteristics (Moquilaza et al., 2017) and although their use was initially intended as a tool for software developers, the approach has since been adopted across different fields such as design, marketing and business and has become a crucial part of the educational curriculum for product designers (Revella, 2015).

The theory behind the use of user personas is for designers to think about the personas as if they were real people in reference to their names, simulating conversations with them and describing their interests (An et al., 2018). This method of thinking encourages empathy and promotes user-centred designs (Humphrey, 2017). A typical persona includes the user's first name, surname, age and demographic information, personal and professional information, goals related to the intervention as well as experience, education, and skills (Almaliki, Ncube and Ali, 2015). This type of persona normally includes information about the user's known associates or relationships, psychological needs, attitudes, disabilities, and a photograph (Wolff and Seffah, 2011). Although researchers pose the argument that user personas should be based on qualitative interviews like in the case of actual users (Korsgaard, 2020) and regularly updated, personas used in practice are usually based on readily available data or informal observations (Tomlin, 2018). Pruitt and Adlin (2010) describe personas as detailed descriptions of imaginary people constructed out of well understood and highly specified data about real people.

The use of personas in design can guide decisions about features in a technological solution (Zulkafli et al., 2017). In doing this, the personas created can be referred to at different points in the design process especially when faced with design challenges (Qaed and Almurbati, 2021). The creation of personas does not serve as a replacement for the existing processes for evaluation and feedback, but rather as a tool for structuring user-centred thinking throughout the design and development process (Ward, 2010).

There are three key beneficiaries to this PhD work: (1) caregivers/activity coordinators who need to provide meaningful activities; (2) people living with dementia who will engage in these activities, and (3) families or care home/hospital managers who need to fund such interventions. Whilst the individuals or managers are important in terms of funding the interventions and hence them being affordable, in the context of creating the design for a non-pharmacological intervention for use by

caregivers or activity coordinators to engage and stimulate people living with dementia, a set of personas have been developed to represent several potential types of people with dementia who will benefit from engaging with the intervention, and several types of caregivers or activity coordinators across different settings who will benefit from having the use of such interventions in their activity sessions. Based on information from Chapter 2, personas can be extended to also include the type of dementia a person has and the types of therapy that may be appropriate for them; and for caregivers the type of care facility or care role they have as described in Chapter 3.

The personas in Figures 4.3 to 4.8 show people living with different stages of dementia in different care locations, their backgrounds, interests, likes and dislikes, as well as those of their caregivers or activity coordinators. Recommendations are then given based on the research performed in this PhD, on the most appropriate non-pharmacological interventions for these potential users based on their profile. These recommendations consider the user backgrounds, the non-pharmacological therapies that have been proven beneficial for people living with dementia, and the key attributes for technologies and interventions.

Ruby Pearson, 72, London

Background

Ruby is a retired engineer born in South Africa where she lived for over 20 years. She currently lives in a care home facility in London and is frequently visited by her husband and two sons. She enjoys gardening, group activities and animals.

Interests

- Gardening
- Animals
- Puzzles

Bio

- Female
- Sunnyvale care home
- Married
- Retired engineer
- Hearing impaired
- Moderate dementia

- Bubbly
- Enjoys group activities
- Loves plants

- Prone to boredom
- Dislikes strong smells
- Easily agitated

Therapies for Consideration

Art

Music

Aromatherapy

Light

Cognitive Stimulation

Reminiscence

Intervention Attributes

Affordability

Portability

Adaptability

Accessibility

Usability

Personalisation

Figure 4.7: User Persona 1 (Person with Dementia – Ruby)

It is important to note this user's persona and its potential effect on the adoption of any intervention. An intervention that provides a range of therapies and multisensory stimulation such as art, music, aromatherapy, light therapy, cognitive stimulation, and reminiscence therapy is considered important due to the benefits recorded in literature (Pinto et al., 2020). However, it is also important to ensure that Ruby is provided with the appropriate amount of stimulation from these therapies based on her persona. To create a personalised experience, photos related to Ruby's time spent in South Africa can be used in reminiscence therapy. Her love for gardening and animals also means she will enjoy stimulation from plants and pictures of animals. However, due to Ruby's hearing impairment, she doesn't enjoy music therapy, her dislike for strong smells also

means that she does not enjoy aromatherapy. Therefore, an intervention that can be personalised will allow for adjustments to be made to fit Ruby's persona. Also, her residency in a care home facility means that some of the attributes of the intervention such as affordability might not be of utmost consideration as will she not have to create a personal budget to purchase the intervention. Also, care home facilities usually have a dedicated space for activities; therefore, portability might also not be considered a priority in the adoption of an intervention for Ruby. Finally, Ruby's intervention should be easy to use to ensure maximum engagement and prevent frustration.

Emilio Johnson, 81, Durham

Background

Emilio is a retired professional artist and sculptor. Although retired, he still paints during his spare time and enjoys doing yoga and watching tennis. He currently lives at home in Durham with his dogs where he is cared for by a professional caregiver.

Bio

- Male
- Durham
- Widowed
- Retired artist and sculptor
- Mild dementia

Interests

- Dogs
- Painting
- Yoga
- Tennis

- Loves dogs
- Enjoys peace and quiet
- Loves to paint
- Enjoys talking about tennis

- Experiences apathy
- Dislikes noisy groups

Therapies for Consideration

Art

Music

Aromatherapy

Light

Cognitive Stimulation

Reminiscence

Intervention Attributes

Affordability

Portability

Adaptability

Accessibility

Usability

Personalisation

Figure 4.8: User Persona 2 (Person with Dementia – Emilio)

79

In considering an intervention for Emilio, his interests such as art, yoga, tennis, and dogs should be incorporated using photos and other elements to improve user acceptance. Emilio will enjoy activities such as reminiscence therapy, discussing about dogs, art therapy and photos or activities related to tennis. However, his disinterest in noisy groups may mean a slight disinterest in music therapy due to the possibility of loudness. Also, since Emilio lives at his personal home, attributes such as affordability would be essential due to the presence of a personal budget. Portability is also a top consideration as a user living at home would prefer a portable intervention that does not require an entire room dedicated to it, especially in the case of limited space in the home. Although Emilio only has a mild form of dementia, the progressive nature of the disease requires that he adopts an intervention that is adaptable enough to remain relevant throughout the progression of his illness. The intervention should also be easy to use and interact with to promote engagement and usability. It is also useful to note that accessibility might not be considered a key attribute for this user due to his lack of impairment and disability. Finally, personalisation will be considered as an important attribute for this user as Emilio's single user environment means the intervention can be personalised to fit him and his interests by incorporating photos and other elements pertaining to his interests into the intervention.

Michael Reynolds, 78, Newcastle

Background

Michael is a retired salesman from Ireland who has lived in England for 30 years. He is currently a patient at the Royal Victoria Infirmary in Newcastle where he was admitted after suffering from Pneumonia. He enjoys group discussions and spends his time chatting with other patients and care staff.

Bio

- Male
- Newcastle
- Single
- Retired salesman
- Severe dementia
- Wheelchair user

Interests

- Singing
- Group discussions
- Comedy
- Puzzles

- Enjoys chatting
- Games
- Puzzles
- Loves to laugh

- Experiences agitation
- Tires easily

Therapies for Consideration

Art

Music

Aromatherapy

Light

Cognitive Stimulation

Reminiscence

Intervention Attributes

Affordability

Portability

Adaptability

Accessibility

Usability

Personalisation

Figure 4.9: User Persona 3 (Person with Dementia – Michael)

In considering an appropriate intervention for Michael, it is important to put his interests such as singing, group discussions, comedy, and puzzles into consideration. All these interests should be incorporated into the intervention to improve user acceptance for this individual. Because Michael enjoys chatting and group discussions, he usually attends chatty cafes and events organised within the dementia community prior to hospitalisation. However, since he is currently in hospital, he will want to adopt an intervention that still provides activities and therapies that can be done in groups. Also, due to Michael's current location, affordability might not be a primary attribute when considering the adoption of an intervention, due to the lack of a personal budget for engagement.

Since hospitals have dedicated spaces for activities, portability will not be as important in the consideration process as it would have been if the intervention were to be in Michael's home. Also, the transient nature of hospitals will not require that the intervention be personalised to just one person's interests or level of dementia and will more likely make use of general themes and multimedia elements stemming from different past eras like the 50s, 60s and 70s. Because Michael has severe dementia, it is very important that the intervention is easy to use without any form of complexity. Finally, since Michael uses a wheelchair, it is of utmost importance that whatever intervention he adopts be suited to him and make allowances for his disability while still providing him with the appropriate level of engagement and stimulation.
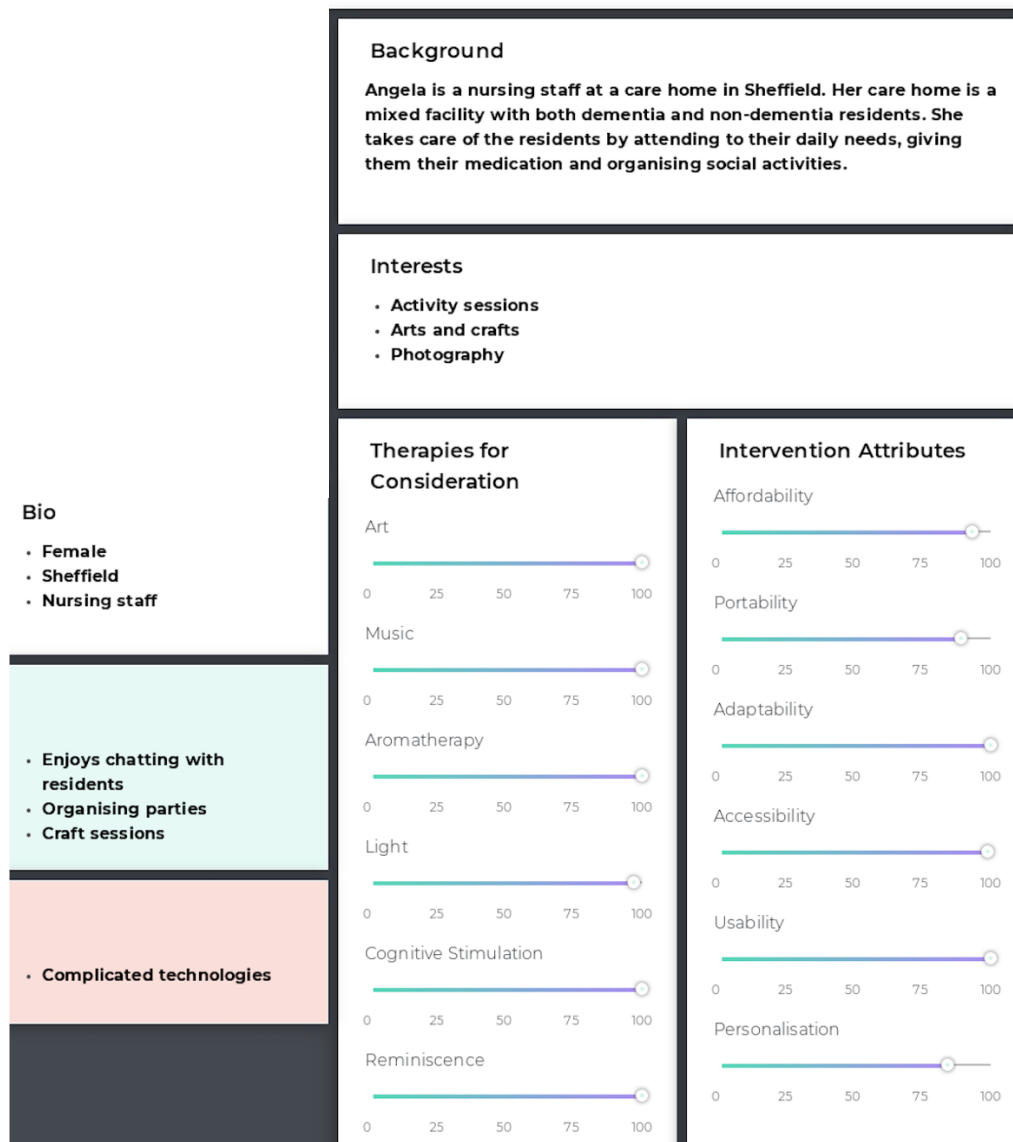
Figure 4.10: User persona 4 (Activity Coordinator – Angela)

Angela works in a care home; therefore, the type of intervention she adopts for use with her residents will be one that benefits her as a nursing staff as well as the residents. She enjoys arts and crafts, photography, chatting with the residents and organising parties. Therefore, she will favour an intervention that offers an avenue for creativity and communication. The different types of residents in the care home means that Angela will also benefit from an intervention that offers a variety of therapies. Since care homes usually have an allocated budget for interventions, Angela's interests will be in an affordable intervention that fits within the allocated budget. Care homes also typically have a dedicated activity area or communal room; therefore, portability might not be the most important attribute in the selection process unless in cases where the intervention is to be moved around within the care home or be stored away when not in use.

Due to the general nature of care homes and the presence of residents with different stages of dementia, it is important that Angela selects an intervention that is adaptable to the different stages of dementia and accessible to be used by people with impairments or other comorbidities. The intervention should also be easy to use and interact with because of the type of users, and because Angela also does not enjoy complicated technologies. Finally, because the intervention is to be used by different people or groups, there will be no need for it to be personalised to a particular person's interests. However, it can be themed to fit a relatable topic such as a location or an event.

Emmanuel Ife, 20, London

Background

Emmanuel is a member of the care crew at St Thomas' Hospital and organises activity sessions to promote social engagement in their geriatric wards. He enjoys listening to stories from the session attendees and dressing up in different costumes to entertain them.

Interests

- Reminiscence sessions
- Costumes
- Themed activities

Bio

- Male
- London
- Care crew member

- Photos
- Storytelling
- Role play

- Boring activities

Therapies for Consideration

Art

Music

Aromatherapy

Light

Cognitive Stimulation

Reminiscence

Intervention Attributes

Affordability

Portability

Adaptability

Accessibility

Usability

Personalisation

Figure 4.11: User persona 5 (Activity Coordinator – Emmanuel)

Emmanuel's love for reminiscence, storytelling, costumes, photos, and role play will influence the choice of interventions he selects for use with the patients in the geriatric wards. The general nature of hospitals means that the intervention will have multiple users rather than a single user; therefore, it is important that Emmanuel considers a technology that provides a variety of activities and therapies. He also does not enjoy boring activities; therefore, he will consider an intervention that is engaging to both him and the attendees of his activity sessions.

Like care homes, hospitals also have an allocated budget for interventions; therefore, Emmanuel's interests will be in an intervention that fits within the specified budget. Hospitals also typically have

communal spaces for the patients to socialise with each other or engage with family and friends, therefore most interventions adopted in this location do not require frequent movement. Attributes such as adaptability, accessibility, and usability will also influence Emmanuel's decision because of the nature of the users. Finally, the transient nature of hospitals means that personalisation is not one of the key attributes to be considered in the decision-making process as the intervention will not be required to be personalised to fit the interests of one user or a group of users but can be themed.

Rachael Bunmi, 23, Newcastle

Background

Rachael is a member of the care staff at a company that provides home care for people living with dementia. She travels to the homes of each of her care recipients and enjoys playing games and engaging in other stimulating activities with them.

Bio

- Female
- Newcastle
- Care staff

Interests

- Games
- Music
- Photography

- Photo props
- Music and singing
- Puzzles

- Large and heavy interventions

Therapies for Consideration

Art
| 0 | 25 | 50 | 75 | 100 |

Music
| 0 | 25 | 50 | 75 | 100 |

Aromatherapy
| 0 | 25 | 50 | 75 | 100 |

Light
| 0 | 25 | 50 | 75 | 100 |

Cognitive Stimulation
| 0 | 25 | 50 | 75 | 100 |

Reminiscence
| 0 | 25 | 50 | 75 | 100 |

Intervention Attributes

Affordability
| 0 | 25 | 50 | 75 | 100 |

Portability
| 0 | 25 | 50 | 75 | 100 |

Adaptability
| 0 | 25 | 50 | 75 | 100 |

Accessibility
| 0 | 25 | 50 | 75 | 100 |

Usability
| 0 | 25 | 50 | 75 | 100 |

Personalisation
| 0 | 25 | 50 | 75 | 100 |

Figure 4.12: User persona 6 (Activity Coordinator – Rachael)

Rachael works for a care company that provides home care for people living with dementia which means that she selects her activities based on the interests of her care recipients. She will therefore select an intervention that offers a variety of therapies, especially because of the different interests of the people she cares for, especially one that offers photo props so that she can incorporate photography into her activity sessions. Rachel regards portability as an important attribute in the selection process because she moves around between the homes of her different care recipients. Therefore, she will benefit from an intervention that is portable enough to fit in her vehicle and be moved from one place to another or one that can be separated into different useful parts to be taken with her to her care locations without having to take along the whole intervention. Rachael will not consider personalisation to be an important attribute. However, she will benefit from an intervention that offers themed activities as these are usually well received by different user groups.

These user personas were developed from a combination of the literature review and an understanding of people living with dementia and those that care for them via the method of observation. It was important to consider the different kinds of people that would be adopting this new intervention and how best to fit the intervention into their lives. The user personas were constantly referred to at various stages in the design process and helped to steer the process in the right direction as well as improve the chances of user adoption of the intervention.

4.7 Observations with a hospital care crew

The creation of the user personas above was made possible by conducting an extensive review of the literature on the available interventions and avenues for creating activities and engagement for people living with dementia, as well as a review of some of the interventions used in practice. In addition to these, various forms of expert engagement were undertaken including observation sessions with the Care Crew at the geriatric wards of a hospital in Reading to understand more about people living with dementia, their relationship with their caregivers, how they communicate among themselves and their interaction with the games and activities provided for their engagement.

The use of observation in research has been employed as a common technique in the study of human behaviour for a very long time and is an important method of data collection in qualitative research that can occur in different variations (Sileyew, 2019). In recent years, observation has been used by researchers to collect data, determine outcomes of specific practices and document

specific processes (Paterson, Bottorff and Hewat, 2003). Due to the increasing popularity of ethnography in research, methods like observation have been adopted by researchers to record activities for analysis and interpretation. Ethnography in this case may involve participation in events, observation of activities, note taking and the collection of unstructured data as a record of the study (Hammersley and Atkinson, 2019). During the process of an observation, a researcher may choose to take on a participant role where they become a part of the study or a non-participant role where they act as a neutral observer depending on which of these methods is appropriate for the study (cotton, Stokes and Cotton, 2010).

Observation methods can also be used in conjunction with other forms of data collection to form a better understanding of the situation (Roulston and Choi, 2018). This method could either take a formal approach where the observation is structured by the research agenda and only events relevant to the research are observed, or an informal approach where the observation is unstructured, giving the researcher freedom to choose what to observe and how to observe it (Robson, 2002). The use of ethnography in qualitative research involves the participation of the researcher overtly or covertly in the daily life of people for an extended period by watching events and happenings, listening to conversations, asking questions, and collecting data related to the focus of the research (Hammersley and Atkinson, 2019). Therefore, observation typically concerns an element of ethnography that allows the researcher to capture an understanding of social processes by observing them in context (Reeves, Kuper and Hodges, 2008).

One of the technologies reviewed in this thesis is the Tovertafel (Anderiesen, 2017), a motion-based gaming technology that projects interactive games in the form of light onto a table through which people living with dementia, especially those in the moderate to severe stages can be stimulated. The hospital we worked with in Reading has one unit of the Tovertafel in each of their geriatric wards and an observation of this technology and other similar forms of non-pharmacological intervention used by the care team with people living with dementia was important and relevant to this PhD. The aim of this observation was to witness the interaction of the care team with the patients in the geriatric wards and observe some of the activities carried out to provide engagement to these patients. The terms of the observation had previously been agreed upon between the university and the hospital and the observation involved shadowing the care staff, asking questions, and helping when needed. Although it was acceptable for notes to be taken for record purposes, none of the patients in the hospital were identified by name or recorded via video.

The observation was carried out in September 2019 and involved two researchers from the University of Reading. The Tovertafel had been properly researched prior to the observation but had not been physically observed and was therefore selected as the first intervention. This observation included studying the location and placement of the technology as well as its games and how they were played. An initial conversation with one of the members of the care team described the technology as a "hit and miss", detailing that while the Tovertafel was recorded as a success with some groups of people, others saw it as too simple as the games were not challenging enough to hold their attention. It was hypothesized that this could have been because the game was developed for people with moderate to severe dementia and therefore people with mild or no dementia would have found it too simple and under stimulating. During the observation of the Tovertafel games, two of the males in a group of five were particularly competitive while playing the games and would have liked to see more competitive elements and scoring options in the games. They also enjoyed playing the beach ball game, sometimes projecting the game on the floor to kick the beachball to each other. Also, the music element of the Tovertafel games led to discussions about the group's favourite music artists, bands and eras.

The observation also included a shadowing exercise with members of the care team which provided an avenue to observe their activity sessions. The exercise included partaking in a "make your own lantern" session held in one of the wards. This activity session was attended by four participants, three female and one male and resulted in the successful creation of lanterns, following guidance and encouragement from the care staff. Other elements such as maps were used in the session and the attendees took turns discussing locations they had lived in or visited in the past. The care staff prompted the participants with questions such as "What interesting places have you visited?" and "Have you ever lived anywhere apart from Reading?", which helped to steer the conversation around the session and ensure that every attendee was included in the discussions. A painting session involving five attendees; three male and two female was also observed in a different ward. This session involved painting flowerpots and creating paintings on sheets of paper with the help and encouragement of the care staff.

At the end of the sessions, the following key points had been noted:

1. Contrary to the initial opinion that the Tovertafel would be a focal point for daily use in all the geriatric wards, it was discovered that it was only being used occasionally as part of a

selection of activities including arts and crafts. It also put pressure on care team staff to know how to use the technology.

2. It was observed that a care crew of three staff had a challenging task of covering five elderly care wards especially when gathering patients to the location of the activities, as no patient could be left unsupervised at any point.

3. The condition of the session attendees largely varied due to the different levels of severity of their dementia and the different types of comorbidities for which they were admitted.

4. The care crew was unable to hold the attention of the attendees for long as some of them seemed to lose interest in the activities after a while, choosing to either just sit and not participate anymore or request to be taken back to their beds.

5. The location of these activity sessions was too far for some of the patients to reach due to their comorbidities. This long distance resulted in a limited number of attendees due to a lack of interest or energy.

6. Only one activity was organised at each of the elderly care wards per day and had to be chosen from a selection of activities.

7. Some of the patients were very competitive while playing some of the games such as the beach ball game but did not engage with some of the other games due to their lack of complexity.

8. The activities led to reminiscence about different topics e.g., the session with the map led to discussions about where people lived, which led to activities they did while growing up such as gardening.

The findings from these observations helped to shape this research and further highlighted the need for a portable piece of technology that could be moved around easily and taken to the patients rather than require that the patients be taken to it, as this was observed to place some stress on the patients within the hospital, with some patients even declining participation in the activities because of the distance to the activity area. The different stages of dementia among the attendees in these sessions further revealed the need for the development of an intervention that could be adapted to different stages of dementia and could either serve multiple people living with dementia, or one person throughout the progression of their dementia. Also, the administration of only one activity session per day emphasized the need for an intervention that could provide multisensory stimulation in one session, which would result in the attendees getting different forms of stimulation rather just one, like in the case of painting sessions.

Furthermore, this observation gave an insight into how activity sessions were typically run and revealed the positive relationship and dynamic between the patients and their caregivers in hospital. It also emphasized the short attention span linked to people living with dementia (Feng et al., 2019) as the attendees were observed to lose interest in the activities after a while regardless of the kind of activity, the member of the care team or the selection of attendees. This further encouraged the creation of a multisensory intervention that can provide multiple forms of stimulation within a short session.

Finally, a common theme from the activity sessions observed was that the care crew had to dispose of all the paper-based elements used in the sessions such as the coloured papers used in the crafts session and the sheets of painting paper used during the arts session. This constituted a lot of waste and meant that these supplies had to be replenished regularly in each one of these wards. This presented the need for an intervention that incorporated digital elements as well as traditional elements because, not only will this be more economical and beneficial, but it will also be better for the environment due to the production of less waste.

4.8 Co-Design with dementia experts

After conducting the literature review and observing care crew sessions at the hospital, the need for an intervention that closed the gap identified in the research and practice of non-pharmacological interventions for dementia care was paramount. In response to this, the concept of an **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) was ideated as per Step 3 of the Design Thinking method. To determine the relevance of the AMuSED concept in practice, it was important to evaluate it with people living with dementia and their caregivers. Ideally, focus groups would have been conducted, but due to the COVID-19 pandemic and continuous lockdowns this became impossible and hence it was important to find an alternative means for evaluating the concept which could also provide meaningful feedback that would be instrumental in the design and development of the intervention. Co-design of the AMuSED concept with an expert group was thus chosen as an alternative approach.

The concept of co-design is one that has been prominent in design research for several years and is rooted in the participatory design movement of the 1970s (Sanders and Stappers, 2008). It refers to the active collaboration with stakeholders in value creation, or the inclusion and participation of the design users in the design process (Overdiek and Warnaby, 2020). The use of the prefix "co" in co-design signals the collaborative, collective, connective, and cooperative nature of this design

process (Campbell, et al., 2021). The collaboration in this process usually involves people coming together despite or because of their varying needs, agendas, knowledge, and skills. This usually involves researchers or academics, experts, practitioners, and communities working together to understand certain situations and develop concepts into solutions (Zamenopoulos and Alexiou, 2018). The co-design process also sometimes engages the end user across all stages of the design process in different forms and different levels of intensity (Bird et al., 2021), ranging from being passively engaged to being actively involved and highly engaged in the design process. Slattery, Saeri and Bragge (2020) explain that the level of involvement of external parties in the co-design approach is classified in different ways such as consultation where the researcher seeks public views on a research subject, collaboration which refers to a continuous partnership between the researcher and the external parties throughout the research process, and 'publicly led' co-design where the research is mainly done by the public or external parties and the researcher is invited to participate.

Since the co-design approach allows users into the design process as experts of their experiences, the users can therefore provide insight into their needs as well as contribute to the development of new concepts, ideas, and solutions (Dietrich et al., 2017). Co-design in research has also been shown to be beneficial to researchers by creating links between the researcher and the community (Thamrin et al., 2019) which can help in the generation of access to participants especially with recruitment from less popular groups, improvement of response rates, higher levels of empathy with research participants and better-informed consent due to the presence of better-informed participants (Brett et al., 2010). This approach to design between researchers and collaborators is devoid of an implied hierarchy between both parties as collaborators are usually involved in the design process at different stages and contribute to outcomes throughout the multiple stages of the design (Bjögvinsson, Ehn and Hilgren, 2012). Therefore, neither the researchers nor collaborators are positioned above the other in the design process as the process involves joint labour between both groups.

Although the engagement of people in the design and decision-making process of an idea or solution that affects them is a positive idea (Petrescu, Petcou and Baibarac, 2016), it is important to perform a critical evaluation of the structures of participation to determine who can or should participate in the co-design process (Binder et al., 2015). In some cases, it is also possible to extend the co-design process into communities to encourage open and broad participation (Munthe-Kaas and Hoffmann, 2017). This exploration of knowledge from users in communities helps to prevent

an overreliance on empathy in the design process, as the use of empathy tools alone can risk the insights into user experiences being clouded by the interpreter's experiences (Vink and Oertzen, 2018). Therefore, the engagement of people who have experienced certain situations first-hand helps to mitigate this risk.

The recent global occurrence of the COVID-19 pandemic resulted in a disruption of face-to-face co-design processes and led to the restructuring of collaboration methods. The institution of lockdown procedures and the need for social distancing in many countries prevented the collaboration of people in physical spaces. This resulted in the restriction on face-to-face interactions and led to the reconsideration of collaboration and co-design methods (Davis et al., 2021), leading to widespread adoption of virtual or digital avenues for co-design especially in cases where the collaborators have access to computers and internet services. These avenues have become increasingly popular and usually involve the scheduling and organisation of virtual meetings via the use of video conferencing software platforms such as WebEx, Zoom, or Microsoft Teams.

Due to COVID-19 preventing the further planned sessions for evaluating AMuSED in hospitals or care homes, the research approach was realigned and conducted through a co-design approach with the Dementia Friendly Reading Steering Group, United Kingdom. This Steering Group is a group of experts with very considerable knowledge of dementia in the health and social care sector. The group is made up of people with senior positions of responsibility associated with people living with dementia including those holding positions in other dementia focused groups and organisations such as Alzheimer's Society, NHS (National Health Srvice), Dementia UK, Alzheimer's Research, Age UK, and multiple care homes. The main aim of the group is to steer communities to take practical action to benefit people living with dementia (Dementia Action Alliance, 2021).

After researching the Dementia Friendly Reading Steering Group, initiating contact, and meeting with the coordinator of the group, ethical approval for discussions with the members of the group (see Appendix A) was obtained from the Ethics Committee within the School of Biological Sciences at the University of Reading. Ethical principles were taken into consideration when planning these discussions and were strictly adhered to throughout the duration of the process. The concept was introduced to the group via a presentation of the idea, rationale, conceptual design, and elements included in the intervention to get early ideas and solutions from them that would influence the design of the intervention.

Due to the COVID-19 pandemic, the meetings were conducted virtually via Microsoft Teams. The initial meeting involved introductions between the members of the university and some of the members of the Steering Group who had an active interest in the research after reading the introductory pre-distributed document. At this meeting, the experts were asked about their roles and responsibilities with people living with dementia to ascertain that everyone present passed the inclusion criteria. They were also shown a very early prototype, with many of the attendees reporting being familiar with some of the elements but that the overall concept was novel. Significant discussion was generated, and very positive feedback received about the AMuSED concept in its early form.

Subsequent presentations were carried out and information was gathered at each meeting from the Steering Group using open and closed questions to discover their evolving thoughts on the AMuSED concept and how they felt it would be received in care homes, hospitals, community settings, and personal homes of people living with dementia. Qualitative data was collected using in-depth, semi-structured discussions with the experts and feedback was given at the different prototype stages with adjustments made to each prototype based on the feedback provided. The feedback given by the dementia experts during the meetings were recorded on paper and included useful insight and information on what activities and elements were already successful with people living with dementia in their care homes and how they could be incorporated into AMuSED. It was also important to find out the forms of technologies or interventions the group were familiar with in the provision of engagement to people living with dementia.

Four presentations, including video footage and online demonstrations, were given to the group between October 2020 and April 2021 during their two hour-long sessions, with an average of 12 experts in attendance at each meeting. These presentations were useful in providing the group with updates on the design process as well as displaying the different prototype stages. The discussions held after each presentation were avenues for the exchange of ideas and revolved around AMuSED, the interventions used with people living with dementia in practice, best practices, and how best to incorporate relevant elements into the design of the AMuSED toolkit. All the information and feedback provided by the expert in the Steering Group at the presentation of each prototype stage was very beneficial in the design process resulting in a co-designed intervention.

Most of the feedback was highly positive with all the experts agreeing that an active multisensory environment would be useful in the engagement of people living with dementia, however they

made many useful suggestions that defined the nature and direction of the development of the AMuSED intervention.

One of the most important suggestions that helped to shape the research was suggested in one meeting when a member of the group advised that people living with dementia responded better to themes than to generic concepts, as it was easier for them to link themes to real life. This expert, a care home manager, gave an example of a section of their care home that was decorated with images of the beach and how the residents enjoyed visiting this 'beach'. It was therefore suggested that incorporating themes such as the beach/seaside into the design and development of the intervention would be better for people living with dementia than a generic collection of items. Further research of literature (Tsuchiya et al., 2022; Hendrix et al., 2019; Kendall, 2021) also backed up this feedback and supported the incorporation of themes into AMuSED.

The impact on COVID-19 on having an intervention that can be cleaned and sanitised was an obvious factor for discussion. Other key suggestions from the Group were related to features such as safety, security and damage especially in connection with environments such as care homes and hospitals where items can easily get broken from being dropped; destroyed, for example by residents or patients 'colouring' on top of an iPad screen; lost in a hectic environment such as a hospital ward; or 'taken' as many people with dementia like to 'walk around and pop things into their pockets' as they go!

Whether or not to include iPad's in the AMuSED toolkits led to several interesting discussions linked to affordability, potential for damage, and whether they could be overstimulating for some residents, with the decision being that they would not be a standard inclusion in the toolkit but that some items in the toolkit could link to them to provide additional media and music elements should the individual or care facility have access to them and deem their use suitable with their residents or patients.

Other experts raised the notion of affordability and the need for training of staff in the use of an intervention and in how to run reminiscence sessions and how to focus on the positive memories but also deal with bad memories should they arise. Whilst the design of the AMuSED toolkit was universally liked and the concept of having panels form a large cube for reminiscence sessions universally liked, feedback was given on the fiddly nature of having cable ties to hold the panels of the box together in the cube form and so the design was subsequently changed to be easier for the

caregivers or activity coordinators to use. Carrying around the AMuSED toolkit was also raised and solutions to this developed as described in Chapter 5.

The co-design process with the Dementia Friendly Reading Steering Group was very beneficial to this research as it brought the right perspective into the concept. It provided an avenue for the general idea and design concept of this PhD to be evaluated by experts with immeasurable knowledge on people living with dementia, their caregivers and the types of activities and stimulation they best respond to. It created opportunities for errors in the design process such as the use of cable ties and large screens to be rectified and it helped to steer the design process in the right direction that would be most suitable for caregivers and activity coordinators as well as people living with dementia.

Finally, the co-design with the Steering Group led to connections and collaborations with other dementia focused groups such as an invited presentation to the Dementia Friendly West Berkshire Steering Group and a collaboration with the Museum of English Rural Life (MERL).

4.9 Collaboration with The Museum of English Rural Life (MERL)

The Museum of English Rural Life (MERL) is part of the University of Reading and boasts a diverse collection that explores how the skills of farmers and craftspeople, past and present, can shape our future lives. The museum also caters to people living with dementia and partners with dementia organisations such as Age UK on projects that support people living with dementia. One of such avenue of support is the chatty café organised by The MERL on the second Tuesday of every month with the aim of getting people living with dementia engaged and communicating with each other, with their caregivers, and with The MERL staff while also enjoying the tea and cakes provided by The MERL.

Due to their work with people living with dementia, some of The MERL staff are also affiliated with the Dementia Friendly Reading Steering Group. During one of the meetings with the Steering Group, one of the managers at The MERL proposed that the concept of AMuSED would be beneficial in the implementation of their chatty cafés. Following this proposal, virtual meetings were organised with The MERL via the Microsoft Teams platform.

Further discussion with The MERL revealed that the main theme of the chatty café was reminiscence, and the sessions were usually organised with the aim of getting people living with

dementia to reminisce about positive experiences. The sessions were organised by The MERL staff and included volunteer activity coordinators. These sessions engaged the use of reminiscent images mainly of farming and the old English countryside with the aid of prompt cards to induce reminiscence in the attendees.

The proposed collaboration with The MERL was for the co-design and development of a Countryside AMuSED theme. The aim of this collaboration was to incorporate some of the resources already used by MERL while also including further elements for multisensory stimulation. The collaboration spanned 8 months from April 2021 and was mostly executed via scheduled meetings on the Microsoft Teams platform due to the COVID-19 pandemic until September 2021 when physical meetings were able to be held at the MERL. The process included the development of an initial 'mini' countryside prototype with feedback gathered and used to develop the final AMuSED Countryside theme AMuSED toolkit. The chatty cafés which were suspended due to the pandemic were resumed in October 2021.

During the collaboration with The MERL, it was discovered that the hospital observed in section 4.6 organised reminiscence sessions using resources from The MERL for the patients in their geriatric wards. These sessions were carried out by the care crew and activity coordinators of the hospital and incorporated elements such as images of the old English countryside, farmers, old maps of Reading as well as physical elements from the museum's collection such as butter churners and household items used in past eras. The AMuSED Countryside theme was scheduled to be used at hospital by the activity coordinators and they therefore had to be trained on how to use the novel intervention.

A reminiscence training session was organised for the hospital's old and new care crew at the MERL and was attended by four members of the care crew: three female and one male. In this session, the training facilitator from The MERL gave a presentation on reminiscence, the use of reminiscence therapy for people living with dementia and how to handle the stories and experiences that might be brought to the remembrance of their patients, especially the negative memories that could occur in this form of therapy. After this, another presentation was given by the researcher on the collaboration with the MERL, the novel AMuSED Countryside theme, the rationale and idea behind the intervention, the elements in the intervention and how they could be used to engage people living with dementia in hospital. This presentation was supported with a prototype and feedback

was sought regarding the design, the elements and how the care crew believed it could be best implemented in the hospital wards.

Prior to the presentation, when the attendees were asked open-ended questions about the activities they typically carried out with the patients, they stated that their activities included crafts, bingo, nail salon/barbershop and were usually attended by an average of 3 patients at a time. They also stated that this number was reduced from 6 due to the COVID-19 pandemic restrictions within the hospital and that they typically ran three activities a day with the activity sessions usually lasting an average of 90 minutes depending on the participants.

When asked about their first impressions of the AMuSED Countryside prototype, comments given by the care crew included "*instant icebreaker*", "*I like that the sides can be taken off*", "*I like that some of the images are large, it'll be easy for them (people living with dementia) to view it*". They all also agreed that the intervention would be useful during their sessions. When asked their favourite thing about the design, one of the attendees reported that she felt the colour used was vibrant and would be good for visually impaired people. Finally, when asked if they felt there was anything that could be improved, one of the attendees pointed out the absence of the dementia forget-me-not flower and added that the incorporation of the flower into the design would make it easily stand out as an intervention for people living with dementia. This attendee made an example of the pink ribbon associated with breast cancer and how it was usually incorporated into anything related to the condition.

The responses received from the care crew during the training was largely positive and the feedback suggested for the improvement for the design was documented and incorporated into the design process. The process of prototyping, Step 4 in the Design Thinking method, was very useful in the research as most of the feedback received from experts and caregivers and activity coordinators was based on the different prototyping iterations being demonstrated and discussed during the co-design and feedback sessions and helped in the development of better iterations and the final products.

4.10 Prototyping

The concept of prototyping is very popular and linked with product, service, and systems development. A prototype is a pre-production representation of a concept or design and often approximates the features of the product or service (Otto, 2003). The use of prototyping in the

design process has been documented throughout history, such as the Henry Ford's exploration of at least 19 models and prototypes before the realisation of the revolutionary model T design (Womack, Jones and Ross, 2007). Prototyping in design is sometimes driven by the need to achieve specifications, especially in the development of large and complex systems. At other times, prototypes can be developed in the exploration and development process of a new concept (Deininger et al., 2019).

There are many aims of prototyping in design. Camburn et al., (2017) explain that many prototyping benefits are related to design refinement where the prototypes created are used in the validation of requirements, reduction of errors, identification of design changes, feature optimisation and design refinement using multiple testing efforts (Viswanathan and Linsey, 2012). Prototyping is also adopted in the enhancement of design usability (Dowding et al., 2019), as the use of prototypes can be of value in the communication of the design information to users (Barbieri et al., 2013). The prototypes in this case enable end user interaction and afford the designer the opportunity to observe this interaction among users and between the users and the design (Reich-Stiebert et al., 2019). Another aim of prototyping in the design process is for active learning (Castelan and Bard, 2018). This involves the continuous process of gathering information and knowledge about the design. The development of prototypes for active learning can also aid the advancement of the designer's analytical models of interaction (Telenko et al., 2016) as well as provide an avenue for the re-evaluation of failure and the enhancement of progress (Gerber and Carroll, 2012).

The form of prototyping used in this research was iterative prototyping (Murphy et al., 2022), which involves the constant testing and refinement of a prototype until it reaches the final product (Christie et al., 2012) and is particularly useful in satisfying challenging requirements. Studies have shown that design teams which adopt iterative prototyping in their design process are more successful than teams that do not, and they also report higher levels of requirement satisfaction (Camburn et al., 2015). During this research, there were four different iterations of the AMuSED toolkit and two iterations of the MERL Countryside theme.

4.10.1 Iteration 1

After research had been conducted and the solution identified, an exploding box concept was selected as the best way to package and deliver the elements for the AMuSED toolkit. This first prototype was a rectangular box – length of 48.3cm, breadth of 34.6cm and height of 34cm – that incorporated the use of foamboard for the sides and cover, as well as coloured paper for the lining

of the interior of the box, the different pieces of foamboard that made up the sides of the box were attached together with Velcro both at the sides and at the bottom. It also made use of reminiscence photos printed on A4 sheets of paper and attached to the exterior of the box. All the elements in the box were digital elements such as a fibreoptic lamp, a lava lamp, an aromatherapy diffuser an iPad, a buzz wire game, a digital keyboard, Tap It game and a musical flowerpot. This prototype, affectionally referred to as 'The Ugly Prototype', showed promise with the exploding box concept as well as the portability attribute that was essential in the concept of AMuSED. However, the main issue with this prototype was that it did not present the idea of AMuSED in the right way and was not of an appropriate standard to show to the Steering Group.

Figure 4.13: Iteration 1

4.10.2 Iteration 2; The AMuSED toolkit

Following review of the first prototype, it was decided that a square box would be easier to develop than a rectangular box and would be aesthetically more pleasing. The second iteration of the prototype retained the exploding box concept, the use of foamboard and the internal elements used in the first prototype and was initially modelled using a small 12 x 12 x 12 cm cube with foam 'bumpers' to hold the sides together before being developed into a larger version. This iteration adopted a square 35cm by 35 cm design rather than the initial rectangular box, was more colourful and vibrant, had the reminiscent images printed to scale and glued on the exterior of the box and had colourful images glued to the interior of the box rather than just coloured paper as in the first prototype. The top and bottom parts of the box were supported with an additional foamboard border to provide extra rigidity and structure to the box, and all the sides were held together with the use of short Velcro cable ties. This box was the first to have "AMuSED Toolkit" printed on its cover and was the first physical prototype to be shown to the Dementia Steering Group using a

short introductory video. This video explained what the AMuSED concept was, the prototype, the elements that made up the toolkit and their relevance, as well as how to take the different sides apart and put them back together with the use of the cable ties.

Figure 4.14: Iteration 2, The AMuSED toolkit

4.10.3 Iteration 3; The mini toolkits

After the video was presented and the toolkit was discussed, a lot of positive feedback and comments were received from the experts in the Dementia Steering Group regarding how useful they believed the toolkit would be to people living with dementia and the caregivers and activity coordinators who had to provide activities that were engaging and stimulating. However, as initially mentioned in Section 4.7, some of the feedback received was that the cable ties used in taking apart and putting the box back together would be too fiddly to be done quickly in the activity sessions; there were potential issues of overstimulation and damage to the iPad; and that whilst the sensory elements were a great inclusion, people living with dementia tended to respond better to themed activities and elements rather than generic ones. This led to a discussion about what themes were deemed appropriate for engaging people living with dementia with suggestions of countryside, seaside, fairground, movies, events such as Christmas, and locations such as Reading being suggested. The example of a beach area being very well received in a care home was shared at the

meeting and this prompted the development of a Seaside AMuSED box, alongside the Countryside AMuSED box in collaboration with the MERL as showing in Figure 24 and discussed in detail in Chapter 5. Another important piece of feedback received was that people with dementia might not respond as much to a box filled with only digital potentially unfamiliar elements and would respond better to a box filled with familiar elements, especially since most of them had limited background and experience with technology and technological products.

To incorporate some of these suggestions and demonstrate them to the Steering Group, 'mini' two third scale models (20 x 20 x 20 cm) of the seaside and countryside editions of the AMuSED boxes were developed to highlight proposed designs for the final AMuSED boxes. Working at this scale allowed high quality designs for discussion to be produced, but in an affordable cost as they could be printed on personal inkjets, something that was also essential due to University lockdowns of the Creative Print Unit who printed the designs for Iteration 2.

The 'mini' AMuSED box incorporating the seaside theme still incorporated the use of foamboard and the square design. However, the images on the exterior of the box were all related to the seaside theme and rather than incorporating generic elements as in the previous prototype iterations, this box included elements related to the seaside theme such as sand, seashells, sea animals, seaside smell capsules, jellyfish lamps rather than lava lamps, seaside nostalgia elements, seaside puzzles, aqua paints of seaside scenes etc. This box also replaced the fiddly Velcro cable ties and opted for the use of Lego bricks rather than foamboard for the borders due to Lego bricks not only providing more rigidity and a better structure, but also being visually appealing as well as easier to clean and sanitise being plastic.

A similar template was used to develop the MERL Countryside edition mini prototype, but this time the images on the exterior and interior of the box were provided by The MERL to align with their countryside theme and remain true to their curated museum images and artifacts. In a similar fashion to the seaside mini box, the MERL Countryside mini box also incorporated the use of Lego bricks to hold the sides together in its cube formation, together with a Velcro band to provide extra rigidity and stability for the box. Also, as in the Seaside Edition box, a combination of themed digital and non-digital elements such as sheep's wool, Morris dancing bells and music, a catapult, various themed smell capsules and a digital photo album narrating images and artifacts provided by The MERL were incorporated in the delivery of the box.
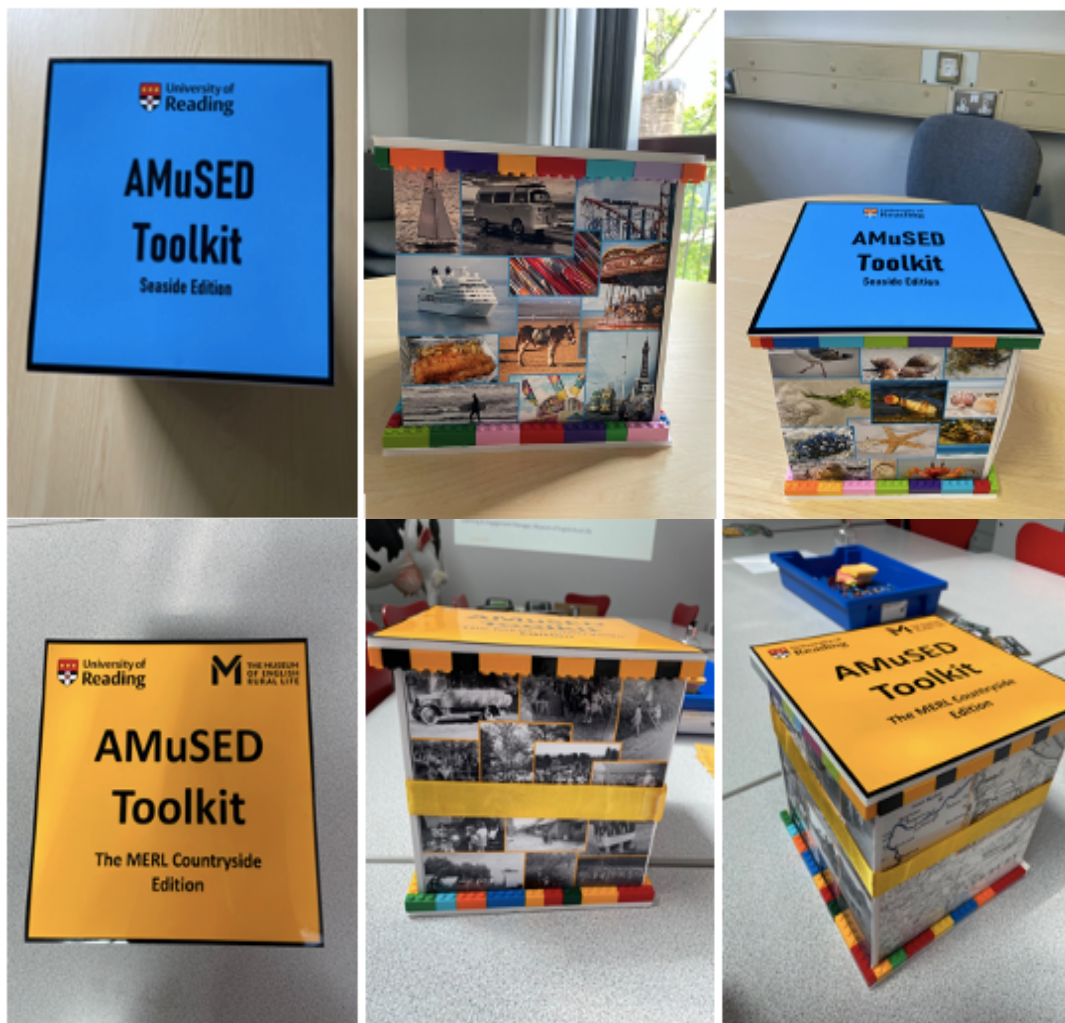
Figure 4.15: Iteration 3, the mini Seaside and MERL edition toolkits

4.10.4 Iteration 4; The final toolkits

The mini seaside toolkit was tested (part of Step 5 of the Design Thinking method) at one of the Dementia Friendly Reading Steering Group and at a Dementia Friendly West Berkshire Steering Group meeting. This iteration of the AMuSED toolkit received extremely positive feedback regarding the focus on a seaside theme, the combination of both digital and non-digital elements, and the use of the Lego bricks to help secure the box. Following these Steering Group meetings, the Seaside toolkit was deemed as being ready to be evaluated in care homes and therefore, a full-sized Seaside edition toolkit was developed. This 36 x 36 x 36 cm box followed the same template and design as the mini boxes with the same elements proposed in the development of the mini seaside box used in the final product. However, the regular white foamboard used in the development of previous prototypes was replaced with a denser and higher quality black foam board on the recommendation of the experts in the University's Creative Print Unit (CPU). The reminiscence images on the outside and the insides of the box panels were printed by the CPU on vinyl (able to

be wiped down with water) which were then laminated (able to be wiped down and sanitised with antibacterial alcohol sprays) before being glued to the foamboard to create a covid safe AMuSED toolkit.

The mini MERL countryside edition toolkit, as stated above in Section 4.8, was evaluated at the MERL reminiscence training session for the care crew from the hospital with the main design amendment suggested being the inclusion of the dementia forget-me-not flower which was subsequently incorporated into all the different themes of the final AMuSED toolkits. The same elements demonstrated alongside the MERL mini prototype were used in the development of the final MERL Countryside toolkit. However, because the final AMuSED toolkits were made with stronger and higher quality materials, there was no longer a need for the Velcro band to help hold the sides in place. As for the final versions of the other AMuSED toolkits, they were professionally printed and laminated to allow for proper cleaning and sanitising after use.

Two other themed AMuSED toolkits were created using the same concept and structure of the Seaside and Countryside themes. These included a Christmas edition incorporating reminiscence photos and elements related to the Christmas season, and an Entertainment AMuSED toolkit with photos, images and activities linked to entertainment, movies, sport, and life in the Berkshire area. The elements to be included in the Entertainment toolkit were discussed with the dementia experts in order to obtain feedback about the activities to be incorporated into the toolkit. Reminiscence images related to fairgrounds, arcades and games such as bingo, buzz wire and hook the duck were displayed on a small sized box to enhance the discussion.

Figure 4.16: Display of the reminiscence images for the Entertainment toolkit

Images of the final AMuSED toolkits are shown in Figure 4.12 with the final designs and their multi-sensory and multi-activity contents and intended use being discussed in Chapter 5.

Figure 4.17: Iteration 4, the final Seaside, MERL, Christmas and Entertainment toolkits

4.11 Summary

This chapter examined the design thinking methodology used in this PhD and how the literature review conducted in chapter 2 helped to empathize and gain a deeper understanding of the challenges associated with providing engaging and stimulating activities to people living with dementia. Steps were also taken to define these challenges in more detail by the review conducted in chapter 3 of the interventions available in practice, which helped to ideate a range of solutions to meet the requirements of the caregivers and activity coordinators for a non-pharmacological product that can engage and stimulate people living with dementia. This led to the concept of an **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) as a way of bringing together different aspects of dementia therapy into a single portable box for use by carers, care teams and dementia activity coordinators with people living with dementia to engage and stimulate them physically, mentally, and socially through a combination of sensory elements and themed activities.

The chapter also defines the requirements for an active multisensory environment such as affordability, portability, adaptability, accessibility, personalisation and usability which form part of the AMuSED model in chapter 6, and how these attributes were incorporated into user centred design and combined with a co-design approach with dementia experts to create several prototype iterations of the AMuSED toolkit. The final themes of the AMuSED toolkit – Seaside, MERL, Christmas and Entertainment – are fully described in chapter 5 and tested through evaluation at different care locations in chapter 7.

Chapter 5: The AMuSED Toolkit

This chapter introduces the AMuSED Toolkit, the first novel output of this PhD. It showcases the AMuSED box (the panels) and the AMuSED toolkit (the contents). Both terms are used interchangeably within this chapter and throughout the thesis. This chapter details the elements included in the toolkit and their relevance to providing engagement to people living with dementia. Chapter 4 explored the Design Thinking methodology and how each of its stages contributed to the development of the AMuSED concept and its transformation into the four themed AMuSED toolkits: MERL Countryside, Seaside, Christmas and Entertainment. Additionally, the attributes identified in chapter 4 were incorporated into the AMuSED concept and subsequently embedded in the design of the AMuSED toolkits. These include:

- Therapies: art, music, reminiscence, light, coordination, cognitive and aromatherapy.
- Attributes: portability, affordability, accessibility, adaptability, usability and personalisation.
- Constraints: safety, security, cleanliness and damage to components.
- Location: personal homes, care homes, hospital and community.

This chapter describes in detail the design of each of the AMuSED toolkits and explains how it meets the needs of the beneficiaries of the work such as (1) carers/activity coordinators who need to provide meaningful activities and (2) people living with dementia who will engage in and be stimulated by these activities.

5.1 AMuSED toolkit format and construction

The AMuSED toolkit is an exciting and innovative non-pharmacological intervention that promotes engagement, stimulation and social interaction in people living with dementia through the use of traditional and digital media elements that aim to mitigate the behavioural and psychological symptoms of dementia. It includes different forms of technology to promote reminiscence and communication using various digital elements which are combined with traditional elements following from feedback provided by the dementia experts that people living with dementia perceive traditional elements as more familiar and relatable. This fusion of themed digital and traditional elements provides an engaging and stimulating toolkit that promotes reminiscence and social interaction among people living with dementia.

The toolkit was modelled after the exploding box concept and comprises of four panels with reminiscence images printed on both sides which create a cube shaped box and slot into a bottom

panel bordered by colourful Lego bricks that not only provide visual stimulation but act as a border and helps to keep the four side panels upright and intact. The resulting box is covered by a bright coloured top panel also bordered by colourful Lego bricks with "AMuSED Toolkit" and the corresponding theme branded on it. It also features the dementia forget-me-not flower in accordance with the feedback received in chapter 4.

Figure 5.1 The AMuSED box and toolkit

To promote portability and allow the caregivers and activity coordinators to move it around freely, the AMuSED toolkit and its elements are delivered in a transparent plastic box with a separate bottom compartment for the elements and a top compartment for the panels of the box and activity booklet. This type of box was selected because its transparent material allows the caregivers and activity coordinators to see all the elements immediately before opening the box, which makes the selection of elements and activities needed in sessions easier. A document labelled "your box at a glance" is attached to the top of the box and displays the pictures and names of all the elements in the toolkit. The box also comprises of a safety latch on each side that ensures that the AMuSED toolkit and all its elements are secure.

Figure 5.2: AMuSED toolkits carefully packaged in transparent plastic boxes

Instructions were included in the activity booklet that showed the activity coordinators how to properly set up the AMuSED toolkit, advising them to lay the bottom panel on a flat surface, slot one side panel with the small images facing outwards into the Lego guides of the bottom panel, making sure that it is pushed right to the edge so that a small gap is left just at one end, then slot the next side panel into the base so that it fills up the small gap that was left and creates one of its own. The instructions advise that this is done until all the panels are securely in place and the lid of the box can be placed at the top.

Figure 5.3: The setup of the AMuSED toolkit

The elements incorporated were into the AMuSED toolkit were carefully and specifically selected to fit the aim of the PhD and the review of the interventions and methods used in practice revealed different elements that provide various forms of stimulation such as visual, audio, olfactory, tactile

and cognitive stimulation. The delivery of these different forms of stimulation is very essential in the mitigation of behavioural symptoms for people living with dementia (Verkaik et al., 2019) and the different forms of stimulation together with a few examples of how they are incorporated in the AMuSED toolkit are showcased in section 5.1.1 to 5.1.6.

5.1.1 Visual stimulation

Visual stimulation in the AMuSED toolkit is provided using reminiscence images on both sides of each of the panels. Each of these images are related to the corresponding theme and printed in large sizes to aid visibility. These images are designed to cover a range of related topics to account for the diverse nature and different lived experiences of the users and ensure that each person using the toolkit can relate to at least one of the images. It also provides different topics to be discussed during the reminiscence sessions. All images were also carefully selected so that the different topics related to the theme come together to portray a full experience especially when used in combination with prompt questions to promote smoother conversations and better reminiscence sessions.

In addition to the reminiscence images, digital elements such as visually stimulating lamps are included in the toolkit as a substitute for the bubble tubes and fibreoptic cables which have been directly linked to the provision of calm feelings and the reduction of anxiety levels in people living with dementia (Lorusso et al., 2020) and are commonly used for visual stimulation in multisensory rooms. This is in line with the portability attribute of the AMuSED toolkit which aims to incorporate the multisensory stimulation from Snoezelen into a portable tabletop box and eliminate the need for a large space and separate room for multisensory stimulation.

5.1.2 Audio stimulation

The AMuSED toolkit provides audio stimulation through recordable sound buttons, CDs for singalongs, sound machines and other digital elements related to the corresponding theme and can either be used with the images or incorporated into activity sessions to deliver audio cues and improve the reminiscence experience. The audio stimulation in the AMuSED toolkit is also further expanded in some of the toolkit editions to include elements that combine audio stimulation with other forms of stimulation such as the QR code cubes which combine audio with visual stimulation and link to short videos corresponding to the theme, a recordable photo album that showcases as well as narrates information about photos and other elements, and the sound boxes that combine audio with tactile stimulation.

Figure 5.4: Sound machine, QR code cube, sound buttons and recordable photo album

5.1.3 Olfactory stimulation

Olfactory stimulation is provided by the AMuSED toolkits through the inclusion of different elements such as fruits, oils and smell capsules, each of which were carefully selected with the aim of evoking memories related to the theme. All the smells used in the toolkit relate to their corresponding themes such as farmyard and cut grass for the countryside theme, pomanders for the Christmas theme, and scentscapes for the entertainment theme. These smells can be used alongside other forms of stimulation such as visual, audio and tactile stimulation to promote engagement and create a cohesive reminiscence experience.

Figure 5.5: Smell capsules, pomanders and scentscapes

Source: Amazon

5.1.4 Tactile stimulation

The AMuSED toolkit incorporates tactile stimulation by including tactile elements of different materials such as plastic, sand and foam, each of which are related to the theme and can be combined with the reminiscence images on the toolkit panels to improve reminiscence sessions or developed into activities to provide more engagement especially in group sessions. For example, the sand included in the Seaside toolkit links to the reminiscence images of sand on the toolkit panels and can be used when discussing trips to the seaside, building sandcastles, picking up seashells etc. It can also be used in an activity by burying seashells and having people find them or

building sandcastles. The birds included in the MERL toolkit combine tactile and audio stimulation by making the sound attributed to real birds. This ties in with the reminiscence images of the Countryside theme and remind people of experiences related to living or being in the Countryside.

Figure 5.6: Plush bird, fuzzy balls, kinetic sand and plastic sea animals

Source: Amazon

5.1.5 Gustatory stimulation

This form of stimulation although important, is often missing in multisensory rooms. Therefore, food elements such as popcorn were included in the AMuSED toolkit as a way of bringing the reminiscence sessions to life. For example, eating popcorn while at a reminiscence session about movies and cinema can help to create a movie scenario and make people feel like they are at the cinema. This helps to strengthen the theme by acting as an additional memory cue and can improve the reminiscence sessions. A candy floss machine was initially included in the AMuSED toolkit but was later removed on safety grounds due to the machine spitting out hot sugar.

Figure 5.7: Popcorn and popcorn machine

5.1.6 Cognitive stimulation

Cognitive stimulating elements such as jigsaw puzzles were also included in the AMuSED toolkit to fit each of the themes. All jigsaw puzzles were sourced from dementia-friendly vendors (Relish, n.d) and comprised of a range of twelve to thirty-five pieces, ensuring that they were dementia friendly

and guaranteeing that the users would obtain the right amount of cognitive stimulation from the AMuSED toolkit without facing any difficulty. Dementia friendly word search sheets were also included in the toolkit to provide an element of challenge into the activity sessions which was a missing element missing in the Tovertafel observed at the hospital in chapter 4. These word search sheets provided an appropriate level of challenge and mostly included four to six letter words in the search. Maps were also included for their ability to provide stimulation and improve orientation (Bertrand et al., 2019) and for their success in the observation performed in chapter 4 where people were able to identify locations on the map and share experiences pertaining to these locations.

The exploding box concept of the toolkit allows the activity coordinator or caregiver to either use it as a single tool for communication within a group or to deconstruct it into separate panels that can be used by individuals for more focused discussions. The toolkit incorporates different senses; therefore, a selected panel can be used alongside elements and activities that correspond with it. For instance, the panel on the Christmas toolkit with reminiscence images of snowmen can be used in a session and combined with a "build your own snowman" activity, along with conversations about building snowmen in the past. The cohesiveness of the elements, activities and reminiscence images in the AMuSED toolkit helps the activity coordinator to bring these different aspects of the toolkit together to create an experience for people living with dementia.

Four different themes – Countryside (MERL), Seaside, Christmas and Entertainment – were developed from the AMuSED toolkit after feedback provided in chapter 4 of how people living with dementia respond better to themes and themed activities. Thoughts were put into the constructions of each theme with considerations made on the level of appropriateness, relevance to theme, engagement and stimulation of each of the elements included. These elements and their relevance to the different themes are described in turn in section 5.2 to 5.5.

5.2 AMuSED MERL Countryside Edition

Developed with the Museum of English Rural Life (MERL), this toolkit shown in figure 5.8 incorporates reminiscence photos and artifacts provided by The MERL. The cover features the bright yellow colour of The MERL and the logos of both the university and The MERL to display the collaboration. It also features the dementia forget-me-not flower and the name of the toolkit. The elements featured in this theme were included to remind people of activities of rural life such as farming, with images of people, activities and vehicles in the English Countryside from as early as the 1930s printed unto vinyl and laminated on the side panels of the toolkit to support easy cleaning

and sanitisation. It also includes smell capsules related to the farmyard (see Figure 5.12) such as stables and horses, potatoes, cut grass and summertime strawberries as well as animals such as birds and animal products like sheep's wool.

The toolkit includes mystery boxes (see Figure 5.11) that contain elements such as sheep's wool and Morris dancing bells for people to guess. The boxes provide a hint by playing a sound when opened. This toolkit also includes a recordable photo album filled with images and elements provided by The MERL, plush birds such as the robin and a raven which provide tactile stimulation as well as audio stimulation by making their corresponding bird sound. It also contains elements such as garden quoits, aqua paints and jigsaw puzzles to be used in activities alongside the prompt questions provided by The MERL.

Figure 5.8: The MERL Countryside toolkit and its elements

5.2.1 Panels

The toolkit has four 36cm by 36cm panels on each side which a bottom and top cover. Each of which includes reminiscence photos printed on both sides. The panels are made into a box by sliding all four side panels into their appropriate slots in the bottom panel and topping this off with the cover panel. The reminisce photos on the panels cover topics such as: farm harvests, farm animals (sheep, birds, cows and pigs), transport vehicles, childhood, cooking utensils, ration book, MERL artifacts such as Morris dancing bells, squash racket and ping pong paddle, picnic hamper, cricket balls, old fashioned metal quoit, road milestone, youth hostel badge, cycling badge, as well as maps of the river Thames through Berkshire and Oxfordshire and onto the Cotswolds. The images on the panels were from the MERL collection with dates ranging from 1900 to 1960 and were included to serve as visual cues for memories related to countryside, farming and rural life especially for people who grew up in the Berkshire and Oxfordshire area. The maps also provide discussion points for people who lived in places with the river Thames running through them such as Reading, Oxford, Windsor and Maidenhead and can be linked to activities such as rowing.

The panels are linked to the elements and activities in the toolkit such that they can be combined for use in an activity session. For example, the images of farm animals on the panels can be used to start a conversation about farms, being on a farm and farm animals such as cows, pigs, birds, horses, sheep etc. which can be progressed by including the smells of farmyard, horses and stables into the conversation through the introduction of the smell capsules. The birds can also be included to provide tactile stimulation as well as audio to remind people of the bird sounds common in the farmyard. Finally, to include an activity and extra forms of stimulation, the mystery box containing tactile farmyard elements such as sheep's wool can be passed around to all the session attendees

with hints provided to help them guess "What's in the box", and the audio on the box describing the process of obtaining wool from sheep is automatically played as soon as the box is opened.

This level of cohesiveness is seen throughout the toolkit, with the different elements in the toolkit and images on panels able to be combined to generate exciting activity sessions, such as discussing the maps on one of the panels, the familiar locations and combining this with the map in the toolkit, or discussing the reminiscence images on the panel showing harvests such as hops picking, combining this with olfactory stimulation from the grass, potato and strawberry smell capsules to discuss harvests and harvested food items, and rounding this up with a "What's in the Box?" activity involving tactile plants such as hops or other plants or foods that can be harvested on a farmyard.

This combination of different forms of stimulation connected in a well thought out way to provide a complete reminiscence experience is part of what makes the AMuSED toolkit novel and different from all the interventions reviewed in chapter 3.

Figure 5.9: The panels of the MERL Countryside toolkit

5.2.2 Sensory elements

In order to align with the theme and images on the panels, sensory elements such as the following were included in the toolkit:

- Recordable photo album that can provide up to 6 minutes of audio recording per page. This album was captioned "Around the World" and included photos and items from different locations provided by The MERL such as that of an English butcher inspecting Australian beef, Canadian flour mill sack, Sri Lankan tea, as well as elements such as English wool.

- Mystery boxes or "What's in the box?" containing tactile objects such as sheep's wool and Morris dancing bells. These boxes also provide audio stimulation and education by narrating the shearing process of sheep as in the sheep's wool box or playing the music to the Morris dancing activity as in the Morris bells box.

- Smell capsules providing smells related to farming and life on the countryside such as potato, stables and horses, strawberry summertime and cut grass.

- Plush birds linked to the images of the birds on the panel that provided tactile stimulation due to their soft material as well as audio stimulation by recreating the actual bird sounds when pressed in the middle.

- Catapult and fuzzy balls linked to the reminiscence images on the toolkit. Actual balls were substituted for fuzzy balls to prevent harm to the users and ensure that the toolkit was safe for use.

Figure 5.10: The recordable photo album showing elements from different locations

Figure 5.11: The mystery boxes displaying sheep's wool and Morris dancing bells

Figure 5.12: The different smell capsules

Figure 5.13: Plush birds and fuzzy balls

Source: Amazon.com

5.2.3 Cognitive elements and themed activities

The mystery boxes were included in the toolkit to provide cognitive stimulation with the inclusion of audio clues to reduce the level of difficulty of the activity. A map of reading was also included showing The MERL In the middle, and people were occasionally challenged to find this location on the map. Activities such as aqua paints with garden scenes and plant growing kits were also included in accordance with the farming theme of the toolkit.

Figure 5.14: Themed activities in the MERL toolkit

5.2.4 Question prompt and activity booklet

Due to the chatty café being set up for the community and advertised locally with no need to sign up, it was difficult to determine who would be in attendance as the attendees at each session can vary in number as well as type, and severity of their dementia. Therefore, the sessions had a free-flowing structure and did not require the use of an activity booklet. The Countryside AMuSED toolkit was also co-designed with The MERL and their staff and volunteers were well versed on the types of activities that could be done with the chatty café attendees using the AMuSED toolkit.

However, question prompts (see Appendix K) were useful to guide the conversation during the sessions. The prompts used in this toolkit were developed by The MERL and were already being used in their reminiscence sessions and chatty cafés prior to the inclusion of the AMuSED toolkit. These prompt questions were linked to the Countryside theme, reminiscence images and elements, to be used by the activity coordinator during the session to facilitate communication and reminiscence among the attendees and steer the conversation in a positive direction.

A Day Out in the Country

Do you consider yourself a Town or Country person? Do you prefer one to the other and why?

What do you associate most with the countryside?

How important was the countryside to you when growing up?

Would you ever visit the countryside and why?

Where would you go? Who would you go with?

How did you travel there?

What did you do while you were there?

Did you have a favourite place to visit?

Have you lived or do you live in the countryside?

Have you ever worked in the countryside? What did that work involve?

Has the countryside changed over the years in your experience? If so, how?

What's your most memorable countryside moment?

Figure 5.15: The MERL prompt questions

The Countryside toolkit was carefully crafted to bring different elements of the countryside into one multisensory and multiactivity intervention. It incorporates areas such as farming, farm animals, artifacts, elements and activities of the countryside and introduces this through the reminiscence images on the panels which are further combined with the sensory elements and activities to create a multisensory experience at the countryside. The development of this toolkit was aimed at improving the quality of the chatty café sessions at The MERL by combining multisensory stimulation with the images typically used in the sessions.

5.3 AMuSED Seaside Edition

Developed after feedback from the dementia experts in chapter 4, this seaside themed toolkit shown in figure 5.16 was aimed at bringing real life seaside experiences to people living with dementia. Featuring a bright blue top, this toolkit includes several reminiscence images and elements which when combined together with prompt and activity sheets help to deliver a cohesive seaside adventure. The toolkit includes a combination of digital and traditional elements such as lamps, sound buttons, kinetic sand, postcards, message in a bottle, windmills, seashells, and smells such as sea breeze, suntan lotion, out at sea, seashore, smoked fish and rock pools. These are carefully combined in the activity booklet to enable caregivers and activity coordinators deliver

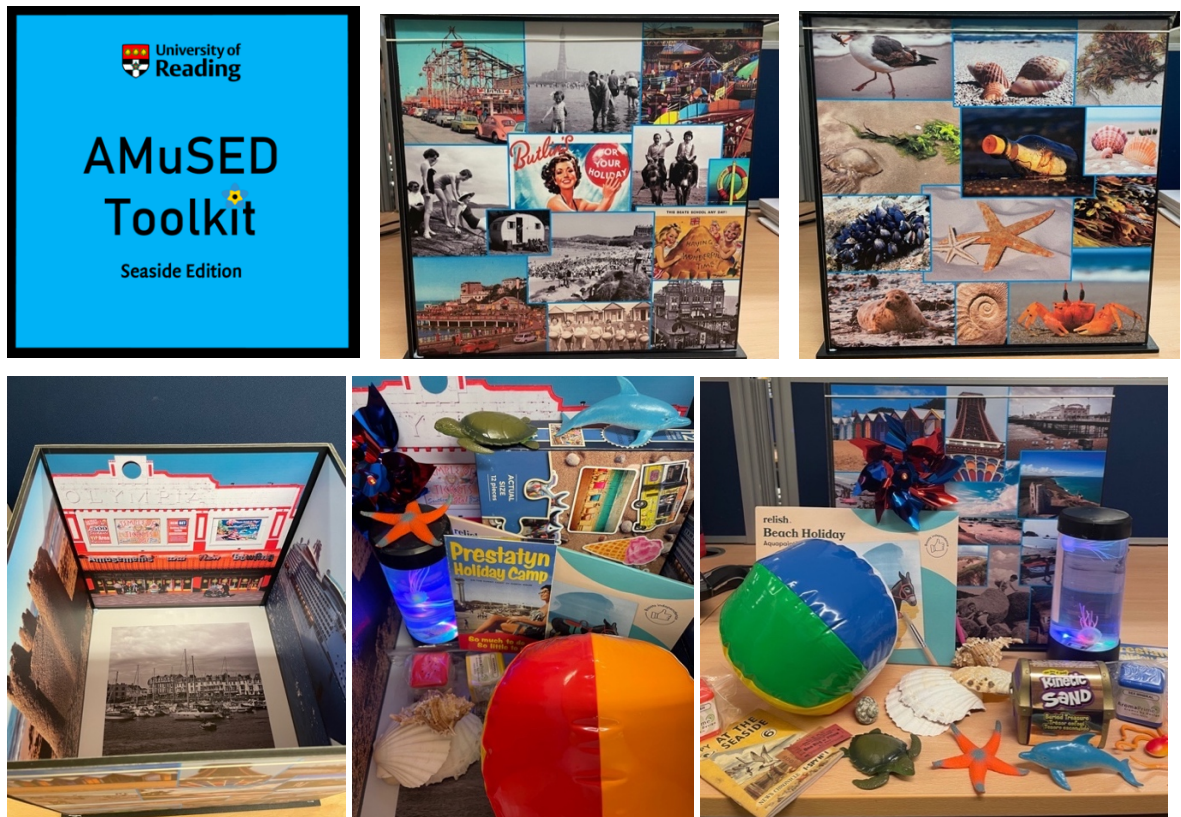multisensory and multiactivity sessions to people living with dementia with the aid of the prompt questions.

Figure 5.16: The AMuSED Seaside edition toolkit

5.3.1 Panels

The panels display bright and colourful reminiscence images of the seaside such as people playing with sand and building sandcastles, people playing with beach balls, rock pools, arcades at the pier, Butlin's family holiday, animals commonly found at the beach (seagulls, starfish, jellyfish), seashells, message in a bottle, cruise ships and foods consumed at the seaside such as fish and chips. The outer part of the panels displays a collection of these photos in a collage while the inner parts display single photos. The panels of this AMuSED toolkit can be used to start discussions such as on animals at the seaside and people can list the sea animals they are familiar with and narrate their experiences at the seaside with these animals. Additional stimulation can be included into this discussion by playing the sounds of the sea, seagulls and other appropriate sounds using the recordable sound buttons (see Figure 5.18) and including the different smell capsules such as sea breeze, seashore and rockpools. This reminiscence session can be further strengthened by including tactile sea animals and discussing these. This level of cohesiveness between all the different parts

of the toolkit is common throughout the toolkit, allowing for different cohesive and themed activities to be developed from these different sensory elements and activities.

Figure 5.17: The panels of the Seaside toolkit

5.3.2 Sensory elements

The sensory elements included in this toolkit were in line with the seaside theme and the photos on the panels on the toolkit. They include the following:

- A jellyfish lamp for visual stimulation. In line with the portability attribute of the AMuSED toolkit, visually stimulating items used in Snoezelen such as bubble tubes were substituted for visually stimulating lamps. This jellyfish lamp emulates the colourful lights and bubbles of a bubble tube and incorporates some floating jellyfish in accordance with the seaside theme. The inclusion of the jellyfish lamp in this toolkit is aimed at recreating the visual

stimulation linked with the use of bubble tubes and firbreoptic cables in multisensory rooms, but in a portable form.

- Digital recordable sound buttons which featured sounds such as the squawking of seagulls and sounds of the ocean in accordance with the seaside theme of the toolkit. These were included as a means of bringing the reminiscence images and seaside experience to life, as well as providing audio stimulation to the users.

- Kinetic sand, seashells and plastic and plush sea animals for tactile stimulation. The kinetic sand was included due to its safety attribute and also because it does not create the mess associated with traditional sand. The toolkit featured two forms of kinetic sand, a larger one to be explored and used for making sandcastles, and a smaller sand chest with hidden treasure for the users to find. Seashells of various shapes and sizes were also included in the toolkit in accordance with the theme and could be buried in the sand during activity sessions. Sea animals such as jellyfish, starfish, sea turtles and whales, made from plastic and plush materials were also included in the toolkit for both visual and tactile stimulation. These tactile elements were incorporated into various activities in the activity booklet to be used alongside other forms of stimulation such as audio stimulation like the sound of the sea, visual stimulation from photos of the seaside and cognitive stimulation from the recitation of popular seaside themed tongue twisters such as "She collects seashells by the seashore".

- Smell capsules including smells such as sea breeze, seashore, sea mineral, suntan lotion, smoked fish and rockpools. Each of which were included to be used with the other forms of stimulation available in the toolkit in order to create a cohesive reminiscence and engagement experience.

Figure 5.18: The sensory elements of the Seaside toolkit

Source: Amazon

5.3.3 Cognitive elements and themed activities

The seaside toolkit included cognitively stimulating seaside themed elements such as a word search, the popular tongue twister "She collects seashells by the seashore", and dementia friendly jigsaw puzzles. It also contained activities such as a magnetic fishing game, a seaside memorabilia pack containing reminiscent postcards and brochures, bottles for people to put in messages and send out to sea, postcards to send to families and loved ones, colouring, quoits, seaside themed aquapaints, bubbles, photo props for activity sessions. Beach balls were also included for the users to play with and toss around to each other as a result of observing the patients' use of the Tovertafel at the hospital during the observation in chapter 4 and discovering that they engaged with and enjoyed the beachball game because of the challenge it offered.
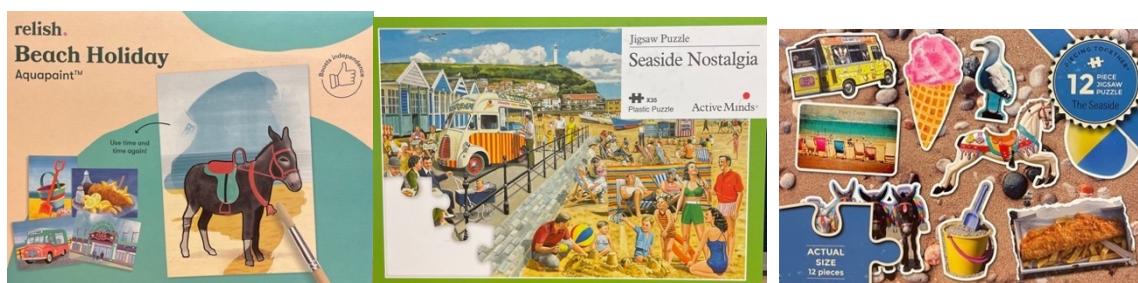
Figure 5.19: The cognitive and themed activities of the Seaside toolkit

5.3.4 Question prompt and activity booklet

An activity booklet (see Appendix L) was included in the seaside toolkit to give information about the toolkit and provide the caregiver or activity coordinator with suggested activities. The first page of this booklet was designed to give an initial introduction to the AMuSED toolkit using images. This page displays the name of the technology, pictures of the AMuSED toolkit in full form, photos alluding to the theme such as a starfish and beach, the logo of the university and the dementia forget-me-not flower. The next part of the booklet gives a brief description of the AMuSED concept, the elements and their basis on the literature review conducted and what is required from the activity coordinators regarding the evaluation. This is followed by a section which displays the toolkit at a glance, showing pictures and names of the elements in the toolkit as well as an invitation for the activity coordinators to either use the box however they please or take a cue from the suggestions and question prompts in the activity booklet.

The main element of the activity booklet is the "Example Activity" section which contains suggestions of activities that can be carried out by the activity coordinators using the toolkit elements. It details different activities that combine the elements together in order to provide the right amount of multisensory stimulation within each session. It is included as a guide for the activity coordinators, providing prompts such as "let the people tell their stories about times spent at the beach", "Press the buttons to play the sound of the seagulls and the waves". These suggestions are aimed at getting the activity coordinators familiar with the elements in the toolkit as well as providing guidelines to help them develop their personal ideas on how the toolkit could best be used. In addition to the prompt questions, the activity booklet also contains the contact information of the researchers to ensure that a channel was available if help is needed with any of the elements or in the case of damage or the requirements of extra elements and ideas. This was also communicated verbally at every location during the drop-off process in order to help with any complexity that might arise with the toolkit and further improve its usability.

Figure 5.20: The Seaside toolkit activity booklet

The activity booklet also contains prompt questions to guide the reminiscence sessions. These are leading questions included for the activity coordinators to ask the session attendees to get them to narrate their experiences and stories. All the questions were carefully constructed so that they incorporate different parts of the toolkit such as the reminiscence images, sensory elements and activity booklet.

Example Prompt Questions

- Have you ever been to the seaside? Where did you go?
- How did you travel there?
- Where did you stay?
- What activities did you do while you were there?
- Did you ever ride on a donkey?
- Did you collect seashells?
- Did you have a favourite beach to visit?
- What is your most memorable moment at the seaside?
- If you were writing a message in a bottle to put into the sea, what would you write?
- Have you ever been on a cruise? Where did you go?
- What's your favourite seafood or fish?
- Who would you send a postcard to?
- Did you enjoy swimming or sailing?

Figure 5.21: The Seaside toolkit prompt questions

The AMuSED Seaside edition toolkit was created to help caregivers and activity coordinators deliver multisensory and multiactivity seaside experiences to people living with dementia. It incorporated some of the results of the literature review conducted in chapters 2 and 3 such as the inclusion of the jellyfish lamp to mirror the bubble tubes in Snoezelen and the inclusion of multisensory stimulating elements. It also considered and included some of the results from the observation conducted at the hospital such as the inclusion of challenging activities like jigsaw puzzles, word search, tongue twisters and elements like the beachball.

5.4 AMuSED Christmas Edition

The concept of the Christmas themed AMuSED toolkit emerged after a care home manager provided feedback that the residents would enjoy a Christmas themed toolkit for the Christmas holiday season. This toolkit sports a bright green colourful cover reminiscent of the Christmas season and was designed to help people reminiscence about their childhood Christmas holidays. It includes Christmas related images such as Christmas trees, carolling, presents, snowmen and sledges, Santa Claus, reindeer, Christmas foods and toys, as well as elements from the Christmas season such as Santa hoop games, snow globes, wreath decorations, Christmas trees and tinsel. It also incorporates elements of childhood such as childhood movies like Aladdin, Puss in Boots, Cinderella, Mother Goose and Humpty Dumpty.
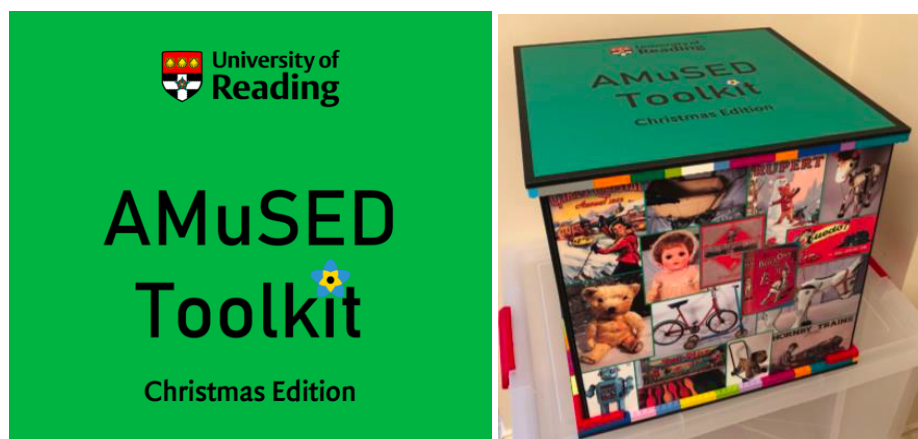
Figure 5.22: The AMuSED Christmas edition toolkit

5.4.1 Panels

The panels of this toolkit display reminiscence images related to Christmas on their outer parts such as Christmas trees, foods, shops, decorations such as wreaths and tinsel, reindeer, Santa Clause and toys, as well as people engaged in Christmas activities such as carolling, sledging and building snowmen. One of the panels of the toolkit includes posters of childhood movies such as Puss in Boots, Cinderella, Aladdin, Mother Goose and Humpty Dumpty. The inner parts of the panels display single large images such as Christmas pomanders, the twelve days of Christmas, shops and Christmas decorations. The collection of all the images on the panels were aimed at providing memory cues to help people living with dementia reminisce about their childhood Christmas holidays and activities.

One of such activities is the making of Christmas pomanders which is included in the AMuSED Christmas toolkit. One of the panels of this toolkit contains a large photo of a Christmas pomander (see Figure 5.23). This visually stimulating photo can be used within a reminiscence discussion of childhood Christmas activities and can also be combined with the Christmas carols played by the snow globe (see Figure 5.24). The toolkit also includes oranges and cloves which can be added to further strengthen the reminiscence session, as attendees can touch and feel these items for tactile stimulation as well as engage in discussions about pomanders. An activity can be introduced to take the reminiscence session further by having the attendees make Christmas pomanders with the oranges and cloves to hang up as a decorative piece just like they did during their childhood. The rest of the oranges can also be consumed for gustatory stimulation. This reminiscence session specified uses just a few elements of the AMuSED toolkit but can provoke strong childhood memories and result in people sharing their family Christmas traditions, activities and foods.

Figure 5.23: The panels of the Christmas toolkit

5.4.2 Sensory elements

The sensory elements in the Christmas edition toolkit correspond with the theme and include the following:

- A singing snow globe to provide both visual and audio stimulation. This snow globe features a Santa Claus figurine and includes music of different Christmas carols such as Silent night, O Holy night and Jingle bells.

- Colour changing Christmas lights for visual stimulation, included to replicate the fibre optic cables used in Snoezelen.

- Sound buttons on which sounds of Santa Claus and sleigh bells were recorded to be used along with the reminiscence images on the panels.

- Smell capsules that give off Christmas related smells such as peppermint and Christmas tree for olfactory stimulation.

- Oranges to be used along with cloves for making Christmas pomanders or to be eaten on its own

- Tinsel for tactile stimulation.

These sensory elements were included in the toolkit to provide multisensory stimulation especially when used with the images on the toolkit panels during reminiscence sessions. They also include strong Christmas related elements such as carols, decorations and tress to serve as memory cues during the sessions.

Figure 5.24: The sensory elements of the Christmas toolkit

5.4.3 Cognitive elements and themed activities

Cognitive elements such as Christmas themed jigsaw puzzles, word search and a Christmas quiz are included in the toolkit. Both 12-piece and 35-piece jigsaw puzzles were used in this toolkit in accordance with the adaptability attribute of the toolkit to ensure that people at various stages of dementia would receive cognitive stimulation from the toolkit. Several other Christmas themed activities are included such as creating Christmas pomanders using the oranges and cloves provided, Christmas chain making using the papers provided, wreath decorations, Christmas Bingo, collage making, Christmas tree building, Santa hoop game, colouring and photo activities using the Christmas headbands as props.

Figure 5.25: The cognitive and themed activities of the Christmas toolkit

Source: Amazon

5.4.4 Question prompt and activity booklet

The Christmas edition toolkit includes an activity booklet (see Appendix M) which contains information about the toolkit, instructions on how to set it up, a set of images of the toolkit elements, and sample Christmas activities such as photo sessions, pomander making and wreath decoration to serve as suggestions for the activity coordinators and get them acclimated to using the elements in the toolkit. The prompt questions also incorporate the Christmas themes and the toolkit elements and serve as a tool for the activity coordinators to steer the conversation during the sessions.

AMuSED Toolkit

Christmas Edition

Example Activity
Set the Scene for Christmas

Set the scene for Christmas with your tinsel, traditional fairy lights, bauble, snowflakes and Christmas stocking.

Press the square sound button to hear a message from Father Christmas and the small round button to hear the bells of his sleigh. Add the scents of Christmas and turn on the music and lights of the snow globe for extra yuletide cheer.

Get further into the Christmas mood by wearing the headbands and glasses. Take some images on a phone for printing later as a memento of the session.

Ask everyone to sniff the scent cubes and try to identify the smells Christmas, extending this into reminiscence about the smells of Christmas they remember.

Example Activity
Christmas Crafts

Get everyone to create home-made decorations using the wreath making kit and the paper chain making kit. Use the vintage stickers to create a collage on the foam board or use them to decorate the speech bubbles and then record a Christmas message for family or friends.

Invoke the activities and aromas of Christmas past by using oranges, ribbon and cloves to make pomanders and hang them in the room to dry and for everyone to smell. Wrap a ribbon round the orange, pierce the orange skin in patterns no more than ½ cm apart and push a clove into each hole. Hang and leave to dry over a few weeks.

Water the magic tree in one session and show how it has grown into a mini tree by the next session. Decorate the mini tree.

Example Prompt Questions

- Do you enjoy Christmas?
- How did you spend your Christmas holidays?
- Did you travel or stay at home?
- What are your favourite Christmas activities?
- Did you ever write a letter to Santa?
- What reminds you of Christmas?
- How did you decorate your house for Christmas?
- Did you have a Christmas tree? Real or artificial?
- How did you decorate it?
- Did you play games during Christmas?
- What games did you play?
- What was your favourite Christmas gift?
- Do you remember it snowing at Christmas?
- Did you ever build a snowman?
- What is your favourite Christmas food?
- Did you go to the pantomime?

Figure 5.26: The activity booklet and prompt questions of the Christmas toolkit

The Christmas edition toolkit was developed using themed reminiscence images and elements to remind people living with dementia of their childhood Christmas celebrations. It also provides a range of multisensory and multiactivity stimulation that combines the different aspect of the toolkit such as the reminiscence images on the panels, the elements and the activities which are interrelated and can be used to create various multisensory experiences and reminiscence sessions especially when combined with the activity booklet and prompt sheets.

5.5 AMuSED Entertainment Edition

This bright red toolkit was developed as a combination of both entertainment and life themes. It includes reminiscence images related to entertainment such as cinemas, movie tickets and posters, festivals and events, dancing, fairgrounds, arcades, circus, and various music and movie stars. It also includes reminiscence images related to life in Reading and places where people would have experienced different forms of entertainment locally such as shops from the 70s, notable locations in Reading e.g., Union Street, cinemas from the 70s and 80s, Reading Football Club teams from different eras, and other sporting events like Wimbledon, greyhound racing, Henley regatta, Royal Ascot. The elements featured in this toolkit correspond with the theme and were included to promote reminiscence about different forms of entertainment within and outside Reading. They include recordable sound buttons, masks of famous movie stars, sound machine, light box, clapperboard, bingo machine, hooks and ducks and a popcorn machine.
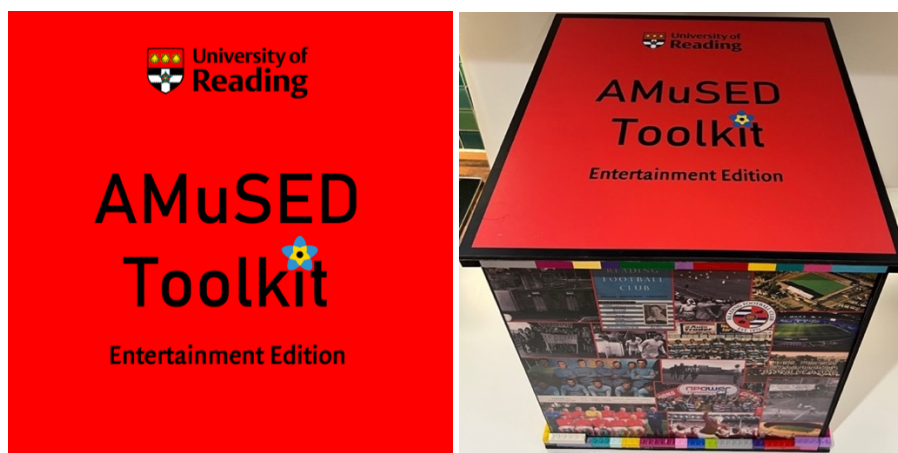
Figure 5.27: The AMuSED Entertainment edition toolkit

5.5.1 Panels

The panels of the entertainment toolkit display reminiscence photos relating to life and entertainment within and outside Reading, displaying images such as the four Bs of Reading; Biscuits (Huntley and Palmers), Beer (H & G Simonds), Bricks (S & E Collier) and Bulbs (Sutton's), The Oracle shopping mall, Jackson's Corner shop in the 80s, Jacobs Jewellers from different eras, shops like Heelas and Woolworths, Union street, Reading Stadium, dinner theatre, ballroom dancing, Reading and WOMAD festivals, Reading football club, Royal Winsor and Royal Ascot races, greyhound racing, Wimbledon, the Royal Regatta, Carters steam fair, circus games like hook the duck, win a goldfish, buzz wire game, foods like candy apple and popcorn, The Granby and Odeon cinemas, famous movie stars, and famous movie posters. The toolkit also includes an extra panel for people who grew up or lived in Newbury featuring reminiscence photos of some of the key landmarks and locations in Newbury. This extra panel was included as a way of personalising the toolkit to fit people from Newbury as well as to ensure that the toolkit is relatable to as many people as possible, because some of the people living with dementia in care locations across Reading grew up or lived in neighbouring towns like Newbury and would enjoy reminiscing about familiar locations.

One of the ways in which this toolkit can be used is by starting a reminiscence discussion using the panels and the prompt sheet. Attendees can interact with the panel displaying reminiscence images related to entertainment in Reading (see Figure 5.28) and discuss images such as the different past cinemas in Reading, when they visited and what movies they enjoyed watching. This conversation can lead to further discussion about their favourite movies and movie stars and the QR code cubes can be introduced into the session for the attendees to watch short videos from some of their

favourite movies while eating freshly made popcorn made with the popcorn machine (see Figure 5.29) also included in the toolkit. This discussion and reminiscence session can lead to an activity where the attendees roleplay as movie producers and describe the type of movies they would make if given the chance. The names of the movies can be set up in a "marquee" by the activity coordinator using the light box (see Figure 5.29) to mimic the marquees commonly used in cinemas in the past, photos of which are also displayed on the panels.

Figure 5.28: The panels of the Entertainment toolkit

5.5.2 Sensory elements

The sensory elements in this toolkit are linked to the Entertainment theme and reminiscence images on the toolkit panels and were included to provide different forms of stimulation and engagement to people living with dementia. They include the following:

- Light box for visual stimulation. This element was added to mimic the marquees typically found at cinemas in the 80s. The box, which can be set to display different colours of light

includes letters, numbers and emojis. Activities were developed around this element such as asking the group what their movie would be called if they were to create one and displaying their answer on the "marquee".

- QR code box with links to clips of famous movies such as Sound of Music and Wizard of Oz for people to sing along to while also engaging in visual and audio stimulation.

- Sound machine to plays different movie sounds such as laughter, applause, sadness, money, and drumroll.

- Smell capsules of various fairground related smells such as toffee apple, candy floss and cinder toffee.

- Popcorn machine and popcorn to simulate the cinema and fairground experience and provide gustatory stimulation.

- Fuzzy balls for tactile stimulation. These were also included in activities such the win a goldfish where people would attempt to throw the balls into bowls of different sizes in order to win the prize

Figure 5.29: The sensory elements of the Entertainment toolkit

5.5.3 Cognitive elements and themed activities

Word search was included in this toolkit to provide cognitive stimulation, as well as other themed activities such as colouring, hook the duck, win a goldfish, buzz wire, Bingo and photo props for photo sessions. These activities were included as a way of providing typical fairground games and

activities in a table-top form to further strengthen the reminiscence theme and promote competition and communication between members of a group.

Figure 5.30: The cognitive and themed elements of the Entertainment toolkit

5.5.4 Question prompt and activity booklet

The activity booklet of the Entertainment toolkit (see Appendix N) includes information about the toolkit and images and names of the elements. It also includes example activities that incorporate the reminiscence images on the toolkit panels and the elements in the toolkit such as using the clapperboard, sound machine and light box to create a movie set while discussing favourite movies and movie stars. The prompt questions included incorporate the Entertainment theme as well as the reminiscence elements and serve as leading questions to guide the discussions.

Figure 5.31: The activity booklet and prompt questions of the Entertainment toolkit

The entertainment toolkit provides an avenue for people living with dementia especially in Reading and surrounding locations to reminisce about growing up and the locations they visited for entertainment. It also provides a platform for people to not only discuss their favourite movies, but also experience some parts of creating a movie. The activities were carefully planned to incorporate the theme, and the supporting elements such as the activity booklet and prompt questions were included to help the caregiver or activity coordinator get the most out of the toolkit and its elements.

5.6 Summary

The inclusion of themes in the AMuSED toolkit was as a result of feedback provided by dementia experts and resulted in an array of themed boxes that display the creativity and versatility of the toolkit. The development of these AMuSED toolkits was done in line with the key requirements for an active multisensory toolkit – portability, affordability, accessibility, adaptability, usability and personalisation -- specified in chapter 4 in order to ensure that they filled the gap identified in literature and practice. The user personas (see Figures 4.3 – 4.8) were also referred to in this process to understand how these different themes would be used in various care provisions by activity coordinators with people living with dementia. In doing so, the AMuSED toolkit was developed to be usable within multiuser locations such care homes and communities with the various adaptable elements that were included to cater to groups of people with varying stages of dementia and different interests. The toolkit was also developed for use within personal homes where it can be deconstructed by the activity coordinator and used as a single panel and collection of elements to run activities.

The four different themes selected help to focus the AMuSED toolkit around specific topics with the aim of making the toolkit more relatable to people living with dementia and their caregivers. Each theme – Countryside, Seaside, Christmas and Entertainment – was aimed at providing multisensory and multiactivity stimulation in accordance with the aim of the PhD. The toolkits are affordable due to their use of low-cost elements and materials. The transparent plastic boxes used to package them also ensure their portability and enabled easy movement throughout the evaluation process detailed in chapter 7. All the toolkits regard accessibility as an important attribute by including a range of multisensory elements such that people with impairments limiting them from experiencing one form of stimulation can benefit from the other forms of stimulation and activities offered by the toolkits.

The use of varying elements and the incorporation of varying levels of challenges such as the use of 12-piece jigsaw puzzles and the more challenging 35-piece puzzles in the activities in the toolkits ensure that each toolkit is adaptable to different stages of dementia and appropriate for use in groups of people with varying stages of dementia. Each toolkit was also developed with ease of use in consideration and the design process ensured the elimination of any complexities. The activity booklets provide instructions on how to set up the toolkit as well as example activities that can be created from the elements. The set up and deconstruction process was also demonstrated at every evaluation site and activity coordinators and care staff were encouraged to recreate both processes

immediately after the demonstration to avoid complexity and ensure familiarity with the process. All editions of the AMuSED toolkit can also be personalised to fit the interests of a person or group of people e.g., the presence of reminiscence images focused on various topics on the panels, the recordable sound buttons that can be used to record and play different sounds related to the theme based on a person's interests, and the inclusion of the Newbury panel into the entertainment toolkit, using the toolkit library of the AMuSED framework detailed in chapter 6.

Table 5.1: The AMuSED toolkit themes in relation to the key requirements of an active multisensory toolkit for people living with dementia

Requirement	Portability	Affordability	Adaptability	Accessibility	Usability	Personalisation
Countryside (MERL)	✓	✓	✓	✓	✓	✓
Seaside	✓	✓	✓	✓	✓	✓
Christmas	✓	✓	✓	✓	✓	✓
Entertainment	✓	✓	✓	✓	✓	✓

Chapter 6: The AMuSED Framework and Model

Chapter 5 described in detail the AMuSED toolkits that were developed by following the structured and user-centred approach of the Design Thinking Method. Observation of the four AMuSED toolkits (Countryside, Seaside, Christmas, and Entertainment) shows that whilst they are individually themed and the images and contents within them are selected to match the theme, there are also many characteristics across all AMuSED toolkits that bind them together as a cohesive set. Additionally, whilst four toolkit themes have been developed within the scope of the PhD, the AMuSED framework has been designed as a tool to be used by activity coordinators and caregivers for the development of further AMuSED toolkits based on factors such as location, severity of dementia, mode of use, and preferred theme. The impact of the AMuSED framework extends beyond the four current themes and is evidenced in section 6.4 where the framework was translated and used in the development of the special Life-Entertainment AMuSED toolkit for a home care organisation based on their clients with dementia. This step-by-step guide can also be used along with the framework by caregivers and activity coordinators to develop new AMuSED toolkit themes one of the future aims of this PhD as described in the Future Work section in Chapter 9.

To 1) encapsulate the important therapy interventions, design attributes and constraints into a formal foundation; 2) document the design priorities and contents of each AMuSED toolkit theme; and 3) enable further AMuSED toolkits to be designed and developed, it is important to capture the outcomes from the design and development process in a framework which can act as a template for subsequent new themes or special requirements for AMuSED toolkits.

This chapter explores the development of an AMuSED framework consisting of the AMuSED Model (therapy interventions, design attributes and operating constraints), the AMuSED Toolkit (the physical and digital contents) and the AMuSED Box (panel artwork) that encapsulates the research, makes development repeatable, and which forms the second novel output of this PhD. This AMuSED framework brings together the information gathered from the literature review (Chapters 2 and 3), the design thinking approach, user engagement and prototypes (Chapter 4) and the final AMuSED Editions (Chapter 5).

To show how the framework can be used in practice we conclude this chapter by showing how a variation on the Entertainment themed AMuSED toolkit (Life-Entertainment Edition) was created

to suit the needs of a particular form of care provision by following a step-by-step process for the creation of new or variant AMuSED boxes. By adding this prescription and consistency of process, the second contribution to the field of this PhD, the AMuSED Framework and Model is demonstrated through enabling activity coordinators, caregivers or other third parties to create further AMuSED toolkits based on care factors such as location, severity of dementia, mode of use, and preferred theme. The potential impact of AMuSED thus extends well beyond the PhD.

6.1 The AMuSED Model

The AMuSED model as shown in Figure 6.1 is represented by five interrelated layers: (1) Baseline that highlights different interventions, design attributes and constraints; (2) Location that considers where the AMuSED toolkit will be used; (3) Severity (and type) of dementia exhibited by an individual or group of people who will use the AMuSED toolkit contents; (4) Type of Activity which considers how the AMuSED toolkit is intended to be used; and (5) Theme (or personalisation) of the AMuSED toolkit. The reasons behind the inclusion of each of these layers will now be explained together with links back to the literature and activities undertaken to support the decisions for their inclusion.
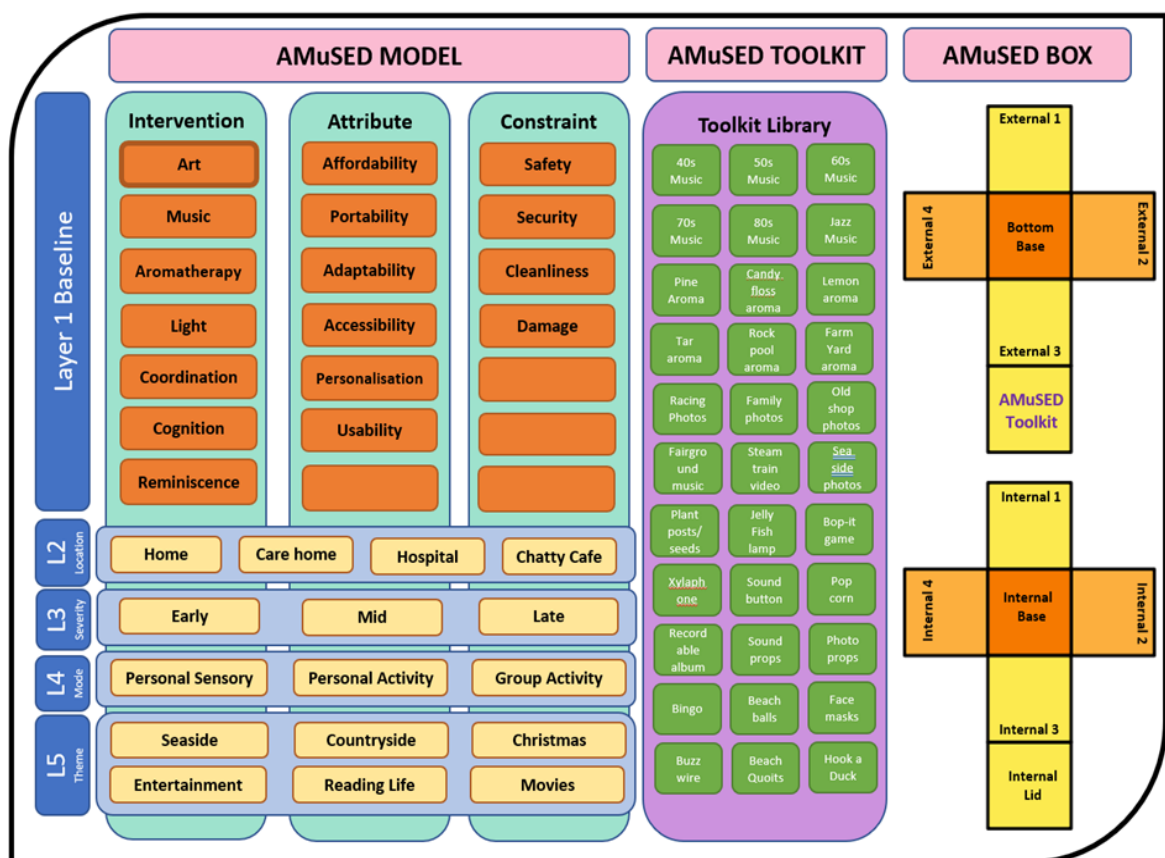
Figure 6.1: The Framework showing the AMuSED Model, the toolkit library and the AMuSED Box

6.1.1 Baseline (Layer 1)

The baseline layer specifies the different interventions, attributes and constraints that are considered important in delivering an effective active multisensory toolkit that will engage and stimulate people living with dementia and which will be appropriate for the environment within which it will be used. In doing so it considers:

Intervention: Review of existing literature and study of the interventions used in practice revealed the benefits of art, music, aromatherapy, light, co-ordination, cognitive and reminiscence therapy to enhancing the mood, emotion, and quality of life of people living with dementia as well as success in mitigating some of the behavioural and psychological symptoms of dementia such as apathy and agitation (Cai et al., 2020; Douglas, James and Ballard, 2004; Theleritis et al., 2018). Therefore, these interventions were considered as being important for inclusion in the design of the AMuSED toolkit with elements providing each of these forms of stimulation being stored in the Toolkit Library which is described Section 6.2.

- Art: creative expression through art therapy can help people living with dementia to regain their sense of identity and explore new skills safely, thereby creating positive interactions that support their wellbeing (Emblad and Mukaetova-Ladinska, 2021). Art therapy is also considered effective for improving communication and promoting reminiscence (Ramsey, Webb and Ellis, 2018).

- Music: linked to the alleviation of some of the behavioural and psychological symptoms of dementia such as apathy and agitation (Lam et al., 2020), music therapy has also been highlighted as having a greater effect on cognitive function than most therapies due to its integration of sounds, rhythms and lyrics, resulting in the activation of multiple areas of the brain (Moreno-Morales et al., 2020).

- Aromatherapy: aromatherapy has been described as an affordable non-pharmacological intervention for people living with dementia (Leach et al., 2021) and has been reported as effective in the management the behavioural and psychological symptoms of dementia (Srirojnoppakun and Tangwongchai, 2013).

- Light: people living with dementia often experience reduced sensory input, therefore the use of light therapy has been recommended for this group (Burns et al., 2009). Light therapy has also been shown to positively affect mood and cognition, especially in people living with mild and moderate dementia (Mitolo et al., 2018).

- Coordination: people living with dementia often experience a reduction in motor functions which can affect their hand-eye coordination (Kim et al., 2018). Therefore, the inclusion of activities that incorporate hand movements has been recommended for not only promoting their emotional wellbeing, but also improving their coordination (Treadaway et al., 2018).

- Cognition: dementia is often characterised by the onset of cognitive deficits which progress over time (Carrion et al., 2018), therefore cognitive stimulation is recommended through the implementation of programmes that create stimulating environments for people living with dementia to engage in a range of activities and discussions (Lobbia et al., 2018).

- Reminiscence: reminiscence therapy promotes person-centred care by drawing upon past memories of people living with dementia (Woods et al., 2016). It includes the use of elements such as themes and memory triggers (Macleod et al., 2021) to evoke memories and stimulate conversation (Carós et al., 2020).

Attribute: For interventions to be widely adoptable and successful in providing a fun and stimulating user experience several attributes were highlighted as being important during the design process including affordability, portability, adaptability, accessibility, personalisation, and usability.

- Affordable non-pharmacological interventions are a key criterion for improving the quality of life of people living with dementia and their caregivers in different care settings (Ihara et al., 2019). This is highly relevant for care facilities such as care homes and hospitals who may be working to limited budgets and even more so for people living with dementia in their personal homes where access to interventions and technologies is often subject to personal budget. The AMuSED Toolkit therefore focuses on using, as far as possible, readily available, and affordable components that can be readily purchased or freely downloaded under appropriate licences.

- Portability facilitates the uptake and adoption of an intervention by care home residents, families, and care staff (Barnett et al., 2017; Irazoki et al., 2020) and contributes to meaningful engagement with the intervention, especially in care facilities (Neal, du Toit and Lovarini, 2020). Portability includes the need for fast and easy set up to avoid potential distraction or loss of interest in the activity (Tabbaa et al., 2019). A further consideration prominent in the AMuSED development is the need for staff to regularly move interventions between rooms, wards, or homes. This led to considerations regarding size, set-up and storage of the AMuSED

toolkit and its contents so that it could be easily moved and rapidly set up when needed and also safely stored away between sessions. This is also useful if AMuSED toolkits are to be taken into individual homes by activity coordinators.

- Adaptability due to the progressive nature of dementia, has been shown to be important so that interventions can adjust and remain relevant to a person and their changing needs and preferences as their dementia progresses (Hammink, Moor and Mohammadi, 2021; Ancient and Good, 2014). The AMuSED toolkit has been designed to be adaptable, both in care homes where activity groups may be comprised of people at different stages of dementia, or indeed, with different types of dementia, as well as for individuals in their own homes where the toolkit has been designed to remain relevant to them as their dementia progresses, for example by including 35-piece and 12-piece jigsaws within the toolkit. Adaptability is also evident in the choice of components in the toolkit whereby people at early stages of dementia may benefit from the more cognitively stimulating and challenging elements in the toolkit, but as their dementia progresses become more interested in the gently stimulating visual, audio and tactile elements.

- Accessibility is an important consideration as people living with dementia, especially in care facilities, often have comorbidities (Chaurasia et al., 2016), visual or aural impairments or problems with their motor control, balance, coordination, gait, or speed (Astell, Czarnuch and Dove, 2018) which can affect the way they interact with an intervention. When implementing non-pharmacological interventions, it is important to ensure that activities are accessible to people with a wide range of physical abilities (Benveniste, Jouvelot and Péquignot, 2010). By incorporating elements that relate to sight, sound, smell, taste and touch, the AMuSED toolkit provides multisensory stimulation allowing users with impairment in one or more senses to still be able to benefit from the other forms of stimulation provided by the Toolkit. Activity coordinators and care staff further widen the experience for people using the AMuSED toolkit by helping them interact with the different sensory elements through prompt questions, touchable objects such as sheep skins or shells, and sound buttons and recordings.

- Personalisation has been shown to positively influence wellbeing, behaviour and social interaction and is recommended in the delivery of person-centred care (Koren, 2010; Kuot et al., 2021). Studies on music therapy, for example, show that personalised music is more effective in eliciting memories than general music (Schoenfelder and Gerdner, 2010). Similarly,

the use of other personalised elements such as personal photos and meaningful objects has been shown to trigger personal memories for both the person living with dementia and their family members as well as increasing avenues and opportunities for interaction with caregivers/activity coordinators and with positive effects continuing even after the reminiscence sessions end (Evans, Garabedian and Bray, 2019). There is a significant opportunity for personalisation in AMuSED toolkits, both in personal homes and in care establishments. In individual AMuSED toolkits, personal photos and images can be incorporated, recordings of loved ones voices made, and fragrances and smells relating to a particular person's lived experiences can be used for olfactory stimulation, for example, users who enjoy a particular kind of flower or food item can have the smells incorporated into their AMuSED toolkit. Personalisation is also possible in group settings where the Toolkit is used by multiple people. For example, images from a particular era such as the 1950s, 60s and 70s can be used and sounds and olfactory cues can also be incorporated such as Christmas songs and carols, and smells invoking memories of Christmas such as pine trees, Christmas puddings, and orange and clove pomanders.

- Usability refers to the satisfaction, effectiveness and efficiency with which users can reach their goals when using a new product, service, or system within a specified context (International Organisation for Standardisation (ISO), 1998). The consideration of usability as an attribute in the design of tools and interventions is paramount to ensure effectiveness (Rodriguez et al., 2018) and positive user experience (Inal et al., 2020). Usability also relates to the design and layout of the intervention, content, functionality, and assistance provided while the intervention is being used (Ottaviani et al., 2021). Interventions that have high levels of complexity are often criticised by users and have lower success rates of user adoption or engagement (Pot, Blom and Willemese, 2015). The AMuSED toolkit has been designed for ease of use. It contains off-the-shelf elements which are familiar to people living with dementia and their caregivers to aid acceptance, facilitate use, and avoid complexity, and also incorporates Prompt and Activity sheets to provide guidance to the caregivers and improve the quality of activity sessions.

Design Constraint: It is important to consider and include in the design, factors and constraints such as safety, security, cleanliness, and damage to components that might impact the safe and effective use of an intervention both within individual homes and in multiuser environments such as care

homes, hospitals and public spaces, though the risk of them occurring might be higher in some locations than others.

- Safety is always of the upmost importance with regards to ensuring all elements are safe for use especially by people living with dementia. This includes, for example, avoiding sharp objects or elements that could cause any form of harm to users or their caregivers. An example of an element removed from our Seaside AMuSED toolkit was the candyfloss maker which despite being a popular device available from a major retailer, would occasionally 'spit' hot sugar when in use which could have resulted in burns to the users.

- Security is an important consideration as some people living with dementia have the tendency to pick-up or 'pilfer' items as they walk around (Nagaratnam, Lim and Hutyn, 2001). At times it may also be difficult for the activity coordinator in group sessions, particular in open environments such as hospitals and cafes, to focus on conducting the session while also monitoring the participants and elements in the AMuSED toolkit. This was a point raised by both care home and dementia ward managers. Hence, security and methods of securing elements should be considered, such as the use of anti-theft security cables for expensive elements like mobile devices to prevent them from going missing or getting lost and damaged. Other ways we addressed this problem in AMuSED was to use recordable buttons and albums and older second-hand mobile phones/tablets rather than expensive new devices. Elements should also be packaged properly and returned to a safe and secure location after each session. The AMuSED toolkit provides a box with a secure latch for the easy containment of all the elements and the deconstructed AMuSED toolkit.

- Cleanliness is important to reduce the spread of germs and has become especially so since the start of the COVID-19 pandemic. It is important to ensure that the elements used in the implementation of the intervention can be cleaned. The AMuSED toolkits are made with laminated materials that allow for easy cleaning and sanitisation with alcohol sprays.

- Damage to, loss of, or running out of some components could occur due to frequent use of the AMuSED toolkit, which might be inconvenient but unlikely to put a stop to the intervention altogether. Where possible, we have tried to use elements that are less susceptible to damage, are robust enough for repeated handling, are cheap and easy to replace, or which can be

reused to cut costs and reduce environmental waste. Each toolkit comes with a support contact number in case there is need for any damage to be fixed or components replaced.

6.1.2 Location (Layer 2)

This layer considers the different locations in which the AMuSED toolkits can be used and in doing so the relative importance of the attributes (affordability, portability, adaptability, accessibility, personalisation, and usability) and the design constraints (safety, security, cleanliness, damage) for each location. Whilst all attributes/constraints are important to the successful and safe use of the AMuSED toolkits at all locations, some locations may enable or require more emphasis on certain constraints, with some examples described below.

Personal Homes: Security is seen as less of a design constraint in personal homes due to the single user environment and the relative level of security already in this environment. Again, due to the single user environment, cleanliness is also seen as less of a design constraint because the spread of germs is less in a home environment due to the reduced number of people interacting with the AMuSED toolkit and its contents. However, whilst perceived as less of a risk, these factors are not eliminated, and good practices should still be observed.

Hospital: While it is highly desirable that an intervention be personalized to fit the interests and lived experiences of users in personal homes and single user environments, the transient nature of hospitals means that the activity sessions conducted in this location will include different people with different lived experiences in each session. Therefore, personalisation might not be such a key attribute and the reminiscence therapy will not be personalised to the same extent as it would be in a family home. However, more generic forms of personalisation can be adopted such as using elements from a particular era that relates to the attendees or elements relating to a particular region or country that everyone has lived experiences of. People are also likely to have comorbidities to the dementia and this can be reflected in considerations of accessibility and usability as well as cleanliness. Safety is also an important attribute to be considered in this location especially due to the comorbidities of the users, therefore interventions used in hospitals should avoid harmful elements or elements that pose safety risks such as falls. Elements like anti-theft cables can also be used in this location to improve security and prevent theft or loss.

Care homes: Many care homes have a dedicated activity room or space for their residents and consider carefully what elements or technologies can be included in this space, whilst others will

147

make use of a day room that can be variously set-up for different activities on different days. Portability should be considered in the design process especially if the intervention requires rapid set-up or movement from one location to another within a care home or between care homes if they are part of a group. Again, individual personalisation is also not a key attribute for consideration in this location due to the general nature and multiuser environment of the home.

Public events: The general nature of organised public drop-in events such as chatty cafés means that personalisation might not be considered a key attribute in the adoption of interventions for activity sessions. The coordinators of these sessions are usually unaware of the type of attendees beforehand as most of the sessions are conducted on a walk-in basis. Therefore, it is difficult to personalise the intervention based on a particular user or demographic and more emphasis may need to be placed on security and cleanliness.

6.1.3 Severity, Progression and Type (Layer 3)

This layer considers the design of the AMuSED toolkit in relation to the severity and progression of a person's dementia, and if relevant the type of dementia a person has been diagnosed with, especially if being personalised for an individual with their own home. It considers non-pharmacological interventions and activities appropriate to early, mid and late stages of dementia and the different forms of engagement and stimulation that fits with behavioural and psychological issues that can occur. For example, people at early and mid-stages of dementia are sometimes more interested in interventions and activities that offer a degree of challenge as opposed to activities that do not, as they find the latter too simple and child-like (Groenewoud et al., 2017). However, it is also important to consider the appropriate level of challenge to incorporate in a group activity because feelings of failure can lower the self-esteem of people living with dementia (Ouldred and Bryant, 2008). Additionally, some people in the late stages of dementia not only have a fear of failure but also exhibit a tendency to give up on activities if they do not immediately succeed at them even while receiving encouragement from their caregivers (Anderiesen, 2017). Whilst cognitively stimulating games and activities such as memory games may be well suited for people at early and mid-stages of dementia, they are often not considered as key components in the development of interventions for people at late stage dementia who generally prefer failure-free gameplay without any scoring because they do not feel any pressure to compete to win in such games and activities (Perugia et al., 2017). Literature has also shown that at latter stages of dementia people benefit more from gentle stimulation such as Snoezelen (Cheng, Baker and Dursun, 2019).

6.1.4 Layer 4 Mode

This layer considers whether the AMuSED toolkit will be used in an individual's home or within a group environment for example:

Personal Sensory: The AMuSED toolkit can be used as a personal sensory environment. People living with dementia are sometimes affected by behavioural and psychological symptoms such as agitation and apathy. The use of multisensory rooms has been successful in mitigating the effects of these symptoms by providing a calming and relaxing environment. Therefore, the AMuSED toolkit aims to also relieve some of these symptoms using different multisensory elements such as lights, sounds and aromas that provide a calming and relaxing environment.

Personal Activity: People living with dementia also suffer from boredom and benefit greatly from participation in stimulating activity. The AMuSED toolkit offers activities that can be partaken on a one-to-one basis by an individual interacting with their caregiver, such as reminiscence activities, colouring, word search, painting, flower planting, jigsaws, buzz wires etc.

Group Activity: The toolkit not only supports one-to-one modes of activity but also one-to-many. This means that the toolkit is appropriate for use in sessions where a caregiver or activity coordinator is tasked with creating interactive and engaging sessions for more than one person at a time. The AMuSED toolkit features elements that support group play such as reminiscence therapy, bingo, music, puzzles, throwing games, photo opportunities, object feeling and guessing, sandcastle competitions, quizzes etc.

6.1.5 Theme (Layer 5)

A result of the evaluation of the AMuSED toolkit by dementia experts one key request was the incorporation of themes. The use of themes in the development of interventions for people living with dementia has been proven to stimulate the mind and make activities more enjoyable (Shoesmith, Charura and Surr, 2021). Themes can be added to fit the group of intended users to make activity sessions more interesting and engaging and can also be useful in focusing the sessions or discussions around a topic or subject matter. Examples of themes commonly included in non-pharmacological interventions include holidays, shopping, festivals, family, movies, sports, home, music, animals etc. The AMuSED toolkit currently has four themes namely, Seaside, Countryside, Christmas and Entertainment and incorporates elements and activities related to these themes.

6.2 Toolkit Library

The toolkit library is formed from the growing collection of elements that can be incorporated into the design of each AMuSED toolkit as described in Chapter 5. It is a dynamic library that can be continually expanded by including digital and physical elements into it, appropriate to the different themes. The toolkit library of the AMuSED framework features elements such as 1940s, 50s, 60s and 70s music, bingo, family photos, aromas, various forms of games, musical elements etc. These elements included in the toolkit library fit the themes of the AMuSED toolkit and create an avenue for a person or organisation to choose which of the elements will be incorporated into a particular intervention or session based on the users and attendees. An audit is kept of each toolkit made and delivered to ensure repeatability when needed, but also personalisation for specific individuals, and distribution of new themes to groups on a regular basis.

6.3 The AMuSED Box

The AMuSED box has been modelled using a concept that allows the box to be used as a centrepiece for discussion or for the panels of the box to be detached to enable easy access to all the images in and around the box. This means that in a group session, people can interact with different sides of the box at the same time, something that has proven particularly useful when running chatty cafes. Each box has an internal base bordered by Lego bricks which create a channel in which to slot the different sides of the box, which are then held securely in place with a lid, also bordered by Lego bricks. The Lego bricks not only provide structure and rigidity to the box, but they also help create the essence of fun due to their colourful nature. By using this mechanism, the box can be set-up and down in under two minutes. As shown in Chapter 5, the box contents and activities described above are linked to a set of themed reminiscence images printed on the inside and outside of the box panels which are designed to stimulate discussion and encourage people to 'revisit' and share their life experiences.

6.4 Using the AMuSED Framework to create a Special Entertainment Edition

The Entertainment edition of the AMuSED toolkit was created for use in personal homes. The development process of this toolkit considered all the interventions highlighted in the AMuSED model such as art, music, aromatherapy, light, coordination, cognition and reminiscence by incorporating different elements and activities that provide this form of stimulation. However, because this toolkit was created to be used by activity coordinators with people living with

dementia in personal homes, more personal and one-to-one activities such as colouring and buzzwire game were included from the toolkit library than group activities. The toolkit substituted group activities like hoop game and quoits for more reminiscence packs and activities such as movie quizzes and Hook the Duck.

Due to the single user environment that this toolkit was designed for, it was more convenient for the caregivers to use one or two different panels and elements at an activity session rather than take the whole toolkit into each personal home, as this could also result in overstimulation for the care recipient. Therefore, reminiscence images were printed in a collage form on both sides of the toolkit panels to ensure that many images were included without overstimulating the person with dementia. Also, reminiscence images not only related to the general entertainment theme but also to life in Reading and the surrounding locations were included in order to make the theme more relatable to people at home and allow them share stories of the activities and places they visited for entertainment in and around Reading. To account for safety and usability, the Activity booklet included information on the correct way to set up the toolkit. The toolkit and its elements were also packaged in a secure transparent box with latches on each side to ensure that the elements and panels were kept secure and also to allow the caregiver to see all the elements at once before opening the box and reduce time wasted rummaging through the box to find elements for the personal activity sessions.

People living with dementia in personal homes require a range of care needs which are usually met by care staff and activity coordinators – such as Rachael (see figure 4.8) – of organisations and facilities that provide in-home care to this group of people. Based on the care assessment of clients – the requirements of the toolkit can either be done on a group basis for an individual to get the full toolkit, or on an individual basis as part of their care plan to determine which elements will be taken into the client's house by the caregiver or activity coordinator – the contents and design of a toolkit can be created. Regarding use in personal homes, the AMuSED toolkit can be designed to cater for different types of clients with varying interests. For example:

1. Margaret is a retired florist who has lived in Reading for the past 70 years. For a while, she worked in John Lewis department store when it was called Hellas and she used to love dancing and going to the cinema. She also used to love gardening but is unable to access her garden anymore due to a lack of mobility. Margaret enjoys doing wordsearches and sharing stories about her childhood.

2. Bill grew up in Reading in the 50s and used to enjoy visiting Reading Stadium to watch the greyhound racing and Speedway, he also used to love cars and engines and would visit the Woodcote Rally with his friends to explore the steam engines. Bill does not visit the Rally anymore having lost majority of his hearing but enjoys making crafts and solving jigsaw puzzles.

3. Sally is a retired teacher who lived in Newbury for over 50 years, she loves animals and used to enjoy the Royal County of Berkshire Show. Sally is also a huge fan of tennis and used to play in the 70s, she also used to travel to London to watch the Wimbledon tournaments. However, she does not play tennis anymore but still enjoys watching tennis matches. Sally also loves colouring and painting.

4. John was born in the 40s and has lived in Reading all his life, he schooled in Reading and worked at the cinema during the holidays when he was younger. John enjoys going to the funfair and used to visit events such as Carter's Steam Fair with his friends. He loves listening to music, singing and playing games.

Using Layers L1 – L5 of the AMuSED Model to assess the care environment

In creating an AMuSED toolkit for an in-home care facility, different steps related to the layers of the AMuSED model were considered to ensure that the elements incorporated into the toolkit were the right fit for their clients.

Step 1: Assess relevant interventions

- Reminiscence
- Coordination
- Gardening
- Art
- Travel
- Music

Step 2: Assess Attributes (on basis of overall care facility)

- Portability: the AMuSED toolkit or elements of it will be taken into clients' homes and should be portable enough to be moved from one location to another easily.
- Affordability: AMuSED toolkit should contain affordable elements to make it cost effective to suit the budgets of both the managers of the facility and their clients.

- Adaptability: the care facility caters to clients at different stages of dementia and will require that their AMuSED toolkit is adaptable to early, mid and late-stage dementia and can be used with clients at any of the stages.

- Accessibility: some of their clients have comorbidities – such as Margaret's lack of mobility and Bill's hearing loss – that might prevent them from taking part in some activities. Therefore, the toolkit should include various multisensory elements that will allow for every client to be stimulated regardless of their comorbidity. For example, toolkit should be able to provide other forms of stimulation such as visual, audio, olfactory etc. for their hearing-impaired clients.

- Usability: the elements in their AMuSED toolkit should be easy for the activity coordinators to use with each of the clients. Activity sheets and prompt questions should also be included to provide example activities to the coordinators.

- Personalisation: their clients have different needs and interests; therefore, the facility requires an AMuSED toolkit whose elements can fit each of the interests of the clients such as Margaret's gardening, Bill's love for racing, Sally's tennis and John's music. The elements can be Personalised using the toolkit library by adding or removing elements as needed.

Step 3: Assess constraints (on basis of overall care facility)

- Safety: this is always paramount in every location or care setting. Only elements that pose no harm to both the activity coordinator and client should be included in toolkit and harmful elements such as the "spitting" cotton candy machine mentioned in section 5.1.5 should be excluded.

- Cleanliness: this is very paramount as the items included in the toolkit will be taken from one client to another. The AMuSED toolkit should be wiped and properly sanitised between clients.

- Security: the sessions with clients are one-to-one and take place within the personal home, and therefore pose a minimal security risk.

- Damage to components: this is not a high priority due to the single user situation and one-to-one sessions.

Step 4: Assess location (Layer 2)

In-home care.

Step 5: Assess progression of dementia (Layer 3)

The mix of clients means there will be varied levels of severity of dementia; therefore, the elements in the toolkit should be able to adapt to these different stages by including elements and activities with varying levels of challenges such as puzzles, games, and wordsearch for early and mid-stage dementia and more gentle stimulation like fibre optic lights included to replicate the fibreoptic cables used in Snoezelen for late-stage dementia.

Step 6: Assess mode of interaction

Because this toolkit will be used in in-home care, the mode of interaction will be personal 1 to 1 and reminiscence sessions.

Step 7: Pick theme

The clients assessed have fond memories of different locations such as Reading, Newbury and London. They also have interests from different eras such as Bill growing up in the 50s, Sally playing tennis in the 70s, and John being born in the 40s. All the clients also enjoy enjoyed entertaining activities such as dancing, going to the cinema, Greyhound Racing, Speedway Rally, tennis and going to the funfair. Therefore, an appropriate theme for this care facility to be used with their clients is "Life through the decades – Entertainment" because it will stimulate reminiscence discussions linked to growing up in Reading and Newbury, as well as the exciting activities they enjoyed.

Use the Toolkit Library – Pick relevant objects to fit the Model

The toolkit for this location will include multisensory elements related to the interests of the clients, especially their current interest such as 1950s, 60s and 70s memorabilia packs with familiar elements from when they grew up, a combination of digital and traditional musical elements for audio stimulation like Xylophone and song cube which will especially be of interest to john, gardening elements for Margaret such as sunflower planting box due to her interest in gardening especially since she is no longer able to access her garden at home, craft making activities and jigsaw puzzles for Bill (12 and 35 piece jigsaws are included in order to offer the appropriate level of challenge to the different clients), and aqua paint and colouring sheets for Sally.

Figure 6.2: Elements of the AMuSED Life - Entertainment toolkit

Using the AMuSED Box panels – Select the appropriate reminiscence panels

The images selected for the panels of the toolkit are related to the interests of the clients assessed and include reminiscence images of places for entertainment in Reading and Newbury such as cinemas and halls. It also includes images such as Hellas where Margaret used to work, Reading Stadium where Bill used to visit as well as the greyhound racing and Reading Speedway he used to watch. In addition to images of Newbury where Sally lived, images of the Royal County of Berkshire Show are included in the panel as well as Wimbledon which she enjoyed watching. Finally, Images of the funfair and Carter's Steam Fair are included to serve as memory cues for John.

Figure 6.3: The Life-Entertainment toolkit panels

6.5 Summary

This chapter explored the AMuSED framework and model used in the creation of the toolkits described in chapter 5. It highlighted the interventions, attributes and design considerations of the development process in relation to location, mode of use, severity of dementia and theme. This chapter also showed that all the attributes of the AMuSED toolkit were carefully considered before being incorporated into the development process. The example of the Life-Entertainment edition toolkit showed how the framework brings together the different elements and the AMuSED boxes, revealing how the model and the toolkit library were used to decide which of the elements and activities to include into the toolkit. The same process was also followed for all the different themes – which including the Life-Entertainment toolkit will be evaluated in chapter 7 – and resulted in the successful development of the AMuSED toolkit as an affordable, adaptable and portable toolkit that can be used by caregivers and activity coordinators to provide engaging and stimulating multi-sensory and multi-activity sessions to people living with dementia in a range of care provisions.

Chapter 7: Intervention Research and user evaluation of AMuSED

This chapter details the approach undertaken to evaluate the AMuSED concept and its realisation as the AMuSED toolkits described in Chapter 5. It explains how the data was collected using pre-, during-, and post- session questionnaires and also explains the difficulties faced in the evaluation process due to covid and the impact that covid had on the data collection process. The chapter describes the five evaluation sites which included two care homes, a council run sheltered housing facility, a Chatty Café and a care company that provides home based care and what they thought of the AMuSED toolkits. It also includes an additional evaluation site that runs activities for adults with severe learning difficulties who asked if they could try the AMuSED toolkits. This chapter provides an overview of the evaluation sites and documents the results, findings, and conclusions of each of the studies performed at these different locations.

7.1 Evaluation approach

The evaluation of the AMuSED toolkits was undertaken by the care staff or activity coordinators at the different evaluation sites to determine their view on the AMuSED toolkits and their assessment on first seeing the AMuSED toolkit, when using it, and after using or exploring the AMuSED toolkit for a longer period of time, and of how useful the AMuSED toolkit was or would be in helping them to provide engaging and stimulating multisensory activities to people living with dementia. The primary tool for data collection was pre-, during-, and post- session evaluation questionnaires (see Appendix H – J) which contained both open and close ended questions (Dalati and Gomez, 2018). These were distributed to the evaluation sites along with the AMuSED toolkit. A further questionnaire gathered information from the managers of the evaluation sites regarding information about their care facilities and residents. All the data collected was stored appropriately in accordance with the ethics and manually analysed to identify and document the resulting themes. The questionnaires will be described in more detail in Section 7.4.

7.2 Impact of Covid-19 on evaluation process

It should be noted that this research was undertaken during the Covid-19 pandemic and resultantly there was significant disruption to the research process overall and particularly to the evaluations due to:

- Illness of care home managers, care home staff and activity coordinators due to covid causing staff shortages and a focus away from activities to basic care
- Inability for researchers to be present onsite during the evaluations due to UK wide care home restrictions preventing people other than care home staff being on site
- Lengthy lockdown periods in individual care homes due to covid outbreaks that prevented the planned AMuSED toolkit activities from running as expected, sometimes for three weeks or more
- Cancelled community engagement activities such as chatty cafes for a significant period.
- No photo of the AMuSED toolkits in use (apart from the Chatty Cafes)

This led to fewer AMuSED toolkit activity sessions taking place than initially scheduled, a less structured approach to data collection than planned, incomplete data sets as not all evaluations could take place, and a different interpretation of how the forms should be completed by the activity coordinators. Nevertheless, feedback has been obtained from all evaluation sites and analysed as much and as consistently as possible.

7.3 Evaluation sites

The evaluation sites were selected based on them:

- Having representation on, or recommendation from, the Dementia Friendly Reading Steering Group
- Having a functional activity team or care staff
- Having prior experience of organising or running activity sessions
- Being within the Reading or wider Berkshire area (Newbury)

The sites were as follows:

- Evaluation Site 1 (Chatty Café MERL)
- Evaluation Site 2 (Care home Newbury)
- Evaluation Site 3 (Sheltered housing Reading)
- Evaluation Site 4 (Care home Reading)
- Evaluation Site 5 (In-home delivered care Reading)
- Evaluation Site 6 (Charity for adults with Special Learning Needs Reading)

Originally, it was planned that the different themed AMuSED toolkits would be rotated around the care homes, however, the problems caused by covid and lockdowns necessitated a change in

the procedure such that each care facility (apart from the Chatty Café which was a special case) was given the AMuSED toolkits to evaluate and subsequently keep for continued use by their residents following the evaluation period.

Scheduled Evaluation of the AMuSED toolkits was as follows:

Table 7.1 Scheduled evaluation of the AMuSED toolkits

Site	Provision	AMuSED Theme 1	AMuSED Theme 2
Evaluation Site 1	Chatty Café MERL	Countryside	-
Evaluation Site 2	Care home Newbury	Seaside	Entertainment
Evaluation Site 3	Sheltered housing Reading	Christmas	Entertainment
Evaluation Site 4	Care home Reading	Seaside	Christmas
Evaluation Site 5	In-home care Reading	Seaside	Life-Entertainment
Evaluation Site 6	Adults with Special Needs Reading	Seaside	Christmas

7.4 Data Collection

Four types of questionnaires were provided to each evaluation site along with information sheets and consent forms. A training session on the AMuSED toolkit was given to each evaluation site prior to, or at the time of delivery of their first AMuSED toolkit. Instructions were also provided during the delivery process at each location on the use of the questionnaires and how and when they should be completed. A brief description of the different questionnaires and their purpose are as follows.

7.4.1 Manager Questionnaire

This questionnaire (see Figure 7.1 and Appendix G for a full-sized version) was prepared for the managers of the evaluation sites with its main purpose being to collect general information about the size of the evaluation site, the predominant type of dementia their residents or session attendees had and an estimation of the severity of their disease to help set the scene for the evaluation site.

AMuSED Box - Manager Questionnaire

So that we can assess the appropriateness of our AMuSED boxes for people at different stages of dementia, and different forms of dementia, please let us know the general characteristics of the residents of your care home or other location where organised activities for people with dementia take place.

Care Location:	
Your Role:	
Date:	

How many residents in your care provision take part in organised activities?

Have the residents in your care home been clinically diagnosed with dementia? (Please tick as appropriate)

Yes – all		Yes - some		No		Unsure	

In general, what forms of dementia do your residents most commonly have (Please give as a percentage)

Alzheimer's	
Vascular dementia	
Dementia with Lewy Bodies	
Other forms of dementia	
Not clearly diagnosed	

In general, what is the most prevalent stage of dementia in your residents? (Please give as a percentage)

Early (mild) stages of dementia	
Mid (moderate) stages of dementia	
Late (severe) stages of dementia	
Not easy to categorise	

Thank you for setting the scene regarding your residents.

Figure 7.1: Manager questionnaire

7.4.2 Pre- session evaluation questionnaire

The 'Pre- evaluation' questionnaire (see Figure 7.2 and Appendix H for a full-sized version) was developed to allow members of the care team or activity co-ordinators (the respondents and participants of the study) to record their first impressions of the AMuSED toolkit following the initial demonstration of the toolkit and its contents.

This demonstration revealed and described the importance of all the elements in the toolkit and showed the participants how to put the toolkit together using the reminiscence panels, and take it apart, so that they could appreciate the size and form of the AMuSED toolkit. Following the demonstration, the participants were encouraged to put the toolkit together and dismantle it themselves to encourage familiarity with it. The pre- questionnaire was divided into 4 sections to collect information about 1) activities they currently undertook; 2) their first impressions of the AMuSED Toolkit and its contents; 3) what elements they were keen to use (or to avoid!) and how

they might use the AMuSED toolkit as part of their sessions; and 4) three key words that sum-up their first impressions of the AMuSED toolkit and any immediately identified ways of how it could be improved.

Figure 7.2: Pre- session evaluation questionnaire

7.4.3 During- session evaluation questionnaire

This questionnaire (see figure 7.3 and Appendix I for the full-sized version) was intended to be completed by the activity coordinators to document which elements of the AMuSED toolkit they used in each session and whether in their opinion, the session was able to engage attendees at different stages of dementia, one of the objectives for the AMuSED toolkit. With the diversity of the elements in the AMuSED toolkit, it was useful to see (A) which of the elements were used during each session to identify the most and least used elements by the activity coordinators, and (B) to see which of those selected elements and activities engaged or disengaged their attendees the most, to influence design of future AMuSED toolkits. Further uses of this form were to see if the activity coordinators used the activity examples or prompt questions.

Due to restrictions imposed by covid, I was unable to be present to help record observations for these sessions, and this led to this questionnaire being completed in a less consistent manner than originally intended, although the comments and other feedback received from each evaluation site were extremely useful.

Figure 7.3: During- session evaluation questionnaire

7.4.4 Post-session evaluation questionnaire

This questionnaire (see Figure 7.4 and Appendix J for the full-sized version) was used to collect information about the AMuSED toolkit at the end of a period of evaluation to see if the activity coordinators had changed their views on the AMuSED toolkit having had the opportunity to use it; which elements they had used frequently, occasionally or not at all over the evaluation period; which elements and activities had been most successful and enjoyable and which elements less so; along with suggestions for other themes. The final section of the questionnaire collected activity coordinators' final thoughts on the AMuSED toolkit and how it could be improved.

Carer/Care Team Post-Evaluation Questionnaire

So that we can assess the appropriateness of our AMuSED boxes to help you run your activities for people with dementia, please let us know your impressions of the box now that you have used it for a couple of weeks. We are interested in getting as many views as possible.

Care Location:	
Your Role:	
Date:	

Section 1 – Your AMuSED Box Activities

How many days a week did you typically use AMuSED in activity sessions?	
How many activity sessions did you typically use AMuSED in a day?	
How many people with dementia were typically in each of your sessions?	
Were you aware of the type/stage of dementia that your attendees have in a particular session?	
Did you continue to run any of your 'normal' activities in addition to the AMuSED box activities?	

Section 2 – Overall Impressions of the AMuSED Box after 2 weeks

Please state how much you agree or disagree with the following statements about the AMuSED Box (tick appropriately)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The box is well made					
The box is an appropriate size					
The box is easy to open					
The box is easy to put back together again					
The construction of the box is sturdy enough					
The box when placed on a table immediately stimulates interest					
The images are of good quality					
Images on the outside of the box are of an appropriate size					
Images prompt reminiscence					
The larger images on the inside of the box are useful for further discussion					
The larger images on the inside of the box link to activities inside the box					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The question prompt cards are helpful (use is optional)					
The activity card suggestions are helpful (use is optional)					
Having themed boxes is useful					
The theme of the box is coherent					
The box contains an appropriate number of elements and activities					
Having a mix of sensory elements, reminiscence prompts and activities is a good idea					
The box and its contents will engage and stimulate people with dementia					
The box contains elements that are relevant to people at different stages of dementia					
I would be keen to try out this box (or another theme) and its contents in future activity sessions					

Section 3 – Your use of the AMuSED Box

Across the 2 weeks how often did you use the elements from the AMuSED box in your sessions. For each element below please write 'F' for frequently; 'O' for occasionally; 'N' for never

Reminiscence images		Sand box/mini spades		Postcards and pens	
Holiday/travel brochure		Candy floss maker		Photo props	
Seaside nostalgia jigsaw		Sound buttons		Beach quoits	
Seashells		Sea fragrances		Beach balls	
Sea creatures		Aqua paints		Bubble blowers	
Jellyfish lamp		Colouring/word search		Windmills	

Did you make use of the prompt questions or suggested activity sheets?

Which elements or activities did your participants engage with or enjoy the most?

Were there any elements or activities that your participants did not engage with or enjoy or which you were worried about using? Please let us know below.

Did you create your own activities with the AMuSED box other than those suggested in the activity sheet? Please share what you did below.

Based on your sessions over the 2 weeks how well did the AMuSED toolkit engage participants with:	Not at all	A little	On and off	Quite a bit	Very much	N/A
Early dementia						
Mid dementia						
Late dementia						

Section 4 – Your overall impressions of the AMuSED Box

Did the AMuSED box help you plan or run activity sessions?

What do your think are the best features about a multi-sensory/multiactivity AMuSED box?

Overall what were your favourite elements/activities within the box?

Overall, which elements or activities did the group enjoy the most?

Overall, which were your least favourite elements/activities in the AMuSED box?

Can you suggest any other elements/activities to include in the AMuSED box?

Would you be interested in trying a different themed box? ('Y' for yes; 'N' for no)							
Entertainment		Movie Night		Countryside		Life Activities	

Are there any other themes you would like to suggest?

Section 5 – Final thoughts on your impressions having used AMuSED

After 2 weeks what three words would you use to describe the AMuSED box?

Do you have any suggestions for how the AMuSED box can be improved?

Is there anything else you would like to tell us about experiences with using the AMuSED box?

Thank you for giving us your impressions of the AMuSED box – we hope you enjoyed using it and that your residents find it fun and engaging.

Figure 7.4: Post- session evaluation questionnaire

7.5 Evaluation Sites Results and Discussion

As stated in Section 7.2, evaluation of the AMuSED toolkits took place at 6 locations as shown in Table 7.2, with data being obtained on the use of the AMuSED Countryside toolkit (a special co-design with the MERL), Seaside toolkit, Christmas toolkit, and Entertainment toolkit (and a special Life-Entertainment version created for Evaluation Site 5.

Table 7.2 Evaluation of the AMuSED toolkits

Site	Provision	AMuSED Theme 1	AMuSED Theme 2
Evaluation Site 1	Chatty Café MERL	Countryside	-
Evaluation Site 2	Care home Newbury	Seaside	Entertainment
Evaluation Site 3	Sheltered housing Reading	Christmas	Entertainment
Evaluation Site 4	Care home Reading	Seaside	Christmas
Evaluation Site 5	In-home care Reading	Seaside	Entertainment
Evaluation Site 6	Adults with Special Needs Reading	Seaside	Christmas

Due to covid significantly affecting the evaluation process there were reduced numbers of sessions that could take place because of lockdowns; sessions that were cancelled due to lockdowns; and some planned sessions that could not take place within the PhD period. There were also some inconsistencies in the way in which the during-evaluation questionnaires were completed. However, the AMuSED concept and all the AMuSED toolkits were reviewed to some extent with feedback from each site being as follows. In some instances, manager feedback was via notes.

Table 7.3 Summary of responses

Site	Provision	Manager	Pre	During	Post
Evaluation Site 1	Chatty Café MERL	1	4	2	1
Evaluation Site 2	Care home Newbury	Notes	4	1	2
Evaluation Site 3	Sheltered housing Reading	Notes	1	-	-
Evaluation Site 4	Care home Reading	1	2	6	2
Evaluation Site 5	In-home care Reading	1	1	-	-
Evaluation Site 6	Adult Special Needs Reading	1	2	2	2

Due to the small size of respondents at the different evaluation locations, the data collected was manually evaluated using Microsoft Excel. Information on the manager questionnaire was used to enrich the description of the evaluation site. The quantitative questions on the pre- and post-evaluations were assigned a value of 5 (Strongly Agree); 4 (Agree); 3 (Neutral); 2 (Disagree) and 1 (Strongly Disagree) with means calculated for multiple responses from a single site and results presented using Excel to create the graphs. Numbers of respondents were too small for statistics

to be considered but any textual information on the pre- and post-evaluation sheets was used to enrich the quantitative data, as was the information on the during-evaluation sheets. In addition to presenting the quantitative data to give a complete overview of activity coordinators responses to the AMuSED toolkits, the statements about the structure, images, size, themes, elements, and additional materials in the toolkit etc. were also grouped into different categories in the data analysis process to show the relevance of each group of questions to key parameters for engagement with the AMuSED toolkit based on the criteria identified in Chapters 2-4 for an engaging and stimulating toolkit. The categories and their corresponding statements in the questionnaire are displayed in Table 7.4 The remainder of this chapter presents the results obtained from each of the evaluation sites.

Table 7.4: The different categories of the evaluation statements

Category	Statement
1 – Ease of use	The box is well made
	The box is an appropriate size
	The box is easy to open
	The box is easy to put back together again
	The construction of the box is sturdy enough
2 – Images and relevance	The box when placed on the table will immediately stimulate interest
	The images are of good quality
	Images on the outside of the box are of an appropriate size
	Images will prompt reminiscence and communication
	The larger images on the inside of the box are useful for further discussion
	The larger images on the inside of the box link to activities inside the box
3 – Additional materials	The question prompt cards are helpful
	The activity card suggestions are helpful
4 – Use of themes	Having themed boxes is useful
	The theme of the box is coherent
5 – Elements and relevance	The box contains an appropriate number of elements and activities
	Having a mix of sensory elements, reminiscence prompts and activities is a good idea
	The box and its contents will engage and stimulate people with dementia
6 – Adaptability	The box contains elements that are relevant to people at different stages of dementia

7.6 Evaluation Site 1 – The Museum of English Rural Life (MERL), Chatty Cafe

As part of the University of Reading, The MERL boasts a diverse collection of items, photos and media that explore the skills and experiences of farmers and craftspeople from past and present eras and how these skills can help shape present and future lives. The MERL runs a chatty café event on the first Tuesday of every month as an avenue for people living with dementia and their caregivers or families to socialise and interact with the museum's collections and sensory resources, while also sharing thoughts and reflections on these resources. These chatty café sessions organised with Age UK, Berkshire are informal and unstructured reminiscence and discussion sessions run by members of staff of The MERL and volunteers and are designed to make use of images and items from the museum's collection to facilitate discussion and reminiscence. As attested by the Managers Questionnaire for the MERL, attendees most commonly have Alzheimer's dementia although people with other forms of dementia also attend. It is often hard to know at what stage in the disease people attending the café are.

The AMuSED Countryside toolkit, which was co-created with The MERL as described in Chapter 4, was used at The MERL over the course of three months from October 2021 to January 2022. Evaluations were undertaken during the monthly Chatty Café sessions and an Alzheimer's Dementia Support session. Due to the COVID-19 pandemic, only three Chatty Café sessions were organised, as the December session had to be cancelled due to the Omicron variant of the virus.

7.6.1 Results of Evaluation Site 1 – MERL

The mean scores based on 5 (Strongly Agree); 4 (Agree); 3 (Neutral); 2 (Disagree) and 1 (Strongly Disagree) from the completed pre- and post- use questionnaires were input into Excel and are displayed below to show the results in figure 7.5. The X-axis scale 0 – 5 represent no data (0), Strongly Disagree (1), Disagree (2), Neutral (3), Agree (4), and Strongly Agree (5).

MERL - Pre-Use

The box is well made
The box is an appropriate size
The box is easy to open
The box is easy to put back together again
The construction of the box is sturdy enough
The box when placed on a table immediately stimulates interest
The images are of good quality
Images on the outside of the box are of an appropriate size
Images will prompt reminiscence and communication
The larger images on the inside of the box are useful for further discussion
The larger images on the inside of the box link to activities inside the box
The question prompt cards are helpful (use is optional)
The activity card suggestions are helpful (use is optional)
Having themed boxes is useful
The theme of the box is coherent
The box contains an appropriate number of elements and activities
Having a mix of sensory elements, reminiscence prompts and activities is a good idea
The box and its contents will engage and stimulate people with dementia
The box contains elements that are relevant to people at different stages of dementia
I am keen to try out the box and its contents in my activity sessions

■ MERL Staff ■ Volunteer ■ Volunteer ■ Learning and Engagement Manager

Figure 7.5: Evaluation site 1 – pre-evaluation results

MERL Post- Use

The box is well made
The box is an appropriate size
The box is easy to open
The box is easy to put back together again
The construction of the box is sturdy enough
The box when placed on a table immediately stimulates interest
The images are of good quality
Images on the outside of the box are of an appropriate size
Images prompt reminiscence
The larger images on the inside of the box are useful for further discussion
The larger images on the inside of the box link to activities inside the box
The question prompt cards are helpful (use is optional)
The activity card suggestions are helpful (use is optional)
Having themed boxes is useful
The theme of the box is coherent
The box contains an appropriate number of elements and activities
Having a mix of sensory elements, reminiscence prompts and activities is a...
The box and its contents will engage and stimulate people with dementia
The box contains elements that are relevant to people at different stages of...
I would be keen to try out this box (or another theme) and its contents in...

Figure 7.6: Evaluation site 1 –post- evaluation results

7.6.2 Discussion of Results from Evaluation Site 1 – MERL

The responses to the different questionnaires and the overall results of the evaluation of the Countryside edition toolkit at The MERL are discussed in this section.

7.6.2.1 Pre session

The first impression of the Countryside edition of the AMuSED toolkit was evaluated by four participants at a MERL chatty café session via the use of the pre- evaluation questionnaire after a demonstration of the toolkit was given to the group. All questionnaires were completed anonymously with no identifier requested other than the role of the participants. This group of participants included the MERL Learning and Engagement Manager, a member of MERL staff and two volunteers.

As part of this pre-evaluation session, it was identified that chatty cafés are usually organised "*Once or twice a month*" with five or six attendees per café session. The MERL staff are only sometimes aware of the type and stage of dementia of the attendees in a particular café session, and the activities currently run at the sessions include the use of selected MERL objects to stimulate conversation, photos from the archives, mind mapping and story sharing.

Figure 7.5 shows the averaged responses of MERL staff, volunteers, and learning and engagement manager's first impressions of the Countryside AMuSED toolkit. As shown, most respondents "*Strongly Agreed*" that the AMuSED toolkit is easy to use and that they believe that the toolkit is well made, of an appropriate size, easy to open, and well-constructed. This is especially relevant given that two of the attributes in the AMuSED model are portability and usability, with a focus on the absence of complexity in the design of multisensory interventions.

Apart from one "*Neutral*" selection, respondents "*Strongly Agreed*" or "*Agreed*" that the images on the toolkit were of high quality and would prompt reminiscence in people living with dementia. Although the use of additional materials in the AMuSED toolkit such as activity and prompt cards was optional, most respondents agreed that they would be helpful. Most respondents also "*Strongly Agreed*" to statements about the usefulness and coherence of the Countryside theme. This is seen as positive because the implementation of themes in the AMuSED toolkit was suggested by several dementia experts from the Steering Group after evaluating the early prototypes and explaining that the use of themes was beneficial in the implementation of activities for people living with dementia.

Following a demonstration of the Countryside AMuSED toolkit elements and how they could be used for activities, two of the four respondents either *"Strongly Agreed"* or *"Agreed"* that the elements in the toolkit would provide stimulation to people living with dementia, with only one person giving a *"Neutral"* response. Respondents also agreed that the elements contained in the toolkit would be relevant to people at different stages of dementia which was pleasing given that the adaptability attribute was outlined as a key criteria to include in the PhD outcome. With regard to being willing to try out the toolkit and its contents in their chatty café activity sessions, three of the respondents selected *"Strongly* Agree" while one again selected *"Neutral"* as an answer.

Three of the four respondents were particularly looking forward to using the smell capsules, sound buttons, mystery boxes, toys and games, with one of the respondents mentioning that she had never used smell capsules and audio tools in dementia sessions before, and another referring to the smell capsules as *"a really clever use of senses"*. None of the respondents had concerns about the contents of the AMuSED toolkit and when asked how they would use the toolkit in their dementia sessions, one suggestion was that that they would let the attendees *"self-explore"* the toolkit as part of a themed session.

Their final thoughts about the first impressions of the toolkit were positive with respondents using words such as *"engaging", "intriguing", "inviting", "colourful", "interesting", "visual"* and *"multipurpose"* when asked to write down three keywords to describe the AMuSED toolkit. One of the respondents also gave a suggestion for how the first impression could be improved by suggesting using few photos on some of the sides of the AMuSED toolkit so as not to be overwhelming.

7.6.2.2 During session evaluation

The COVID-19 pandemic affected attendance at the chatty cafés because people living with dementia were a vulnerable group and their exposure to the outdoors was very limited. Therefore, during this period, most of the chatty café sessions organised at The MERL were only attended by members of staff of The MERL and volunteer activity coordinators rather than people living with dementia. However, as the chatty cafes are drop-in sessions, the activities still needed to be prepared. In preparation for the sessions, the AMuSED toolkit was deconstructed and divided into different parts, with its sides and elements combined with exhibits from The MERL to fit the themes normally used at their chatty cafés. These themes included food, mystery objects, childhood, dressing up and going out, journeys and transport, waking lives, landmarks of life, and makers at

work. All the elements to be included in the sessions were divided into separate trays to display the different themes and were combined with the prompt sheets developed by The MERL (figure 7.6 and Appendix K).

Figure 7.7: The deconstructed AMuSED toolkit and the different MERL themes

The first session where the AMuSED toolkit was displayed was attended by four participants (Male = 2, Female = 2). The sessions were organised to be very casual, so attendees could either choose to be indoors in the learning studio, in the café or outdoors if they wanted some fresh air. In this session, two attendees chose to stay outdoors while two remained indoors in the studio. The outdoor group consisted of a married couple where the husband had dementia and his wife was his primary caregiver. A tray was introduced to them by a volunteer, but the couple refused to engage, stating that they were just there to meet with other caregivers. Although none of the elements or trays were used by the indoor group, they had various discussions surrounding living in Reading, primary and secondary schools, building landmarks, and the water system. However, a woman in this group who was curious about AMuSED asked questions about the toolkit and admired one of its pictures.

The second chatty café session was organised by four (4) activity coordinators and attended by three participants (Male = 2, Female = 1). The couple in the first café session returned for this session and chose to stay outdoors as they did the last time. However, this time, they communicated with the activity coordinators and engaged with the Landmarks of Life theme. At the end of this session, one of the activity coordinators evaluated the use of the AMuSED toolkit during the session. She recorded that only one attendee (the woman in the couple) engaged with the toolkit, and this attendee was happy before, during and after the session. The reminiscence images used were combined with the prompt sheet as the activity coordinator asked questions

about family and life events. The coordinator also reported that the attendee enjoyed the photos and the elements. When asked for general comments or suggestions about the session, the coordinator suggested that "*It might be good to have a good way of bringing up each topic in a natural way, otherwise, it feels forced.*" The remaining attendee (male) chose to stay in the learning studio with the other activity coordinators where exhibits included streets of Reading, books, and schools.

The third Chatty Café session was attended by one male attendee whose wife had dementia and was attending another programme at The MERL. This session was organised by two volunteer activity coordinators who arranged the trays in the regular fashion on the tables in the learning studio. The attendee for this session explored two different themes, starting with the Landmarks of Life theme, and progressing to the Food theme. Although he only engaged with the images provided by The Merl for both themes, he spoke extensively about his life, meeting his wife, and growing up in Reading. He fondly reminisced about going to the cinema with his friends for Saturday morning pictures. He discussed being the primary caregiver of his wife and sometimes getting help from his daughters. Although this attendee shared many stories, he mentioned also losing some of his memories and forgetting things, although not being formally diagnosed with dementia.

Toward the end of the session, his wife joined the chatty café. She engaged with one of the sides of the AMuSED toolkit and asked questions about an image of people engaging in a dance. This question led to a discussion of the Morris dancing at Newtown and the couple were shown the Morris Dancing bells included in the toolkit. One of the feedback comments provided by the attendee to the MERL staff was the need for structure in the sessions to direct the conversation so that specific topics could be focused on.

The final evaluation performed at The MERL was at a charity group session. This group offers different services designed to help people in the community who are directly or indirectly affected by dementia. This charity offers a respite service to people living with dementia as a way of providing fun and stimulation to people with early-stage dementia who are still active and able to move about. The service is also aimed at offering a break to the caregivers of the attendees. The eligibility criteria of the respite service included having a formal early-stage dementia diagnosis, being mobile and being able to manage own personal care.

This session, held at The MERL, was attended by six participants (Male = 3, Female = 3) formally diagnosed with early-stage dementia and four (Male = 2, Female = 2) coordinators from the support group as well as the Learning and Engagement manager at The MERL. The activities on the day were

divided into three sessions. AMuSED was incorporated into the first session and rather than the regular themes used at the chatty café sessions, the theme used for this session was Seasons. Papers displaying all four seasons (Spring, Summer, Autumn, and Winter) were placed on the tables and the AMuSED elements were divided into groups. The goal of the session was for the attendees to match each element – photos, smells, dancing bells, plush birds, hops, wool, map etc. – to their corresponding seasons.

The group was asked to try to guess the smells before looking at the label on the capsule and spent a lot of time communicating amongst each other and sharing clues amongst themselves. People seemed to find the smell capsules "*quite odd*" and could not successfully guess most of the smells. However, they enjoyed the "What's in the box*?*" sessions and became animated while trying to fit them into the right seasons (Figure 7.7).

Figure 7.8: The session attendees sorting the elements into their appropriate seasons

Figure 7.9: The elements successfully sorted into the different seasons

The sorting activity led to more discussion about the seasons and the attendees were asked to say their favourite seasons and give reasons for choosing that season as their favourite. Different attendees shared stories about their favourite seasons from collecting and roasting chestnuts in the winter to picking fruits from the farm in the summer and "*wearing less clothes*". An attendee mentioned loving the spring because of "*the bluebells in the woods and the smell of freshness in the air"* and someone else mentioned "*bright green colours and new life"* as a reason for choosing the spring as their favourite season. The inclusion of the hops in the AMuSED toolkit led to a discussion about harvesting crops such as strawberries which they also linked to the 'Summertime Strawberry' smell capsule. Those who chose Autumn as their favourite season spoke about haystacks which led to a discussion about different haystack warnings such as avoiding walking on haystacks due to the possible dangers. Most of the attendees had countryside backgrounds which resulted in a lot of farming and countryside discussions. After this activity session, the next session involved making clay tiles to showcase elements of the winter season using shapes such as animals like reindeer, Christmas trees and foraged items like twigs, pinecones, and cinnamon sticks.

This AMuSED session was evaluated by the charity's Service Coordinator, and she recorded the general mood of the participants as happy before, during and after the session. In this session, reminiscence images, sheep's fleece, dancing bells, plush birds, "What's in the box?", sound buttons, map, hops, and smell capsules were used from the AMuSED toolkit and were used in conjunction with the prompt sheets. When asked what elements the attendees enjoyed most, the respondent referred to the pictures, the "What's in the box?" activity, and scents, adding that they

served as "*good intro*" to the sessions. The respondent also answered with "*none*" when asked whether there were any elements the attendees did not engage with or enjoy. Also, when asked about how well the AMuSED toolkit engaged people with different stages of dementia during the session, she selected "*Very much*" on the evaluation scale for early and mid-dementia and N/A for late dementia as there were no attendees with this stage of dementia at the session. Finally, in the general comments section of the questionnaire, the respondent wrote "*some (the attendees) showed interest in seeing the museum but (there was) insufficient time. Will be worth focusing on this on a later visit.*"

7.6.2.3 Post session evaluation

This evaluation was completed by the learning and engagement manager after the three-month period within which the AMuSED toolkit was used at The MERL. The respondent (learning and engagement manager) reported that they had typically used AMuSED in their activity sessions twice a week in addition to their normal activities. She "Strongly Agreed" with most statements in the 'Overall Impression' part of the questionnaire as shown in figure 7.6, with one category dropping to 'Agreed' due to the fact that *"sometimes the Lego bits come off."* This comment was unsurprising as the AMuSED Countryside toolkit was the first to be completed and compiled for evaluation. The Legos on the subsequent toolkits (Seaside, Christmas, and Entertainment) were glued using better super glue and with a honed technique. The respondent reported that the reminiscence boxes and sound buttons had been used frequently in the sessions but that the aqua paints were never used.

The respondent also reported that the prompt questions were used during the chatty café and that the attendees engaged most with the photos, audio album, "What's in the box?" and tweeting birds. She explained how AMuSED was used in their sessions by sharing that the activity team supplemented AMuSED with themed photo packs containing laminated photos and prompt questions to allow them to delve deeper into collections. She also selected "*Quite a bit*" for early and mid-stage dementia when asked how well the toolkit engaged participants. However, she selected "N/A" for late dementia due to the absence of attendees with this stage of dementia at the chatty cafés. The respondent agreed that the AMuSED toolkit helped to plan activity sessions and commented that:

"*It gives a flexibility and opportunity for personalised discussions.*"

When asked what she liked most about the toolkit it was that the components were affordable, and that sound could be easily incorporated into the elements.

"Affordable; easily accessible sound"

She also pointed out that overall, the elements the groups enjoyed most were the "What's in the box?", and the 'smells', going further to highlight that although the smells provided a response within the groups, they were not necessarily enjoyable scents making them both the most and least favourable items in the toolkit.

"Provided a response, many observed they did not smell quite like the scent that they should be."

She demonstrated an interest in trying the Entertainment toolkit and suggested that both a Town and Country theme, and a Green Health and Wellbeing theme would be useful additions to the AMuSED range. She described the AMuSED toolkit as "*exciting", "stimulating"* and *"engaging",* and suggested the addition of MERL films as a way the toolkit could be improved. When asked if there was anything she would like to say about her experience using the toolkit, she replied "*Thank you so much for developing such a useful resource."*

While providing some extra feedback on the AMuSED toolkit, the learning and engagement manager described the toolkit as:

"Encompassing many of the elements of reminiscence therapy which we have practiced in museums over a number of years in one incredibly useful source."

She also described the toolkit as allowing for a tailored approach as the use of different elements allowed the team to offer more opportunities that could be tailored to different themes and enable them work closely with care providers to be more responsive to individuals' stages of dementia.

Pointing out the digital inclusion in the toolkit, she said:

"What is really positive about the AMuSED box is that it contains affordable digital elements (such as the 'What's in the Box, the audio photo frame and audio buttons, the tweeting birds) which are

well judged, enhancing but not detracting from the collection elements. These have been very well received by audiences and can be used in a much more undirected way."

She identified the AMuSED toolkit as an opportunity for self-led or volunteer-led services through the following statement:

"For The MERL our reminiscence practice has been heavily staff led as it has involved accessing collections. More recently we have been piloting different models of working e.g. The Chatty Café, which is an informal drop in opportunity. The AMuSED box is fundamental to this offering allowing an engagement with the contents whilst having refreshments, and in a more self-directed, unsupervised manner (something that could not happen if real collections were involved). It has enabled a flexibility of our service"

She identified the portability of the toolkit as its key strength and mentioned that this attribute enabled the team to take the toolkit to different sites and places easily. She also reported that the use of the AMuSED toolkit has enhanced the facilitated reminiscence experiences at The MERL because:

"In addition to allowing for more self-directed engagement opportunities, the toolkit contents and the research which has underpinned its development has enhanced our facilitated workshops – for example recent visits from Alzheimer's Dementia Support: Maidenhead and Windsor and the training of the hospital Care Crew team. It has presented a step change in the variety of multisensory opportunities which we are using as part of these sessions."

The findings from the evaluation undertaken at The MERL show that people living with dementia and their caregivers find the AMuSED toolkit suitable for early and mid-stage dementia. They agree that the toolkit is well made, sturdy, easy to open, and easy to take apart. The images on the toolkit have been proven to prompt reminiscence and encourage communication among people living with dementia and their caregivers, and the elements have been shown to stimulate and engage this group of people as well as provide numerous talking points. The use of prompt questions has also been shown to steer the conversation, and attributes such as affordability, usability and portability were identified in the results of the study, both from the respondents' agreements to the ease of use of the toolkit and the manager's feedback about its affordability and ease of mobility aided by the portability of the toolkit.

Furthermore, the effect of the AMuSED toolkit on the mood of the session attendees was positive, as the general mood during and after the sessions was recorded as happy. The feedback provided showed that both the digital and traditional elements were enjoyed by the attendees and the combination of both types of elements created engaging and interesting sessions for the attendees. However, a reoccurring comment in the feedback was that the smell capsules, while engaging, were not pleasant and did not smell like what was suggested on the label. In stating opportunities for the future, the learning and engagement manager reported that the AMuSED toolkit would continue to be used as part of The MERL's programme for people living with dementia and highlighted further opportunities for the use of more digital elements such as the incorporation of film into the toolkit. She also recommended the use of drawstring bags or smaller trays into which the contents of the toolkit could be divided.

7.7 Evaluation Site 2 – Care home in Newbury

Evaluation Site 2 is a mixed nursing and residential care facility that provides specialist support for people living with dementia. It also provides a nursing floor for people with different comorbidities, and a dementia floor. Sensory activities are carried out throughout the facility by dedicated activity coordinators who plan their activities a month in advance. Due to the COVID-19 pandemic restrictions, evaluations were done by proxy as only the staff of the care home were allowed to organise activities or engage with the residents.

This site evaluated the Seaside AMuSED toolkit and the Entertainment AMuSED toolkit. The number of planned sessions was reduced to just one for the Seaside toolkit due to covid and Christmas; and Entertainment toolkit activities were planned for March onwards so only the pre-evaluation questionnaire could be completed for this toolkit within the PhD evaluation period. The team were however given a comprehensive training and demonstration session on delivery of the Seaside toolkit and were well versed with the AMuSED concept and contents of both AMuSED toolkits before completing their feedback sheets.

7.7.1 Results of Evaluation Site 2 – Seaside Toolkit - Care home Newbury

The mean scores based on (5 (Strongly Agree); 4 (Agree); 3 (Neutral); 2 (Disagree) and 1 (Strongly Disagree)) from the completed pre- and post- use questionnaires we input into Excel and are displayed below to show. The evaluation questionnaires were completed by the Wellbeing and

Activity Team Lead, and an Activities Assistant, but other members of the team also contributed to the evaluation process.
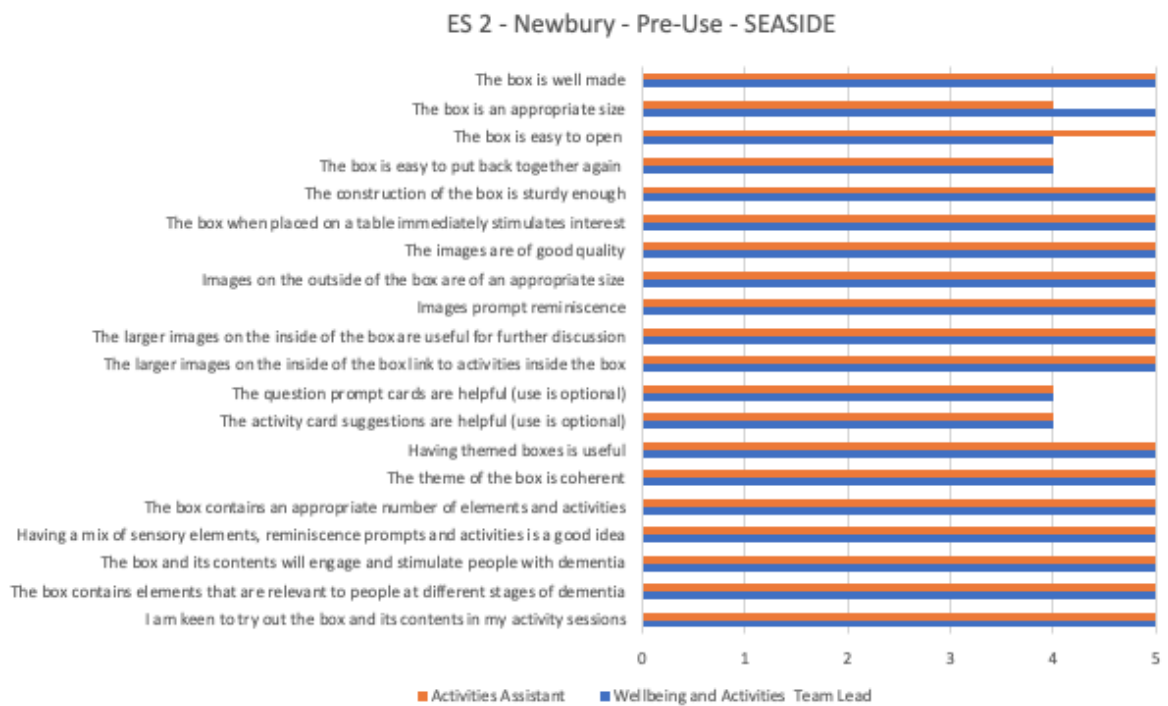
Figure 7.10: Evaluation site 2 – Seaside toolkit pre- evaluation
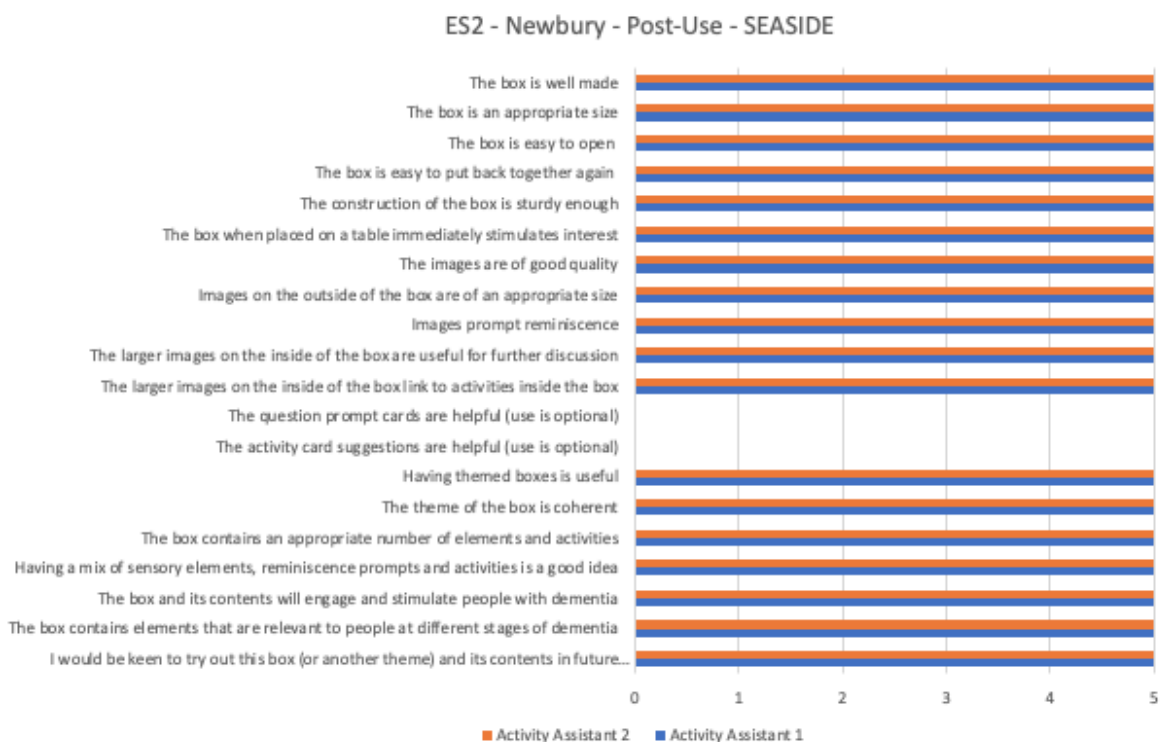
Figure 7.11: Evaluation site 2 – Seaside toolkit post- evaluation

7.7.1.1 Pre-session Evaluation of Seaside Toolkit

First impressions of the Seaside AMuSED toolkit were provided by the Wellbeing and Activity Team Lead and an Activities Assistant. From data supplied about their current activities, the care home offers an active programme of events across 5-7 days of the week. They normally run four sessions in a day typically with three people with dementia in each session and they were usually aware of type of dementia their attendees had.

The respondents offered an insight into the activities usually run at the care home which include chair-based exercises, arts and crafts, board games, reminiscence, cooking, poetry and book club, singing, aromatherapy, sensory sessions, collective worship, baking, games and one-to-one sessions. It was important to note the kinds of activities that were already being run at the care home to assess whether AMuSED could provide new elements and activities outside of what was already being used.

As shown on the graph in Figure 7.10, the respondents either "*Strongly Agreed*" or "*Agreed*" that the AMuSED toolkit was well made, easy to open, and sturdy. Both respondents also "*Strongly Agreed*" that the reminiscence images on the toolkit were of good quality, size, and could prompt reminiscence, communication and discussion among people living with dementia. They also both "*Agreed*" that the prompt cards and activity card suggestions would be helpful. In the category of statements involving the use of themes in the toolkit, both respondents "Strongly Agreed" that the Seaside theme was coherent and useful. This was a positive response as the Seaside theme was created following feedback provided by one of the dementia experts about the successful implementation of a Beach theme at their care home. The respondents also both "Strongly Agreed" to all the statements about the usefulness and relevance of the elements, as well as to asserting that they believed the toolkit contained elements relevant to people at different stages of dementia.

When asked about whether they already used the same or similar items to those in the AMuSED toolkit, they reported their use of sensory smells, Active Minds puzzles, beach balls, colouring, crossword puzzles, aqua paints, and sand. In terms of what they were looking forward to using most they highlighted the fishing game, quoits, message in a bottle, sound buttons, jellyfish lamp, kinetic sand, and the treasure box. They also had no concerns about any of the items included in the AMuSED toolkit. In response to how they would use the AMuSED toolkit with their care home residents, both respondents stated that it would be used to run an afternoon session. The

respondents gave their final thoughts on their first impression of the toolkit by describing it as *"meaningful", "stimulating", "interactive", "fun" and "colourful".* In the space provided for suggestions on how the toolkit could be improved, Respondent 2 suggested that the two-week evaluation period planned might not be enough to use all the elements in the toolkit (which was indeed found to be correct and was rectified but with longer time spans being affected by COVID).

7.7.1.2 During session evaluation – Seaside toolkit

The Seaside themed AMuSED toolkit was evaluated after a morning session which lasted two hours with four male and two female attendees and two activity coordinators. The AMuSED toolkit influenced the mood of the attendees during this session, with the activity coordinators recording a neutral face as the general mood of the participants before the session but showing that the mood improved to a happy face during and after the session.

The elements used in this session were the reminiscence images, seashells, sea creatures, sand box, sound buttons, sea fragrances, aqua paints, photo props, beach balls, bubble blowers and windmills. Prompt questions and the suggested activity sheets were not required for the session, probably because the session was being run by experienced coordinators. When asked which of the elements the attendees engaged with the most, the respondent replied that the windmills, bubbles, sand box, reminiscence and fishing games were the most enjoyed during the session. In response to whether there were any elements or activities the participants did not engage with or enjoy, the respondent replied that not all the toolkit was used as there was not enough time. It was also stated that the attendees were:

> *"Not so keen on the smells, (as the smells) didn't smell of what it was."*

To help ascertain the relevance of the AMuSED toolkit to people living with dementia, the questionnaire asked how well the toolkit engaged attendees with early, mid, and late dementia during the session, to which the respondent selected *"Very much"* for early dementia and mid dementia, leaving severe dementia blank.

7.7.1.3 Post session evaluation - Seaside

The post-evaluation questionnaires were completed by the two activity assistants (see Figure 7.11) after the AMuSED toolkit had been used in a session. They acknowledged that AMuSED was used

in one session and that for the trial, they had continued to run their normal activities in addition to the AMuSED toolkit with one respondent stating that they:

"Only had time to do one session as it was near Christmas, and we were pretty busy."

Both respondents *"Strongly Agreed"* to all the statements about their overall impressions of the toolkit, apart from recording that activity and prompt sheets had not been used during the session. These highly positive responses showed that the activity coordinators believed that the AMuSED toolkit was well made and easy to use, contained good quality images that prompted reminiscence and were useful for discussion, had a useful and coherent theme, contained appropriate elements that stimulated people with dementia, and was relevant to people at different stages of dementia. This was highly pleasing feedback given their experience of running activities within this care home.

When asked which of the elements or activities attendees engaged with or enjoyed the most, windmills, bubbles, photo props, sound buttons, sea creatures and *"Physical interactive elements"* were specifically highlighted. There were no elements or activities the attendees did not enjoy or engage with, but the jellyfish lamp leaked during the session and hence its use was curtailed during the session. Both respondents also replied that they included *"singing"* as additional activities not provided by the toolkit.

To determine the level of adaptability of the AMuSED toolkit, respondents were asked how well it engaged attendees with early dementia, mid dementia and late dementia, to which they replied, *"Very much"* for both early dementia and mid dementia, while one of the respondents replied with *"On and off"* for late dementia and the other selected *"N/A"*. They also replied in the affirmative when asked if the AMuSED toolkit helped to plan their activities. Furthermore, in response to what they believed were the best features about a multisensory/multiactivity box, one of the respondents replied:

"Everyone can be involved, as if someone isn't able to physically participate, they can still be involved through reminiscence and scents/sands."

This feedback supports the aim of the AMuSED toolkit to be adaptable to different stages of dementia so that someone with dementia can not only interact with the elements and activities in the toolkit during the early stages of the disease, but also benefit from gentle stimulation – in the

case of the Seaside themed toolkit, sounds, images, smells, seashells and sand – as the disease progresses. This feedback also highlights the accessibility of the AMuSED toolkit as people who cannot participate in some activities or benefit from some forms of stimulation because of disabilities, impairments or other comorbidities can still benefit from the other forms of stimulation the toolkit has to offer.

Both respondents selected the kinetic sand as their favourite element within the toolkit with one of them calling it "*Amazing*". "*Physical elements*" such as the bubbles and windmills, in addition to the sand were the elements most enjoyed by the attendees. They both suggested the inclusion of singing and themed CDs to the AMuSED toolkit and expressed their interest in trying out the Entertainment and Countryside themed AMuSED toolkits. They also suggested other themes such as "*Fashion, Childhood, Festivals and Weddings*".

Their final thoughts on the AMuSED toolkit were to describe it as "*Reminiscing*", "*visual enjoyment*", "*engagement*", "*engaging*", "*fun*" and "*interactive*", and when asked for comments about their experiences with the AMuSED toolkit, one of the respondents replied with:

<blockquote>"It was very good and catered for everyone"</blockquote>

While the other similarly commented:

<blockquote>"It was very fun and there was something for everyone!"</blockquote>

This feedback on the AMuSED toolkit showed that the activity coordinators found it engaging, fun and interactive in relation to its use with people living with dementia. It was also clear from their responses that they felt the toolkit to be usable, adaptable, and accessible as they believed it could provide different forms of stimulation to every attendee at the session.

7.7.1.4 Manager feedback

Further feedback was provided by the Wellbeing and Activity Team Lead about the AMuSED Seaside Edition toolkit in an email received after the evaluation. He described the AMuSED toolkit as a well thought out, well designed and engineered resource with contents fitting for the care environment. He went on to highlight the novelty of the toolkit by stating that it provided a unique activity that enabled the residents' physical, sensory, emotional, intellectual, and social needs to be met. He stated that:

"The box can stimulate the individual to be active, to reminisce, to socialise, to problem solve, to relax and to connect with others. The contents that are offered means that there are activities that can be inclusive of everybody whilst still allowing the activity to be person centred."

He also pointed out that the AMuSED toolkit could be used by each member of staff and not just the trained activities team.

In describing the toolkit, he commented that it was:

"Easy to move around to different floors/units and the duration that it is used for can be varied to meet the needs of the individual."

He gave an example of using the toolkit in a group session where people with mixed abilities could look at different aspects and activities at the same time while reminiscing about the pictures on the toolkit as a whole group activity. He did however report that the toolkit and the elements could be *"a little fiddley when packing away"* but stated that it was worth it for the functionality of the removable sides of the toolkit.

This feedback from the Activity Team Lead highlighted some of the key attributes that AMuSED was aiming to encompass, including it being appropriate for use in a care environment, novel, and stimulating; being relevant to reminiscence; promoting communication and socialisation within a group of people living with dementia; as well as being adaptive and inclusive. Portability was also mentioned and the ease with which it can be transported between locations. Finally, he appreciated the design of the toolkit which facilitates the removable panels and recognised how easy to use the AMuSED toolkit was by staff with and without formal training.

7.7.1.5 Pre-session Evaluation of Entertainment AMuSED Toolkit

Having highly enjoyed the Seaside AMuSED toolkit, which has been left at the care home for further use by the activity coordinators with their residents, the activity coordinators were keen to evaluate a second AMuSED toolkit – the Entertainment Edition. In recognition of being able to personalise AMuSED toolkits, the version included an additional box panel with images specific to Newbury and its historical events on it. Due to covid and the resultant lockdown of the care home delaying delivery of this toolkit, only the pre-session evaluation could take place within the timescale of the PhD. This was undertaken by two activity coordinators with the results given in Figure 7.12.

ES 2 - Newbury - Pre-Use - SEASIDE

Legend: ■ Activities Assistant   ■ Wellbeing and Activities Team Lead
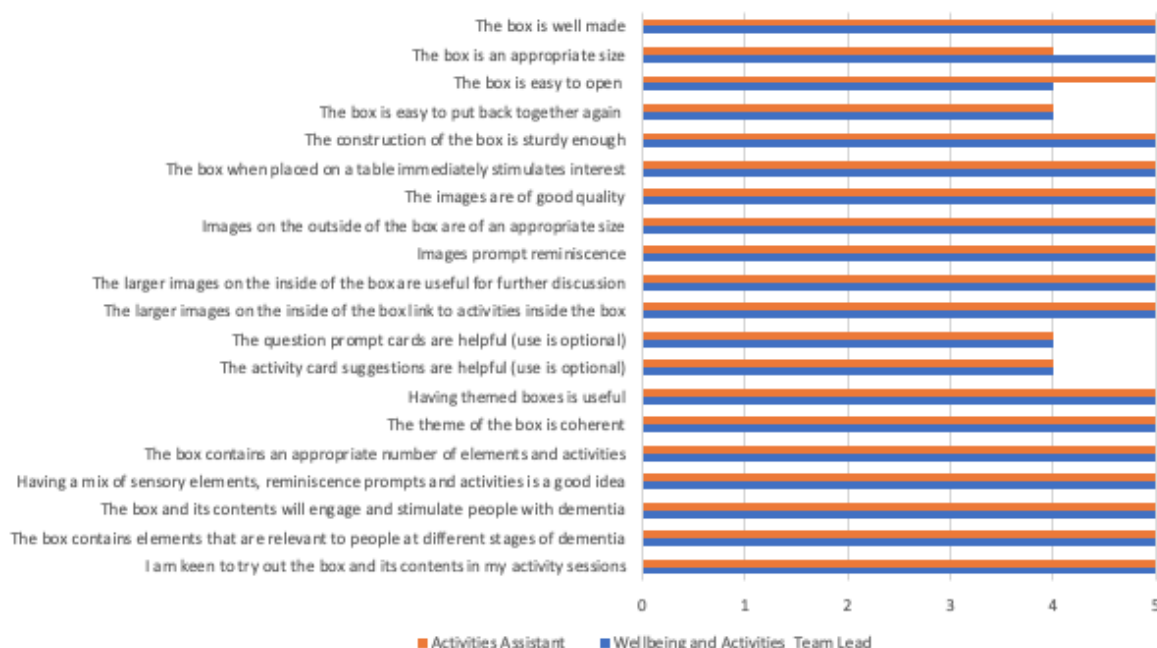
ES 2 - Newbury - Pre-Use - ENTERTAINMENT

Legend: ■ Activity Coordinator 2   ■ Activity Coordinator 1
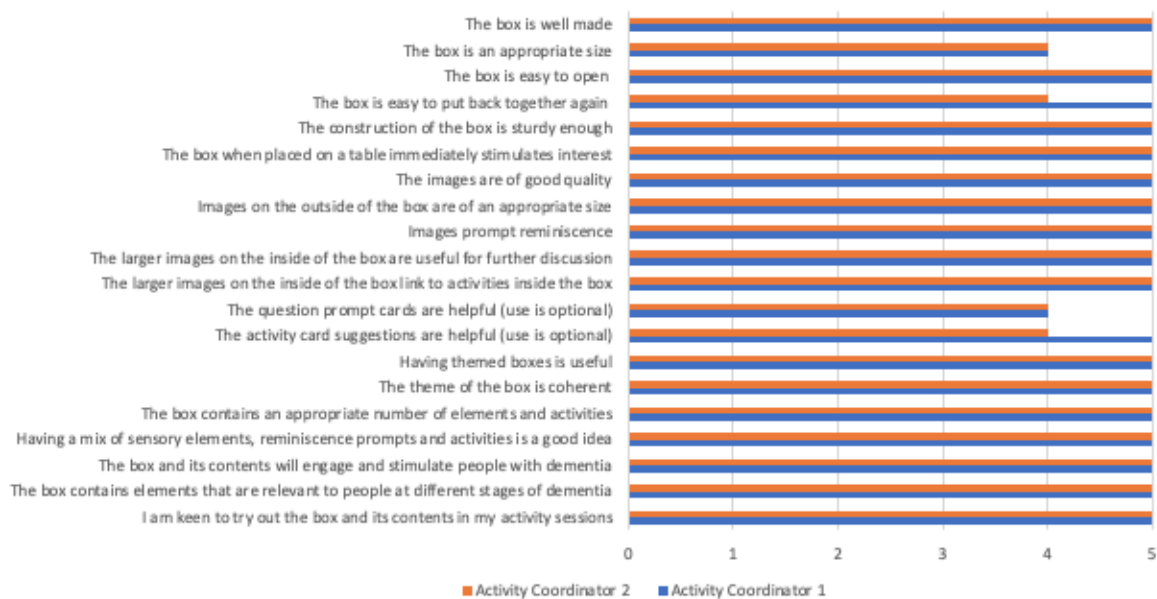
Figure 7.12: Evaluation site 2 – Seaside and Entertainment toolkits pre- evaluation

The data in Figure 7.12 shows that, as for the Seaside AMuSED toolkit (top graph), first impressions of the Entertainment toolkit (bottom graph) were highly positive, with all statements about the toolkit and its contents scored as "*Strongly Agree*" or "*Agree*". Once again, the need for the question prompts and example activities were not seen as being of the utmost importance and there was just minor discrepancy between the size of the toolkit and how easy it was to open and

close it. It would be interesting to explore further with this team and the other evaluation sites whether the AMuSED toolkit is the ideal size at 36cm square for the panels.

When asked what elements they were particularly looking forward to using from the Entertainment toolkit, they reported their plans to organise a "*a day at the movies*" session where they would use the popcorn machine and movie props. They also planned to use the CD in a singsong, an item that was included in the Entertainment toolkit in response to their AMuSED Seaside toolkit comments. The seed boxes were also going to be used to plant flowers, and the buzz wire game used during one-to-one sessions. Use of the AMuSED toolkit was seen as a long-term resource with plans to organise a game of 'hook the duck' in a paddling pool with their residents in the Summer. The goldfish game was less popular with one of the coordinators, and whilst bingo was seen as a good activity, they already did this frequently within their programme. They also planned to use the "large amount of sensory activities" provided.

Other comments made about the AMuSED Entertainment toolkit at this site were:

"I'm incredibly impressed by the large amount of sensory options available e.g., taste, smell, touch. This is incredibly important to us and our nursing floor residents."

"We are over the moon with this edition of the AMuSED box! It ticks all our boxes and contains a large array of imaginative sensory activities."

"We are very pleased with the AMuSED box and have already planned multiple activity sessions using the items provided."

"This edition of the AMuSED box is incredibly imaginative. I think that this one ticks all the boxes and is incredibly inclusive for all our residents needs while still remaining fun and engaging."

"I can imagine the Newbury panel to be very useful, a lot of our residents have lived in Newbury all their lives and like to reminisce."

The AMuSED Entertainment toolkit was described as "*engaging", "entertaining", "imaginative", "fun", "sensory"* and *"fantastic".*

In conclusion, the first impressions of the AMuSED Entertainment toolkit were extremely positive with both activity coordinators showing great excitement about using the toolkit with their residents. They were particularly excited about the number and availability of sensory elements, including the popcorn machine, bringing gustatory stimulation which is often excluded from multisensory interventions (Pinto et al., 2020; Baker et al., 2001) into the sessions. They also agreed that the toolkit was usable and adaptable to various stages of dementia and that the combination of a multisensory and multiactivity toolkit was a good idea.

7.8 Evaluation Site 3 – Sheltered Housing Facility in Reading

This location is an extra care sheltered housing scheme comprising of forty (40) one- and two-bedroom flats. It offers the benefits of an onsite care team, a 24-hour emergency monitoring centre and communal areas where activities are held. The facility hosts people with and without dementia and provides independent living as well as activity sessions to promote socialisation among residents.

7.8.1 Results of Evaluation Site 3 – Entertainment Toolkit - Sheltered Housing Reading

Due to the COVID-19 pandemic, the Christmas themed AMuSED toolkit delivered to this location could not be evaluated as the facility was placed on a month-long lockdown following an outbreak. However, a virtual demonstration of the AMuSED Entertainment toolkit was presented to the activity coordinator of the care home including a demonstration of the unboxing of the toolkit elements and a discussion how all these elements were relevant to reminiscence in, and engagement of, people living with dementia. The different games such as "*hook a duck*", "*buzz wire*", and a throwing game to "*win a goldfish*" were demonstrated along with the different sensory elements. This was followed by a lengthy discussion about how the toolkit would be incorporated into the activity sessions at the location.

The activity team and residents at this location were familiar with the use of reminiscence elements and activities in their sessions as they have typically made use of a memory box subscription service that provides 12 different memory boxes over the course of a year for a cost of twenty pounds. According to the activity coordinator, although this service includes various themes such as travel and a dressing table, a major limitation is that there are only about six items in each box, which means that there is often an insufficient number of elements for their residents to interact with.

When comparing the AMuSED toolkit to the other reminiscence boxes used at the facility, the activity coordinator expressed that the AMuSED toolkit editions were more colourful, appealing, filled with exciting and interactive items, and covered all sensory needs. Also adding that the other activity coordinators were eager to use the Christmas toolkit when it was introduced to them before the lockdown and were disappointed when this couldn't take place – they are looking forward to the build-up to Christmas 2022 when they will make use of the Christmas AMuSED toolkit.

ES 3 - Sheltered Housing - Pre-Use - ENTERTAINMENT
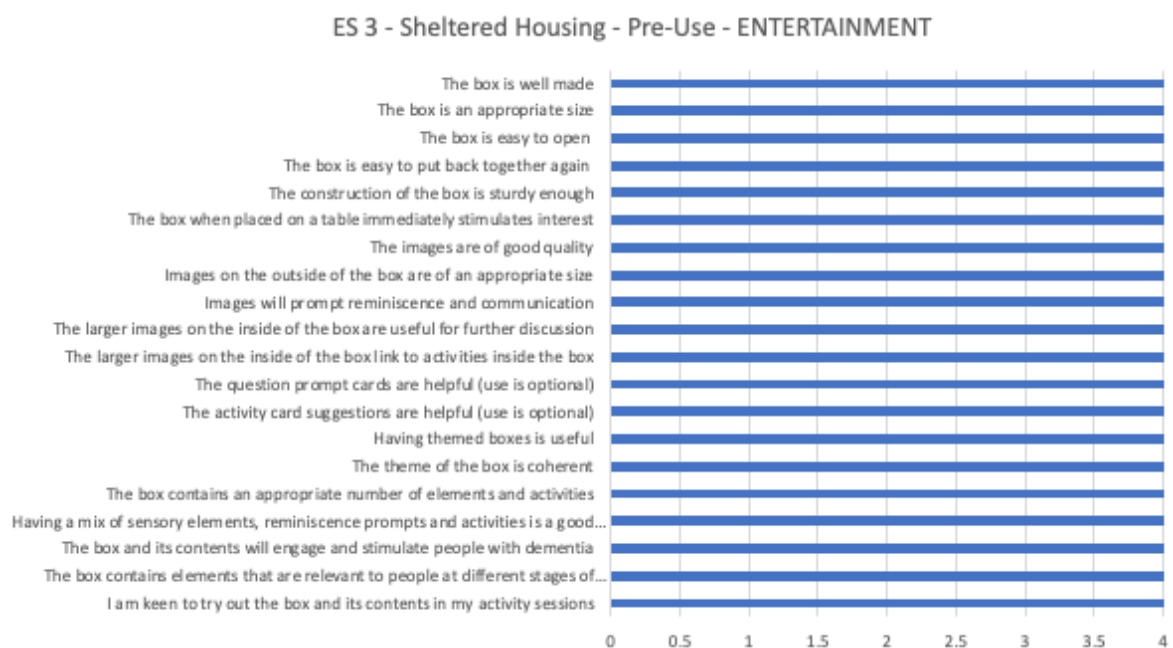
Figure 7.13: Evaluation site 3 – Entertainment toolkit Pre- evaluation

The first impression of the toolkit was evaluated by an activity coordinator. When providing first impression feedback about this toolkit (figure 7.13) after it had been delivered to the location, the activity coordinator agreed that it was well made and easy to set up. She also agreed that the images were relevant to people living with dementia and able to generate engagement and communication, the prompt and activity sheets were useful, and that the theme was coherent and relevant. Finally, the coordinator agreed to the appropriateness and relevance of the elements as well as the relevance of the toolkit to people at different stages of dementia.

The activity coordinator showed further interest in the Entertainment toolkit and mentioned that it was not seasonal like the Christmas toolkit and could therefore be used all year round. She expressed plans to combine the elements with dress-up activities, costumes, and props to further

enhance the experience. She also showed great interest in the movie aspect of the toolkit and revealed plans to include a movie and a red-carpet scene into the activity session using the red-carpet backdrop and celebrity face masks in the toolkit, as well as also turning it into a cinema experience by dressing up as an usher and handing out popcorn, ice cream and movie tickets.

Another idea she expressed was a "History of the cinema" activity where she could incorporate the use of many costumes, from Charlie Chaplin to Star Wars or Grease. The activity coordinator also shared her intent to get other members of staff involved in this activity. In providing further feedback about the AMuSED Entertainment toolkit, the activity coordinator detailed some of the ways she planned to use the toolkit, commenting that:

"I plan to take my time and keep referring back to the box, I see many different opportunities. I would like to reminisce about cinema and film, dress up and follow with a film, using the masks and red-carpet scene. I would turn the whole activity into a cinema experience dressing up as an Usher, (selling/giving) popcorn or ice-creams with cinema tickets."

"I could have a funfair day, I have a 'Wurzler' (Organ) CD we could play hook a duck and the goldfish game, I could also have ice-cream, donuts etc. Maybe in the summer purchase a small paddling pool and get more ducks, we could add other games like quoits."

She also commented specifically on some of the sensory elements, stating that:

"The scents, smells and noise machine would be perfect for guessing, and in addition I could bring in the quiz and the winner could win an Oscar. I will try and make one, I have a template somewhere and gold paper / card."

Finally, in comparing the AMuSED toolkit to the current memory boxes used at the location, the activity coordinator commented:

"Compared to the memory boxes which I have used in the past, the AMuSED box is colourful and full of exciting/interact items. The memory boxes are a good source, but your design is very appealing and as I mentioned when the staff opened the Christmas box, they were very excited and could not wait for me to use it."

In conclusion, the result of the first impression of the Entertainment toolkit at this site was very positive. The activity coordinator although familiar with reminiscence elements and memory boxes, immediately recognised the novelty of the toolkit through its inclusion of interactive, engaging and sensory elements and activities, pointing out that the toolkit covers all sensory needs. She also recognised the diversity of this toolkit and how it can be used for activities at different points during the year by stating plans to incorporate the ducks from the hook the duck game into a paddling pool in the summer for the residents. Finally, she agreed that the toolkit was well made and that its elements were relevant and adaptable to people living with various stages of dementia.

7.8 Evaluation Site 4 – Care home - Reading

Evaluation Site 4 is a care home offering three different categories of care in environments carefully designed to positively impact the health and wellbeing of their residents:

1. A long-term residential care that supports independent living of the residents on a permanent basis and is suitable for residents with other co-morbidities.

2. A short-term respite care that offers a short stay option for people who require post-operative support, hospital care or a break for their regular caregiver. This category of care also caters to emergency situations.

3. A long and short term residential and specialist dementia facility offering a person-centred approach to dementia care.

The number of residents varies but is generally around 55, with the majority having Alzheimer's disease and vascular dementia, with approximately 50% being in early stages of the disease, 40% in the mid stages, and 10% at the late stages. Activity sessions are carried out by the care staff and volunteers, although they are hoping to employ a dedicated activity coordinator. The Care Home manager normally does not get involved in the activities but wanted to use the AMuSED toolkit personally to see how it worked. This site was significantly affected by covid, lockdowns, and staff having to focus on care rather than additional activities, and hence only formal evaluations for the Seaside toolkit were undertaken with evaluation taking place across six activity sessions with multiple attendees at different stages of dementia. Due to the COVID-19 pandemic restrictions, evaluations were done by proxy as only the staff of the care home were allowed to organise activities or engage with the residents. The team was given a comprehensive training and demonstration session on delivery of the Seaside toolkit and were well versed with the AMuSED concept and toolkit contents before completing their feedback sheets.

7.8.1 Results of Evaluation Site 4 – Care Home Reading

ES 4 - Care Home READING - Pre-Use - SEASIDE
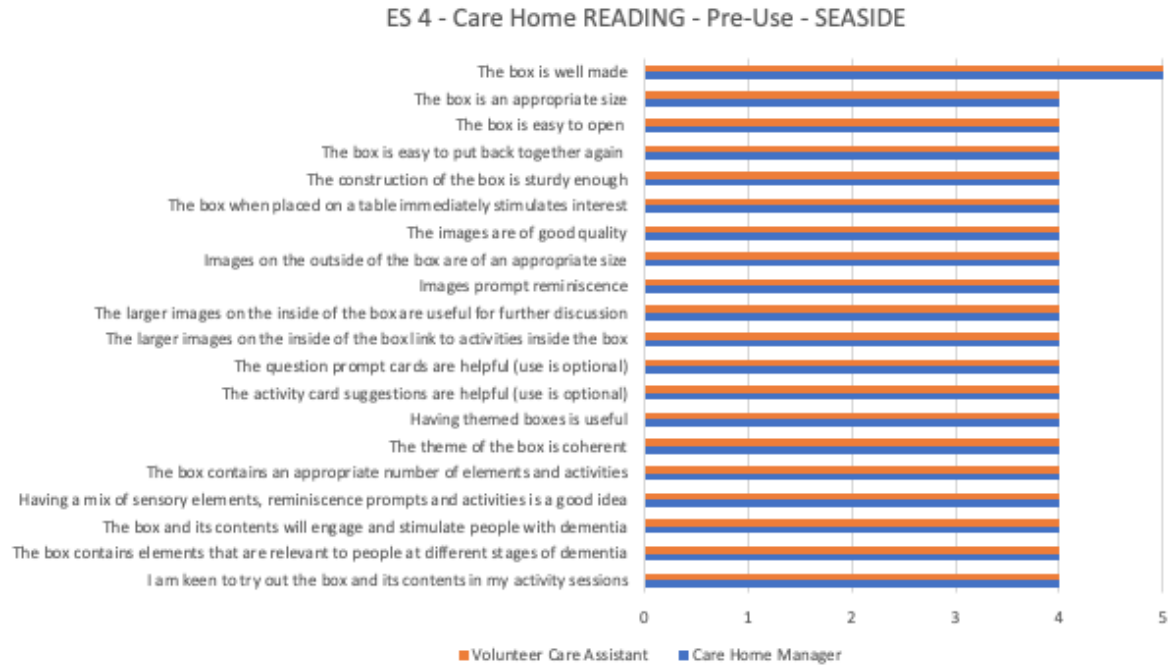
Figure 7.14: Evaluation site 4 – Seaside toolkit Pre- evaluation

ES 4 - Care Home READING - Post-Use - SEASIDE
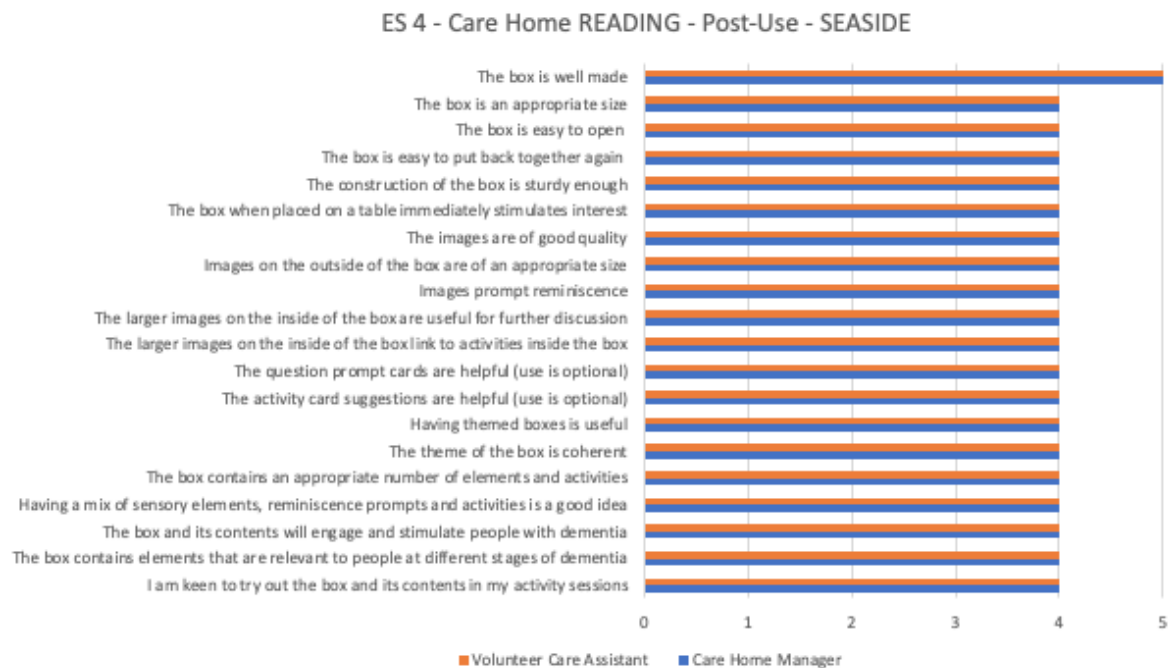
Figure 7.15: Evaluation site 4 – Seaside toolkit post- evaluation

7.8.2 Discussion of Results from Evaluation Site 4 – Care Home Reading

The first review of the Seaside edition of the AMuSED toolkit was undertaken by the Care Home Manager and by a Volunteer Care Assistant. Activity sessions at this site are usually organised 3 days a week with 4 sessions typically run in a day. Each session has an average of four residents attending with varying degrees of dementia. The activities organised before the inclusion of the AMuSED toolkit were listed as bingo, art and craft, quiz and pub and ball games. This list of activities showed that while the AMuSED toolkit provided some familiar elements such as art, most of the elements in the Seaside toolkit were new additions to this location.

7.8.2.1. Pre session

Figure 7.14 shows the averaged responses for the pre- and post-evaluation questionnaires from the two respondents who in fact gave identical responses when scoring their first impressions of the AMuSED Seaside toolkit. From the graph in figure 7.14, it is seen that the Manager and Care Assistant "Agreed" with all the statements on the pre-questionnaire apart from answering "*Strongly Agreed*" to the question about how well made the toolkit was.

They *"Agreed"* to statements about the ease of use of the toolkit such as whether the toolkit is well made, easy to use, easy to open and put back together. They also agreed to statements about the images and relevance of the toolkit which showed that they both believed that the images were of good quality, linked to the activities in the toolkit and able to prompt reminiscence and discussion. When asked about the inclusion of the activity cards and prompt questions, they both "*Agreed*" that these additional materials were useful. They also both "*Agreed*" that the Seaside theme was coherent and that the use of themed boxes in reminiscence sessions were useful.

When asked statements about the elements in the toolkit and their relevance to people living with dementia such as whether the elements were appropriate and could engage and stimulate people living with dementia, both respondents "*Agreed*" to all the statements in this category. This showed that they both believed that the seaside themed elements such as the kinetic sand, seashells, sound buttons, games and activities were appropriate. In this category, they also "Agreed" that a mixture of sensory elements and activities, and reminiscence prompts were a good idea. The results of the first impression evaluation of the AMuSED toolkit at this location also supported the adaptability attribute of the AMuSED toolkit, with both respondents agreeing that the elements in the toolkit were relevant to people at different stages of dementia.

When asked whether they had used or were currently using any of the AMuSED elements in their reminiscence sessions, both reported that they had used reminiscence boxes in the past, with the Manager adding that although they had used some elements similar to those in the Seaside AMuSED toolkit in the past, they had never used a specific Seaside toolkit. The Manager reported looking forward to using the seagull sounds and smell capsules, and the Care Assistant to using all elements in the toolkit! The Care Assistant thought the AMuSED toolkit would stimulate interest and conversation, and the Manager thought that it could be "*used by everyone, whether they were an engagement lead or a volunteer*". Finally, both respondents summed up their first impressions of the AMuSED Seaside toolkit as *"colourful", "interesting", "intriguing"* and *"fun".*

7.8.2.2 - During session

The AMuSED Seaside toolkit was evaluated across six activity sessions taking place in different areas of the care home over a day in late November (sessions 1-2) and a day in early December (sessions 3 to 6) with numbers of attendees in each session shown in Table 7.5. Each evaluation day utilised different elements from the AMuSED toolkit.

Table 7.5: Number of attendees in evaluation site 4

Day	D1	D1	D2	D2	D2	D2
Session	S1	S2	S3	S4	S5	S6
Males	0	2	1	0	0	2
Females	6	2	6	3	4	3
Total	6	4	7	3	4	5

The AMuSED Seaside toolkit was used in two areas of the care home on evaluation day-1. The elements used in these activity sessions were the holiday brochures, seashells, sound buttons, sea fragrances, beach balls and windmills. The activity coordinator reported using the prompt questions to start the sessions before introducing the elements and activities, with the session then evolving through the conversation of the attendees; the male residents particularly talked about rock pools and crabbing. The sensory items – sound buttons, seashells, and smell capsules – were reported as the elements that the attendees engaged with the most, with the holiday brochures "*not particularly interesting*" the attendees in one of the day-1 sessions.

To help determine the relevance of the AMuSED toolkit to people at different stages of dementia, the questionnaire asked how well the toolkit engaged people living with early, mid, and late dementia, to which the activity coordinator responded with *"quite a bit"* for the group with early dementia and *"very much"* for those who had mid dementia. There were no attendees with late dementia at either of these two sessions on this day and the mood for all attendees during and after the sessions was positive. When asked for general comments about how the sessions went, the activity coordinator commented that:

"It was interesting to watch the session evolve as residents started to engage with each other."

The four sessions (S3-S6) run on evaluation day-2 variously made use of the reminiscence images, holiday brochure, seashells, sea creatures, colouring, word search, postcards, photo props, beach quoits and beachballs from the AMuSED toolkit. The sessions involved attendees at different stages of dementia and the moods of the participants varied before and during the sessions but were almost all positive by the end of the session and responses and notes made by the activity coordinator reinforced that they had all enjoyed at least some of the activities with seaside images, the travel posters and seashells being the most enjoyed elements in these Day-2 sessions, and which led to them talking about their own family holiday experiences and places they had visited. The activity coordinator for these sessions reported that the prompt questions and activity sheets were very helpful and were used to help prompt the attendees with their discussions during the sessions.

The attendees in the four sessions on Evaluation Day-2 ranged from residents with no or early dementia to those with late dementia. Only two of the 19 residents (one with mid stage and one with late stages dementia) who took part in the sessions on day 2 did not engage at all with the AMuSED activities, with engagement assessments by the activity coordinators of the other attendees spanning from "a little" to "very much" across attendees with early, mid and late stage dementia showing that it was possible for the AMuSED toolkit to be able to provide different levels of engagement to people at varying stages of dementia. Whilst numbers of attendees are small and results variable as they are very much dependent on individuals and how they are feeling on a particular day, they do help support the premise that the choice offered by the AMuSED toolkit means it can adapt to engage people living with different stages of dementia. This is important because some of the non-pharmacological interventions for people living with dementia have been recorded as either too difficult and complex for some stages of dementia (Tapus, Tapus and

193

Mataric, 2009), such as mid to late dementia, or too simple for people living with early dementia (Anderiesen, 2017).

7.8.2.3 - Post session evaluation

This evaluation was performed by the Manager and a Care Assistant after the AMuSED Seaside toolkit had been used in the six activity sessions described above. They each reported that all the attendees at each of the sessions had varying degrees of dementia and they also reported not running any of their other activity sessions while the AMuSED toolkit was being used.

As shown in figure 7.15, when asked about their overall impression of the toolkit after the evaluation period, their responses to the different categories of evaluation of the toolkit were positive with both respondents strongly agreeing that the toolkit was well made and agreeing that it was easy to use. This response is linked to the usability attribute of the toolkit and shows that the toolkit does not provide any form of complication or complexity when being used.

They also both agreed that the images used were of good quality and relevant to dementia, which was evident in the feedback from the sessions where the activity coordinator reported that the attendees enjoyed the images as it made them think about and discuss their family holidays. Reminiscence images and elements were incorporated into the AMuSED toolkit due to the success of reminiscence therapy recorded in literature (Chang and Chien, 2018). Hence, it is important to note that this success has also been recorded with the AMuSED toolkit and the images and elements of the toolkit have been able to generate positive memories for people living with dementia. Both respondents also agreed that the prompt questions and activity suggestions were useful. This feedback was also recorded in the during session questionnaires where the activity coordinators reported that prompt and activity sheets were useful to start the sessions and guide the conversation. The respondents also agreed that the theme of the toolkit was useful and coherent.

Regarding the elements in the toolkit and their relevance, the respondents agreed to all the statements in this category, including that the combination of sensory elements, reminiscence prompts and activities was a good idea. One of the novel features of the AMuSED toolkit is the inclusion of activities into Snoezelen in order to provide multisensory stimulation as well as cognitive stimulation to people living with dementia. This combination was well received in this location as the session attendees engaged with and enjoyed the activity elements of the toolkit as well as the sensory elements. Finally, both respondents agreed that the toolkit was relevant to

people living with different stages of dementia, which was evident from the results of the during session questionnaire.

The respondents recorded the elements used in all the sessions such as the reminiscence images, holiday brochure, seashells, sea creatures, sound buttons, sea fragrances, colouring, word search postcards, photo props, beach quoits, beach balls and windmills. They also reported that the attendees enjoyed the images of the seaside and following the discussions suggested in the activity sheets the most, as well as using the sensory elements – shells, sound buttons and fragrances – in the toolkit. In response to which elements the attendees did not enjoy, one of the respondents reported that the attendees did not enjoy talking about locations suggested in the toolkit that they did not recognise.

When also asked if they created their own activities in addition to those suggested in the activity sheet, one of the respondents reported not doing so because the activity was planned around the toolkit. This is a testament to the efficiency of the activity sheet as the activities organised in this site were from the activity and prompt sheets. The other respondent commented that:

"In one group, the session evolved through resident conversation, so they led the session"

This feedback is very positive and shows that the AMuSED toolkit not only has the ability to stimulate conversation and communication among a group, but it can also change the role of the activity coordinator from having to both lead and supervise the session, to just supervising and allowing the attendees lead the session. In response to how well the toolkit was able to engage people living with different stages of dementia, their responses mirrored that of the during session questionnaire with both respondents agreeing that the toolkit was able to provide various levels of stimulation to people with different stages of dementia.

The AMuSED toolkit was designed to be a conversation piece that can be used even without the elements, and this design was useful at this evaluation site as the respondents commented that the best feature of the AMuSED toolkit was the interesting exterior that made the residents want to look inside. The other respondent also commented that the AMuSED toolkit had everything in one place and was easy to move around. This is as a result of the portability of the toolkit which was one of the attributes focused on in the development phase. Both respondents also suggested occupations, pub, wedding, baby and school themes for the toolkit. Finally, when asked to describe

their final thoughts on the AMuSED toolkit, they described it as *"Interesting", "fun", "stimulating"* and *"engaging".*

This feedback provided on their final thoughts of the AMuSED toolkit showed that the respondents found the toolkit useful in their activity sessions with their residents and were able to develop conversations and meaningful activities using the activity and prompt sheets. It is also evident from their responses that they enjoyed the multisensory and multiactivity toolkit and found it to be portable, usable and adaptable.

7.9 Evaluation Site 5 – In-home care Reading

This organisation provides personalised home care for the elderly, granting support with activities of daily living, help around the house and companionship. They deliver specialised dementia care which includes providing stimulating activities to people living with dementia at home. A presentation of the AMuSED Life-Entertainment and Seaside toolkits was done at this location for the director and care staff, and the initial feedback was very positive. After three weeks of use with clients, feedback was provided about the first impressions of the toolkits by the Director and Community Liaison Officer of the location who reported that the toolkits were mostly used in one-to-one home sessions with their clients but was also taken to two activity session at a local care group.

Figure 7.16: Evaluation site 5 – Seaside and Life-Entertainment toolkits Pre- evaluation

This respondent "*Strongly Agreed*" to all the statements regarding the ease of use of the toolkits except that the toolkits were easy to put together again after being taken apart where he selected "*Agree*". The respondent also "*Strongly Agreed*" to all statements about the images used in the toolkits and their relevance to communication and reminiscence and "*Agreed*" that the prompt and activity cards were helpful. In response to the statements about the Life-Entertainment and Seaside themes, the respondent "*Strongly Agreed*" that both themes were coherent and useful. He also "*Strongly Agreed*" to most statements about the elements including that they would engage and stimulate people and *"Agreed"* that the toolkits contained an appropriate number of elements and activities. Finally, in terms of the adaptability of the toolkits he "*Strongly Agreed*" that they contained elements that were relevant to people at different stages of dementia.

When asked how the toolkit would be used with their clients, the respondent reported that the care staff would take a small number of elements from the toolkits for use in their clients' homes, as taking the whole toolkit could be overwhelming. He also explained that this model of use would help the care staff focus on one or two activities. When describing his final thoughts on the first impression of the toolkits, the respondent commented that the toolkits had a "*WOW factor"* and referred to them as "*Stimulating", "positive"* and *"Interactive.*

In providing further feedback on the use of the toolkits after 3 weeks, the director of this evaluation site reported that the toolkits had been used in two domestic settings (clients' homes), at two coffee morning events and at another location where the organisation had a stand to discuss care. He reported that the large pictures on the sides of the toolkit were striking and immediately created interest and engagement. He also commented on the Life elements in the Entertainment toolkit such as the driver's license and the ration cards saying that they prompted discussion.

7.10 Evaluation Site 6 – Adults with Special Needs Reading

The AMuSED toolkit was evaluated at a charity that helps adults with learning needs or disabilities, or poor mental health. This charity provides social and practical skills for independent living for these groups of adults and their aim is to deliver a person-centred approach, thereby creating a comfortable, non-judgemental environment for people with physical or learning disabilities to discover their own aptitude and skills. They offer daytime services where attendees can benefit from meaningful activities in a safe, stable environment which provides an avenue for socialisation. One of such services was where the AMuSED Seaside and Christmas edition toolkits were evaluated.

This evaluation was conducted with this group because the charity heard about the AMuSED toolkit and asked to try them in their activity sessions and also asked to be included in the evaluation even though their client group differ from people living with dementia.
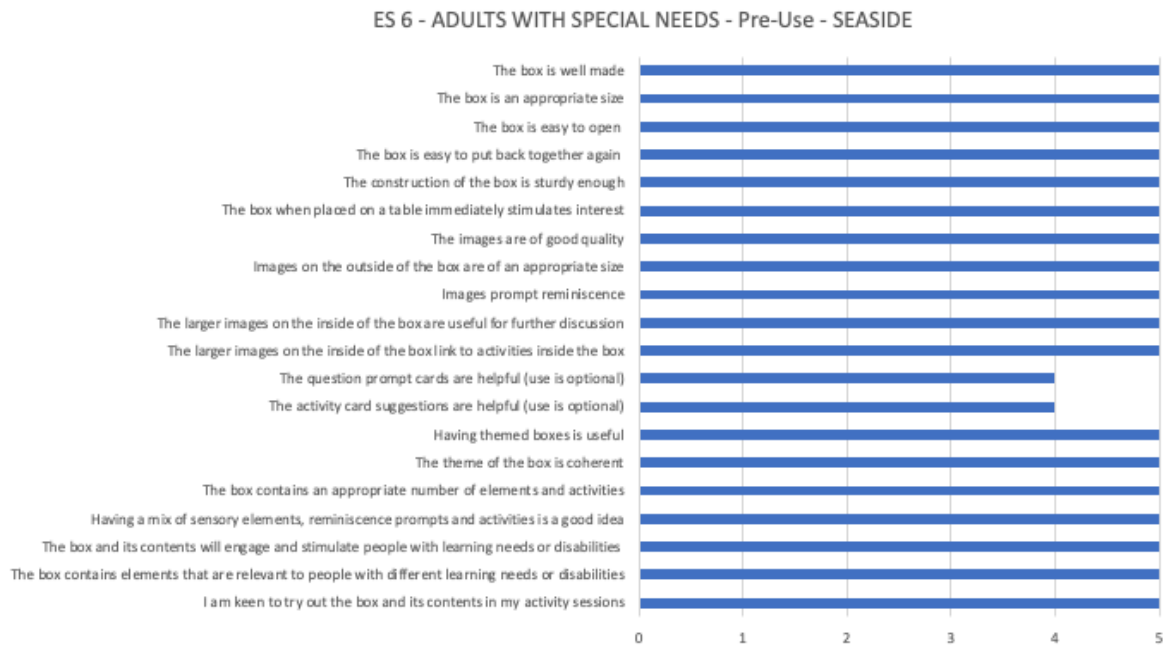
Figure 7.17: Evaluation site 6 – Seaside toolkit Pre- evaluation
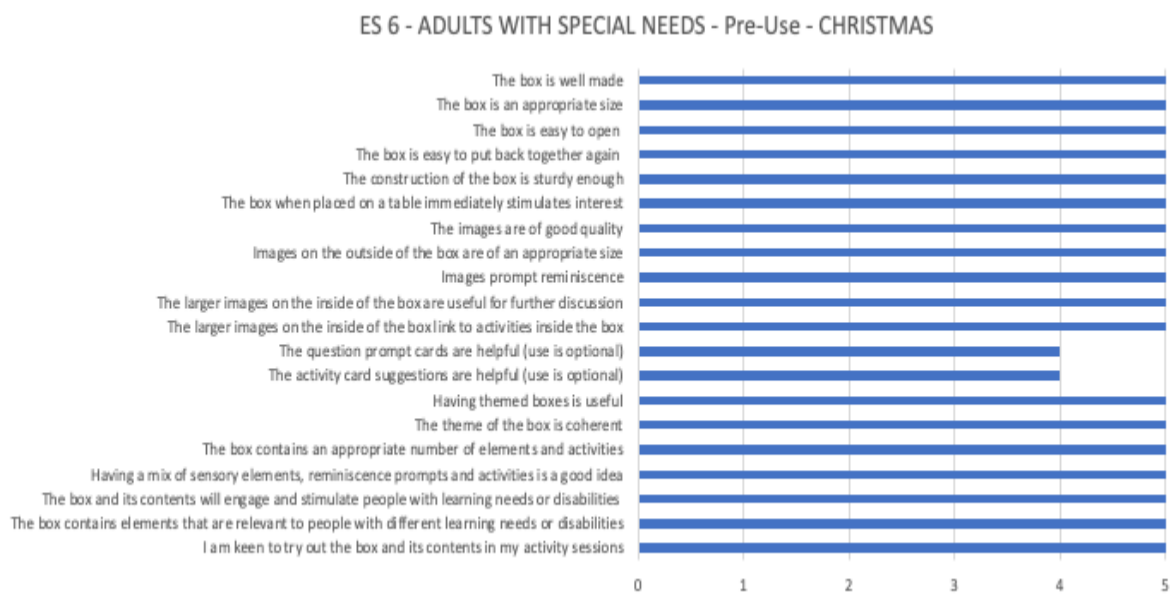
Figure 7.18: Evaluation site 6 – Christmas toolkit Pre- evaluation

The AMuSED Seaside and Christmas edition toolkits were used at the weekly sessions of this charity group which caters to people with physical and learning disabilities rather than people living with dementia. The first impressions of the Seaside toolkit and Christmas toolkit were evaluated by a tutor (activity coordinator) who coordinated the activities. The respondent reported that the activity sessions typically include 6 attendees, all with learning disabilities and involved activities such as music and art therapy, gardening, literacy and numeracy.

At one of the Christmas sessions, a general introduction of the AMuSED toolkit was given to the attendees, after which the activity coordinators at the session used the different panels of the toolkit. The attendees discussed their various experiences of Christmas, and especially enjoyed the pantomime panel of the toolkit which was used as a reminisces session. They also enjoyed talking about their old toys, experiences etc. One of the attendees, a woman who never responded to activities, loved the snow globe especially its flashing lights and musical carols although eventually the carols were silenced by request of the rest of the group, and the lights were just left flashing. As a group they sang the 12 days of Christmas, which they enjoyed singing and the panel acted as a prompt for those who could not remember what came next on the song. The song was also used as a numeracy lesson. The group also took part in and enjoyed the Santa hoopla game where scores were added together for each person and put on a chart. This will be done each week and a competition run across the weeks with scores each week being tallied up and put on the chart.
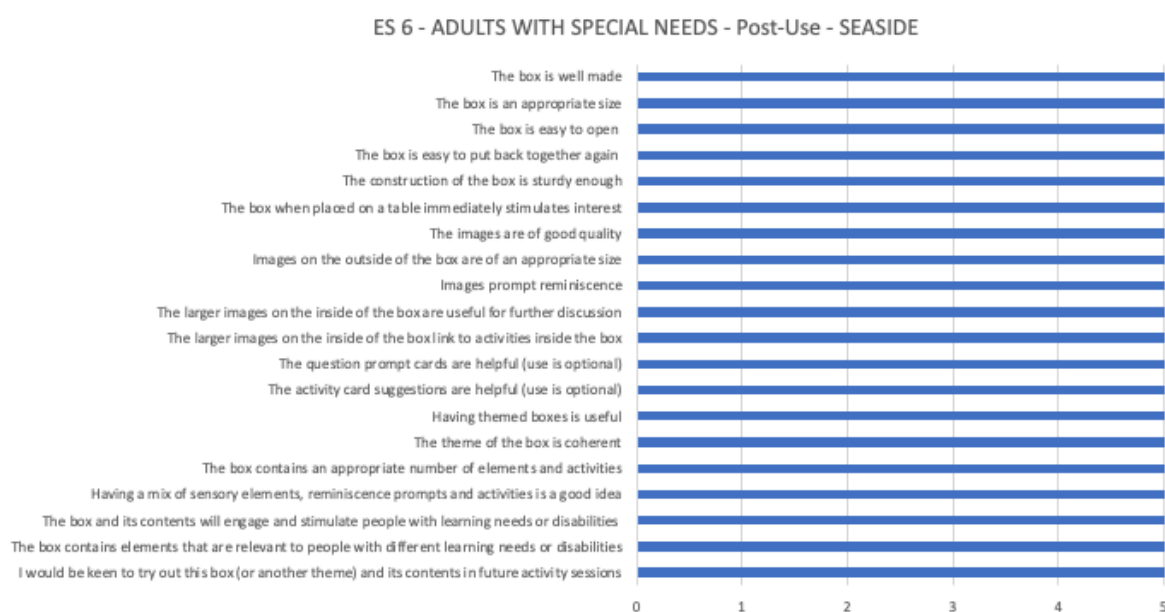
Figure 7.19: Evaluation site 6 – Seaside toolkit Post- evaluation

ES 6 - ADULTS WITH SPECIAL NEEDS - Post-Use - CHRISTMAS

Figure 7.20: Evaluation site 6 – Christmas toolkit Post- evaluation

7.10.1 Pre session

Figures 7.17 and 7.18 show that the first impressions of the activity coordinators to the Seaside and Christmas toolkit were identical. The respondent *"Strongly Agreed"* to statements about the ease of use of the toolkits and ability of the images to prompt communication and stimulate interest. It was also *"Agreed"* that the prompt and activity sheets included in the toolkits were helpful. In response to statements about the use of themes in the toolkits, the respondent *"Strongly Agreed"* that the themes of the toolkits were coherent and useful, and also *"Strongly Agreed"* that the elements included in the toolkits were appropriate and able to stimulate people with learning needs and disabilities. Finally, regarding the adaptability of the toolkit, the respondent *"Strongly Agreed"* that the AMuSED toolkits contained elements that were relevant to people with different learning needs or disabilities.

The activity coordinator reported looking forward to using the images, message in a bottle, sound buttons, Christmas pomander, tree growing and smell capsules, but also stated that the small sand box might not have been used. When asked how the toolkits would be used with attendees, the coordinator reported that it would be used alongside their current activities for large parts of each activity session. It was also reported that it would be used within the group, with individuals and

with getting people to work in pairs, as well as to set tasks for the individuals in the group measured against their abilities, with one of the respondents calling the toolkit a good resource for memory recall and working in teams.

This feedback not only showed that the coordinator acknowledged the usability, accessibility and adaptability attributes through their responses, but also that it was believed that the toolkit would promote communication and collaboration within the group. Although designed for people living with dementia, it was clear from the initial exploration by the staff that the AMuSED toolkit could be beneficial to adults with learning disabilities. The feedback was very positive and important to the research as even though the coordinator catered to people with learning needs and disabilities, the response still corresponded with those of the coordinators of activities for people living with dementia. Both groups' first impressions of the AMuSED toolkit regardless of the theme were positive with all coordinators believing that the toolkit is made properly, easy to use and relevant in stimulating reminiscence and communication within both groups.

7.10.2 During Session

The Christmas and Seaside toolkits were used in activity sessions once a week over the course of four weeks. The sessions had attendees – referred to by the facilitators as trainees – aged between 30-50, some of which were on the Autistic spectrum. The evaluation of the sessions was conducted by two activity coordinators and showed the results of both the Christmas and the Seaside toolkits. The results of the evaluation revealed the mood of the session attendees as happy before, during and after the AMuSED sessions, and that the prompt and activity sheets were used during the sessions alongside the elements. The respondents highlighted the snow globe, box images, hoop game and Christmas tree painting as the activities most enjoyed in the Christmas toolkit, and the message in a bottle, images, jellyfish lamp, beach quoits and sound buttons as those enjoyed most in the sessions organised using the Seaside toolkit. They also mentioned the 1970's memorabilia, small sand box and windmills as elements not engaged with.

7.10.3 Post session

The overall feedback after the evaluation period was very positive. Both post evaluation questionnaires were completed the same activity coordinator for each toolkit (Figures 7.19 and 7.20). The activity coordinator reported that the toolkits were used alongside other activities, and also *"Strongly Agreed"* to most of the statements regarding the ease of use, images and relevance, additional materials, use of themes, elements and relevance, and adaptability of the AMuSED

toolkits. When asked about the additional materials such as the prompt and activity sheets, the coordinator stated that they were used where needed with some members of the group.

In response to what elements the attendees engaged with the most, the respondent reported the message in a bottle, jellyfish lamp, beach balls, images on the box and photo props for the Seaside edition toolkit, and tree planting, hoop game, snow globe and images on the box for the Christmas toolkit. It was not reported that any elements were not engaged with by the attendees, but it was stated that some of the elements were not used due to time constraints such as snowman and wreath making activity, 1970s childhood memorabilia and small sand box. The respondent reported using the AMuSED toolkits as aids in their activities and using it both individually and in pairs, and further stated that group activities were organised using the hoop game with a weekly competition made from this. The process of making the scoreboard and recording scores was reported to help with the numeracy and communication of the groups.

In a similar fashion to the studies with people with dementia, the respondent was asked how well the AMuSED toolkits engaged people with learning needs, physical disabilities, autism and poor mental health, and selected *"Very much"* to learning needs, autism and poor mental health, and *"Quite a bit"* to physical disabilities. These results show that the AMuSED toolkit is adaptable enough to provide engagement to these different groups of people. In terms of accessibility, the AMuSED toolkit also performed well with the different groups, including non-verbal autism which some of the attendees were said to have. The respondent provided extra feedback by adding that the toolkits generated interest from all the users and was well received by the activity staff. It was also added that it was well packaged and easy to use, supporting the usability and lack of complexity of the AMuSED toolkit.

When asked about the best features of the toolkits, the respondent reported that they were portable, well packaged and could be readily accessed, and also added that the toolkits allowed multiple activities and it was easy to find the appropriate activity for the groups. The respondent called the AMuSED toolkits visually stimulating while highlighting the sound buttons and media links. *"Simple online interfaces"* was also suggested as an element to be included in the AMuSED toolkit, as well as the inclusion of a sports theme. When asked to describe the toolkits, the respondent described it as "really useful" and "very adaptable".

Finally, the respondent suggested the inclusion of a user group that allowed activity coordinators using AMuSED in different locations to exchange items with each other as well as share experiences and best practices among themselves, as well as a service where the AMuSED toolkit could be delivered on site with a tutor once or twice a week. Regarding the physical aspect of the toolkit, it was the addition of wheels to the base of the storage box to further improve portability was also suggested.

The feedback from the activity coordinator in this location was very useful and positive. According to the coordinator, the toolkits were universally liked by all staff and end users, were a great resource to stimulate the end users and were very adaptable and usable. The breadth of activities offered by the elements in the toolkits added new dimensions to the programmes already offered by the coordinator and allowed the toolkits to be used flexibly to fit the range of abilities within the group with both the coordinators and the attendees selecting activities based on interest and perceived learning aim.

The activity coordinator also provided details of the sessions and how well the toolkits engaged the attendees. A magical moment recorded at one of the sessions was when an attendee, a non-verbal woman on the autistic spectrum who never joined the activities, was so inspired by the snow globe that she actively engaged in the hoopla rings activity, also scoring with the rings. The coordinators of the sessions reported never seeing her exhibit that level of engagement in any activity before.

The AMuSED toolkits have been adopted for use in subsequent sessions in this location and the Christmas decorations made will be stored ready for next Christmas. It was good to get the group to be active, as they enjoyed the competition and numeracy elements that stemmed from the activities. One of the coordinators of the session also gave feedback on the AMuSED toolkit, referring to the toolkit as:

"A great tool for the facilitator. It takes the strain of having to think of activities for each session. It provides a variety of activities to appeal to all the trainees"

This coordinator also commented about how the AMuSED toolkit has impacted the trainees (session attendees) by stating that:

"A non-verbal trainee has been most enthusiastic about the hoops game and is so keen she has not needed any encouragement to take part. Another trainee who is normally very negative has been very positive about the games and very enthusiastic"

The coordinator also provided feedback on the individual activities and commented on the hoop game:

"Great game, they enjoy it, support and encourage each other. It also helps with the development of their maths skills as they try to add up the points."

"The attendees used the QR code scanning cube provided in the pack to move from lower-level understanding to activating real learning reinforced by linking the activity to an Internet music delivery service."

These comments prove the cognitive stimulating abilities of the AMuSED toolkit and that the inclusion of elements that provide some level of challenge is a good tool in providing cognitive stimulation. The facilitator also revealed that the attendees enjoyed the jigsaw puzzles and sound buttons. However, it was added that although the attendees enjoyed the aqua paint, they finished the activity quickly and lost interest once the picture was painted, therefore the facilitator directed this into another activity by asking them to talk about the picture they selected to paint such as fish and chips, ice cream van etc. It was also pointed out that while this group did not reminisce like an older group would, the pictures painted were still able to be used as discussion points.

The importance of this evaluation site is to demonstrate the flexibility of the AMuSED toolkit to not only cater to people living with dementia, but also to adults with physical and learning disabilities while also promoting social engagement and communication within this new group of people. There is a great opportunity in the provision of multisensory stimulation, engagement, and activities to this group using the AMuSED toolkit and this evaluation showed positive results and responses from people with autism and other learning and physical disabilities toward the AMuSED toolkit.

7.11 6-Month Follow Up

A 6-month follow up survey consisting of open-ended questions was performed with activity coordinators at all the evaluation sites to gather information on the use of AMuSED approximately 6 months after the initial study. The aim of this follow up was to collect feedback about how the AMuSED toolkit had been used at these various locations, how they had performed over time, how

they were incorporated into the activity sessions, the most and least preferred elements, as well as what improvements could be made to the various toolkits. The questionnaire used in this survey contained open-ended questions rather than closed-ended Likert scale statements as a way of allowing the respondents to describe the AMuSED toolkit and its use in their own words. It also included a balanced set of questions about what respondents like about AMuSED as well as about how it could be improved. Feedback was collected from the various evaluation sites via email through the distribution of the questionnaire shown in Figure 7.21.

Figure 7.21: 6-Month Follow-up Questionnaire

7.11.1 Final Feedback

The feedback received from the 6 month follow up was very positive as most of the locations reported using the AMuSED toolkit after the evaluation period and incorporating the different elements into their activity sessions.

Longevity

One of the main reasons for the 6-month follow up was to determine how the AMuSED toolkit had performed at the different evaluation sites over the 6-month period. The respondents were asked how the AMuSED toolkit had stood over time, and their responses included the following:

"Very well, as most can be re used. Bits that can't such as colouring and painting, I have been printing off duplicates from the internet."

"Some of the Lego pieces have come unstuck/ loose over time so it benefits from a bit of maintenance."

"Pretty well, everything is reusable."

Novelty

The respondents were also asked about the ways in which they believed AMuSED to be different from other products on the market and the following responses were given:

"It's far more interactive and adaptable to a situation. Many have commented that its more interesting."

"A lot of content in each box, variety is different. Reminiscence box from the library is mainly talking points whereas AMuSED box is more physically involved with activities, and it caters to everyone's individual needs."

"I think it is the multisensory opportunities the toolkit presents and the flexibility which makes this product different from others on the market. It is also affordable, using easily obtainable contents which can be renewed and refreshed."

Likes

Regarding what the respondents liked most about the toolkit, the following comments were recorded:

"Everything is in one place, easy to find and a good selection of varied sensory items for residents to talk about."

"Its level of activity for all abilities everyone can take part from finding their own memories within or joining in with more physical activities. Along with it being so adaptable to be used in so many ways. Also, a very good talking point."

"The What's in the Box elements are very engaging as is the audio photo album. The smells always provoke a reaction. The hands-on elements are fun. The additional photo packs have really helped in highlighting the museum collections."

"Very creative with the lego cues that form into a box, provides reminiscence. A lot to unpack and there is something for everyone's needs as there are sensory options for those who can't physically participate."

"The games it has inspired me to buy some to add onto this. So, we have purchased tin can alley and another ring toss. Also, the light lamp and fish lamp has been a real winner with the sessions I've done."

Dislikes

When asked what the respondents disliked about the toolkit or their least favourite elements, the following responses were reported:

"The smell cubes these are a great idea in theory but in practice haven't worked. I think the smells should either be improved or removed these are something we have not used at all as [we have] not found them very appealing"

"We found that the bingo cards aren't user friendly as they are too small, and the numbers are close together."

"I think people find the smells hard to identify. They smell quite chemically and after smelling a number of them, they all seem to smell alike!"

Areas for improvement

Some areas of improvement were identified by the different respondents as a result of using the AMuSED toolkit during the 6-month period. The areas of improvement included the following:

"The flower kit didn't go so well, soil to touch and feel would have been more sensory. Seeds that are chunkier would be better like sunflower seeds."

"I think with hindsight it would have been useful to think more about sustainability of the contents of the toolkit. Some of the birds have lost their tweets for instance and there doesn't seem to be a way of changing the battery. Would be useful to think in future of sourcing contents which are rechargeable and are sustainable."

"Maybe a little more instruction or hints"

"Maybe with the picture boxes have somewhere a description of what the pictures are. Everyone loved looking at these but got many questions on when they were taken and where"

"A4 large font bingo sheets"

" A tablecloth to be used along with the box, with pictures, proverbs and sayings related to the subject of the toolkit."

Suggested themes

The respondents were also asked to suggest themes for the AMuSED toolkit that their residents and session attendees would enjoy. The themes suggested included childhood, jobs, wedding, baby, garden, family life, cook kit with food and kitchen related content, and tinkering toolkit for mending and fixing

Likelihood of recommendation

Finally, when asked how likely they were to recommend the AMuSED toolkit to others, the respondents gave the following responses:

"Would definitely recommend"

"Very likely"

"Very likely, we have shared with our neighbouring offices, and all have said they would like to have a go."

7.12 Summary of 6-month follow-up

The responses from the 6-month follow-up survey were very positive. Employing the use of open-ended questions in this questionnaire reduced the potential of bias and gave the different respondents the freedom to articulate their responses and represent their views in their own words without being led on by statements in a closed-ended questionnaire. The responses highlighted the reusability of the AMuSED toolkit and the longevity of the elements in the toolkit, going further to explain that certain elements such as colouring sheets which could not be reused, could be easily refreshed by reprinting.

As with the initial evaluation of the AMuSED toolkit, this follow-up survey also recorded the novelty of the toolkit, with different respondents highlighting that the interactive nature of AMuSED set it apart from other reminiscence boxes and similar interventions used in practice. The results showed that in addition to reminiscence, the AMuSED toolkit allowed residents and session attendees to physically interact with the multisensory elements in the toolkit which not only engaged them, but also provided flexibility for the activity coordinators, as the variety of multisensory elements provided them with a range of activities to choose from for a particular session. The adaptability of the toolkit was also mentioned in different locations, with the availability of activities and elements for everyone constantly highlighted as one of the things that made the AMuSED toolkit novel and liked.

Another important reason for conducting this follow-up survey was to discover some of the deficiencies of the AMuSED toolkit, especially those that could only be recovered after repeated use. As with the initial evaluation, the smells were highlighted again as a dislike, as it was found to be unappealing by some session attendees. Further deficiencies of the usability of some of the

elements in the toolkit highlighted in the results can be addressed by the inclusion of more user-friendly elements such as larger text on the bingo cards or larger A4 sized bingo cards, and larger seeds for the planting kits. Further consideration is also given to the sustainability of elements such as making sure that all the digital elements are rechargeable, or battery operated to avoid occurrences such as the plush birds in the Countryside toolkit losing their sound.

In addition to the positive feedback which supports the aim of the AMuSED toolkit to be used by caregivers and activity coordinators to deliver engaging and stimulating activity sessions for people living with dementia in various care facilities, the high likelihood of recommendation to other potential users reported by all the respondents provides an opportunity for the expansion of the toolkit beyond this PhD, with the possibility of the development of further themes, as well as an expansion of the user group, all of which are explored in the future work section in chapter 9.

7.13 Limitations of the evaluation

7.13.1 COVID-19 Pandemic

The COVID-19 pandemic had an impact on the research and brought about several limitations addressed further in Chapter 9 such as the inability to conduct focus groups, the postponement of activity sessions due to lockdowns and illnesses, and the inability for the researchers to be at the evaluation sites. These restrictions led to evaluation by proxy through the activity coordinators and caregivers at the different evaluation sites. However, in the absence of the pandemic and the resulting lockdowns and restrictions by the care facilities and the government, a focus group made up of people living with dementia and their caregivers would have been conducted at the early stages of the research to evaluate the AMuSED concept. This could have introduced a different perspective into the research as well as included the direct recipients of dementia care into the design and development of the AMuSED toolkit.

The absence of lockdowns would also have resulted in longer evaluation periods and allowed for a more structured approach to the evaluation such as observations of the AMuSED sessions at the different sites, and the possibility of recording the sessions as well as the communication flow between the attendees. This approach to the evaluation would also have resulted in a larger amount of data upon which statistical analysis and thematic analysis could be performed to identify the resulting themes related to the use of the AMuSED toolkit.

7.13.2 Potential bias in Initial Questionnaire

Feedback received from all evaluation sites has been consistently very positive as have been the responses to AMuSED when it has been demonstrated at other public events such as talks to Rotary, older peoples' clubs and public displays in shopping malls. However, a later questionnaire has also been designed to address any potential bias from earlier feedback received, due to the positive framing of the questionnaires used in the evaluations.

In the use of questionnaires especially those with Likert scales, it is important to eliminate bias in the statements. One of the most common biases in questionnaire statements is the lack of balanced framing, as statements are frequently framed with positive effect without balancing it with statements framed in negative effect (Swamy, 2007). Unbalanced framing could not only lead to acquiescence bias but also reduce the likelihood of the respondents reading all the statements carefully when they are framed in the same manner (Ray, 1983). One of the recommended practices in questionnaire design is to incorporate balanced framing, as when the questionnaire is balanced with both positive and negative statements, respondents are compelled to read each of the statements more carefully and rate them more consistently.

The questionnaires used for the evaluation of AMuSED contained only positively framed statements which could have influenced the positive responses and feedback received from all the different evaluation sites. Due to this, a later questionnaire (see Appendix N for full-sized versions of the questionnaire) was designed after the six-month follow-up period following further research about balanced framing and randomisation of questionnaires to compensate for the inadequacies of the pre- and post- questionnaires used in the evaluation. This questionnaire was carefully reviewed to improve the quality of the questions as well as reduce the probability of bias from the respondents by ensuring more balanced framing. Open questions were also included in the same questionnaire to ask about how the person with dementia uses Amused (or a similar intervention), how the AC uses the Amused toolkit, and how the Activity Coordinator interpreted the use of the Amused kit. Although not used within the scope of this thesis it will be used going forwards in any new AMuSED based evaluations.

Final Questionnaire for the AMuSED Box

Dear Manager or Activity Coordinator, we hope that you have enjoyed using your AMuSED box(es) over the past months. We know that you are very busy, but we would be really appreciative if you could answer this final questionnaire about your experience of using the AMuSED box(es) and send it back to us Many thanks for your time 😊.

Section 1 – Overall Impressions of the AMuSED Box

Please state how much you agree or disagree with the following statements about the AMuSED Box (tick appropriately)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The images on the AMuSED box are of good quality					
The AMuSED box is too large					
We are keen to continue using the AMuSED box (or other themes) and its contents in future activity sessions					
There are not enough elements and activities included in an AMuSED box					
The AMuSED box is not sturdy enough					
The AMuSED box contains an appropriate number of elements and activities					
It is a bad idea to mix sensory elements, reminiscence prompts and activities within a single AMuSED box					
The size of the images on the outside of the AMuSED box are not appropriate					
The elements in the AMuSED box are relevant to people at different stages of dementia					
The AMuSED box and its contents do not engage people with dementia					
The AMuSED box is an appropriate size					
The images on the inside of the AMuSED box are not well related to the theme or its activities					
The AMuSED box images do not prompt reminiscence					
The theme of the AMuSED box is coherent					
The construction of the AMuSED box is sturdy enough					
It would be better not to have specific themes for the AMuSED boxes					
The images on the AMuSED box prompt reminiscence					
The AMuSED box is easy to put together from its individual panels					
The images on the AMuSED box are of poor quality					
Having an Activity Booklet is useful					

Section 2 – Use by Activity Coordinator

How did you choose the activities for your sessions?	
Did you combine the AMuSED box with other activities?	
If yes above, what activities did you combine the box with?	
Did the AMuSED box help you plan or run activity sessions?	
What element or activity did you enjoy working with the most?	
What element or activity did you not enjoy?	

Section 3 – Use by participants

Did your participants with dementia engage with the box?	
What elements of the box were your participants most excited about?	
Were there any elements or activities that your participants did not engage with or enjoy?	
Were there any participants that could not participate in the AMuSED sessions due to impairments or other reasons?	

Section 4 – Interpretation of the AMuSED Box

Based on your sessions, how well did the AMuSED toolkit engage participants with:	Not at all	A little	On and off	Quite a bit	Very much
Early dementia					
Mid dementia					
Late dementia					

Do you believe the AMuSED box helps people to reminisce?	
Is there a difference between the AMuSED box and other tools or activities you normally use? Please state the difference.	

Please state how much you agree or disagree with the following statements about the AMuSED Box (tick appropriately)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The AMuSED box and its contents engage people with dementia					
Having different themes for the AMuSED boxes is useful					
We do not wish to continue to use the AMuSED box (or other themes) and their contents in our future sessions					
The images on the outside of the AMuSED box are of an appropriate size					
The AMuSED box is difficult to put together from its individual panels					
The AMuSED box when placed on a table immediately stimulates interest					
Having a mix of sensory elements, reminiscence prompts and activities in a single box is a good idea					
It is not necessary to include an Activity Booklet in the AMuSED box					
The AMuSED box is well made					
The theme of the box is not clear					
The images on the inside of the box do not help to generate further discussions					
Having question prompts included in the Activity Booklet is helpful					
The AMuSED box has does not stimulate interest when placed on a table					
The box is easy to open and use as separate panels					
The elements in the AMuSED box are not relevant to people at different stages of dementia					
The images on the inside of the AMuSED box link to the theme of the box and/or its activities					
The AMuSED box is poorly made					
Having example questions within the Activity Booklet is not useful					
The images on the inside of the box are useful for stimulating further discussion					
The AMuSED box is difficult to split into its separate panels					

Figure 7.22: Final AMuSED Questionnaire

7.14 Chapter Summary

This chapter showed the results of the evaluations of the Seaside, MERL, Christmas and Entertainment toolkits described in chapter 5 at the different evaluation sites. It detailed the data collection process using pre, during and post questionnaires and the corresponding responses. It also highlighted the adaptability attribute of the AMuSED toolkits described in the AMuSED model in chapter 6 by showing the different ways in which they were used with different groups of people, and the different activities that were organised using the elements in the toolkits. All the individual sites were extremely positive, with the post- session result, where available being at least as positive, and often more positive than the pre- session results. The 6-month follow up also showed highly positive feedback in terms of longevity and novelty, with the different respondents highlighting what they liked and disliked about the AMuSED toolkit as well as further areas of improvement and suggested themes. The results of the evaluation are further discussed in chapter 8.

Chapter 8: Discussion

This chapter discusses the evaluation performed with the different AMuSED toolkits at all the different evaluation sites. It highlights the results of the evaluation detailed in chapter 7 and the different ways in which the activity coordinators incorporated the different AMuSED toolkits into their activity sessions. It examines the use of the AMuSED toolkit by caregivers and activity coordinators for people living with dementia in different settings as well as its use with people with learning and physical disabilities. It also discusses the effect of themes on the AMuSED toolkit, the importance of active multisensory environments and interventions for people living with dementia, the reasons for the success of the AMuSED toolkit at the evaluation sites, the deficiencies of the toolkit and ways in which it can be improved.

8.1 Summary of findings

The AMuSED toolkit was developed to be used by caregivers and activity coordinators to provide engaging and stimulating multisensory and multiactivity sessions to people living with dementia in a range of care provisions, and the evaluations were conducted despite the difficulties and limitations posed by the COVID-19 pandemic. Although this affected the number of sessions in the different locations, feedback was still obtained from all the evaluation sites. The results obtained from all the different sites during the evaluation were highly positive as shown in the responses to the questionnaires as well as the accounts of excitement from the activity coordinators at the different locations after the introduction of the toolkit.

There were also positive differences in the comparison between the first and final impressions of the activity coordinators at some of the evaluation sites such as sites 1, 2 and 6 where most of the responses varied between "*Neutral*" and "*Strongly Agree*" in the first impression questionnaires but were only either "*Strongly Agree*" or "*Agree*" after the evaluation period, with none of the post evaluation results going below "*Agree*". This showed how well the AMuSED toolkit impressed the activity coordinators and care staff and surpassed their initial expectations.

The results of the evaluation showed that the activity coordinators believe the AMuSED toolkit to be well made and easy to use. Usability was one of the attributes identified as a key requirement in chapter 4 for the development of multisensory environments for people living with dementia (Contreras-Somoza et al., 2021), as complexity in interventions has been linked to low success rates of adoption and criticism from users (Kormelinck et al., 2021). Therefore, it was imperative that the

AMuSED toolkit be designed with this attribute in mind. However, feedback from the follow up evaluation showed that the AMuSED toolkit would benefit from the inclusion of instructions or further information on how to use the toolkit and its elements. Some of the elements included such as the Bingo cards and the seeds for flower planting were also recorded as not suitable for people living with dementia due to their small sizes, showing areas for improvement in the usability of these elements in the AMuSED toolkit.

The design of the toolkit also promoted its use in different ways during the evaluation. In some of the sites, the toolkit was setup uprightly and used as a focal point alongside other reminiscence elements. However, in locations such as The MERL which made use of specific images and artifacts from their collection in their chatty café sessions before the introduction of the AMuSED toolkit, the toolkit was deconstructed as shown in figure 7.6 and used as a collection of themes – food, mystery objects, childhood, dressing up and going out, journeys and transport, waking lives, landmarks of life, and makers at work – with each of the panels put into separate themed trays along with the corresponding elements. The home care facility also used the AMuSED toolkit differently by suggesting that the use of all the reminiscence images and elements in a one-to-one session with individuals at home might be overstimulating for people living with dementia and therefore adopting a method of using only one or two panels at a time along with a small selection of elements to conduct their activity sessions in people's homes

Another unique way in which the AMuSED toolkit was used was seen in evaluation site 6 where it was reported that the breadth of activities offered by the elements in the toolkits allowed them to be used flexibly in a way that both the activity coordinators and the attendees could select the activities for the session based on interest and perceived learning aim. This resulted in the identification of the AMuSED toolkit as a flexible tool for removing the strain of having to plan activities from the activity coordinator. The same flexibility was also reported in the results from the evaluation at The MERL and has led to the identification of a new, previously unspecified attribute of the AMuSED toolkit.

When used with adults with learning and physical impairments, the AMuSED toolkit was able to properly stimulate, provide engagement and encourage communication within the group. The results gathered from this evaluation show the transferability of the toolkit from people living with dementia to other groups of people since the attributes of the toolkit make it appropriate for use with not only people with dementia, but also people with different forms of learning and physical

impairments. This suggests the possibility of a wider scope for the AMuSED toolkit especially with a younger audience, as the age range for the attendees at the activity sessions was between 30 to 50 years, considerably younger than the age range of people living with dementia (Xu, 2021). This creates the possibility that the AMuSED toolkit can be further adopted for use by a younger audience with other impairments or conditions outside of dementia.

The results also supported all the attributes of the AMuSED toolkit such as portability (Dröes et al., 2019), accessibility (Zwingmann et al., 2020), adaptability (Zhang, 2020), affordability (Ihara et al., 2019), usability (Contreras-Somoza et al., 2021) and personalisation (Ryan et al., 2020). Although the toolkit was recognised as being portable and easy to move around within a care home, wheels were suggested to further improve this attribute. The toolkit was also recorded as affordable due to its use of off-the-shelf elements, adaptable and able to cater to different people with different stages of dementia, accessible by being able to provide stimulation to people with impairments and other forms of comorbidities, personalisable and able to deliver person centred care, and usable due to its lack of complexity and complex components. The results in relation to these attributes fulfils the one of the objectives of the PhD and establishes the AMuSED toolkit as an affordable, adaptable and portable toolkit that can be used by caregivers and activity coordinators to provide engaging and stimulating multisensory and multiactivity sessions to people living with dementia in a range of care provisions.

The results of this evaluation also showed the relevance of the use of images in reminiscence therapy (De Groot et al., 2021; Houben et al., 2021) by highlighting that the images were able to promote engagement (Holloway et al., 2021), communication (Nordgren and Asp, 2019) and reminiscence in people living with dementia by creating discussion points and even allowing conversations among group attendees to evolve on their own through various discussions such as in evaluation site 4. However, further feedback revealed that interaction with the images by the session attendees resulted in questions about the time and location of some of these images. These questions however could not be answered by the caregivers and activity coordinators due to the lack of labels, descriptions, or further information on the images. The limitations covid-19 placed on the evaluations also resulted in the absence of a researcher at the locations to answer these questions. This issue however can be readily resolved by labelling the images or including descriptions of the images in the activity booklet. A focus group of people living with dementia and their caregivers would also have revealed topics, places and media that are more familiar and therefore more recognisable to people living with dementia in the UK.

One of the gaps in literature and practice that the AMuSED toolkit aimed to fill was the absence of interventions that provided both Snoezelen (Pinto et al., 2020) and engaging activities (Cavalcanti et al., 2020) for people living with dementia. The results show that activity coordinators and caregivers approved of the selection of themed digital and traditional elements in the toolkit which provided a combination of both engaging activities and Snoezelen and found them appropriate for the engagement and stimulation of people living with dementia. This was also evident in the comments regarding the novelty of the AMuSED toolkit where the activity coordinators acknowledged the inclusion of interactive, engaging and sensory elements and activities in the toolkit, with one activity coordinator pointing out that it covered all sensory needs, and another stating the presence of exciting and interactive elements while comparing it with a memory box.

The prompt questions (Potts et al., 2020) and activity booklet although not used in some locations, were highlighted as useful during the first impressions. The final impression results were also positive in the locations where they were used such as at The MERL where the activity coordinators found the prompt questions to be useful in steering the conversation and creating a more focused discussion (Rai et al., 2021). The activity booklet was also reported in the evaluation with adults with special needs as not only providing enjoyable and appealing activities to the attendees, but also helping to remove the strain of planning different activities from the activity coordinators.

One of the recurring pieces of feedback provided when asked about how the AMuSED toolkit could be improved was the inclusion of videos, with the manager at The MERL suggesting videos from the MERL archives to be included in the Countryside edition toolkit. It was believed that the inclusion of this additional form of media to the AMuSED toolkit would strengthen the toolkit even further by promoting reminiscence (Donald, 2020) and increasing the level of engagement provided to people living with dementia (Inel Manav and Simsek, 2019). Therefore, cubes displaying QR codes with links to video clips of famous movies from the 60s and 70s era were included in the Entertainment toolkit to be played by the activity coordinators on any smartphone with a QR code scanner in order to increase the amount of reminiscence cues, provide an extra source of stimulation and further strengthen the sessions. These are also being made available to The MERL to be included in the Countryside toolkit once the videos from their archives have been provided. The inclusion of wheels on the AMuSED toolkit was also suggested during the evaluation as a way of promoting mobility and further improving the portability of the toolkit.

8.2 The effect of themes on the AMuSED toolkit

The inclusion of themes in the AMuSED toolkit was introduced during the design stage in chapter 4 following feedback from the dementia experts. Themes are often used in non-pharmacological interventions and sessions as a way of focusing them on a specific subject matter and can make activity sessions more engaging and enjoyable for the attendees (Shoesmith, Charura and Surr, 2021). The results of the study showed that all the AMuSED themes evaluated – seaside, Entertainment, Christmas and MERL – were able to provide similar levels of engagement to the session attendees across all the different evaluation sites. Furthermore, although each theme incorporated the use of different elements, or similar elements used in different forms, such as the sound buttons used to record different sounds corresponding with the theme, all the elements of each theme were carefully selected to stimulate the visual, olfactory, gustatory, audio, and tactile senses. Therefore, all the different toolkit editions were able to deliver multisensory stimulation to the attendees during the sessions.

8.3 The importance of an active multisensory environment

People living with dementia often suffer from some of the behavioural and psychological symptoms of the disease such as apathy and agitation (Mouriz-Corbelle et al., 2021). These symptoms which have a negative effect on their mood and emotions can lead to a low quality of life (Kim, Noh and Kim, 2021). There is also a need to constantly engage people living with dementia to ensure that they are actively stimulated (Henskens et al., 2018). The AMuSED toolkit does this by providing an affordable, adaptable, personalisable, portable and usable source of engagement through the combination of digital and traditional themed elements that work together to provide visual, audio, olfactory, gustatory, and tactile stimulation to its users.

One of the drawbacks of Snoezelen and other forms of multisensory stimulation is that they do not include any form of activity and are therefore sometimes unsuitable for people living with mild and moderate dementia (Achterberg, Kok and Salentijn, 2021). They also do not include any form of challenge and offer little to no amount of cognitive stimulation (Zaree, 2020). The AMuSED toolkit fills this gap by not only providing multisensory stimulation, but also providing activities such as painting, buzzwire, jigsaw puzzles, word search, ring toss etc. that can provide a level of challenge to the users and stimulate them cognitively. At the sessions with the charity, the ring toss game was turned into a competition with the scores recorded and this was developed into a challenge that would span weeks. The inclusion of these different challenging elements to multisensory

stimulation is essential because cognitive stimulation is also an important factor in the wellbeing of individuals, especially people living with dementia (Lobbia et al., 2018). This fusion of themed digital and traditional elements which provides a combination of multisensory, multiactivity and cognitive stimulation is also one of the things that make the AMuSED toolkit novel and sets it apart from the other non-pharmacological interventions used in literature and practice.

The transferability of the AMuSED toolkit from people living with dementia to people living with learning and physical disabilities showed the flexibility of AMuSED, which is further enabled by the AMuSED framework. This framework which contains the AMuSED model, toolkit library, and the layout of the AMuSED box was developed to promote transferability of the AMuSED toolkit to different users or user groups. The AMuSED framework encourages creativity by allowing new AMuSED toolkits to be created based on the parameters defined in the AMuSED model such as intervention, attribute, constraint, location, severity of dementia, mode of use and theme.

This means that a new AMuSED toolkit can be created by a caregiver, activity coordinator, or other person for someone living with dementia by choosing the appropriate interventions, attributes, and constraints from the baseline layer (Layer 1) of the AMuSED model. These baseline parameters should then be measured against the parameters in the other layers of the model such as the user's location (Layer 2), the severity of their dementia (Layer 3), whether they will benefit from a personal or group AMuSED toolkit (Layer 4), and the most relatable theme to the potential user based on their lived experiences (Layer 5). The appropriate elements can then be selected from the many sensory elements in the toolkit library, and multiple reminiscence images related to these elements can be printed on the internal and external panels of the AMuSED box displayed in the framework.

The AMuSED framework serves as a ready to use tool in the creation of an AMuSED toolkit for a person living with dementia. The flexibility of this framework led to the development of the Entertainment-Life toolkit for the home care facility. It has also encouraged the creativity of caregivers and activity coordinators as already existing elements and activities previously used in sessions before the introduction of the AMuSED toolkit can still be incorporated into AMuSED sessions. Further elements such as personalised reminiscence images, pomander making, personalised music and songs, literacy games, arts and crafts, and other activities related to the user, demographic, or location can also be included in the toolkit library in accordance with the theme. The transference of the AMuSED toolkit to user groups outside of people living with dementia as shown in the evaluation with people with physical and learning disabilities also

suggests the possibility of the AMuSED toolkit to be used to create AMuSED toolkits for other users outside of dementia. Recognising the importance of, and providing the ability to, create a non-pharmacological intervention that meets the needs and requirements of people living with dementia and their caregivers or activity coordinators in different care surroundings through the AMuSED Model and overall AMuSED Framework provides a second contribution to knowledge from this thesis.

8.4 The success of Design Thinking

The success of the AMuSED toolkit as an active multisensory environment for people living with dementia can be largely attributed to the use of the design thinking approach which provided a key set of steps that led to gaining a deep understanding of the engagement needs of people living with dementia through literature review, identifying the gaps in the non-pharmacological interventions used for engagement in practice, developing the AMuSED concept through co-design with dementia experts, developing the AMuSED toolkit through prototyping, and evaluating the different AMuSED themes with caregivers and activity coordinators in different care locations. This approach also included a shadowing session with a care team at the hospital to observe the delivery of activities to people living with dementia in practice which helped to gain a deeper understanding of the users and aided the development of the user personas.

It is important to note that due to the symptoms and manifestations of the disease, people living with dementia may have difficulty evaluating an intervention and articulating the benefits and pitfalls of a design (Cohen-Mansfield, Gavendo and Blackburn, 2019). However, evaluations and feedback concerning a design or intervention can be collected from other means such as caregivers and care home staff and activity coordinators (Tsunaka and Chung, 2012). The adoption of the design thinking methodology for this research allowed for co-design with dementia experts at the beginning stages to not only determine the key requirements of an active multisensory environment based on their vast experience and active roles of responsibility for people living with dementia, but also highlight and address the benefits and deficiencies of the AMuSED concept, design, and elements. Also, testing each element before their inclusion into the toolkit revealed certain pitfalls, such as the candy floss machine that constantly "spat" hot sugar.

Design thinking also allowed adjustments to be made to the AMuSED design through iterative prototyping, based on the expert feedback until the toolkit met the needs of the user population.

This was taken even further in the "Test" phase of the design thinking approach where multiple AMuSED toolkits were used by activity coordinators and caregivers with people living with dementia. Here, a more direct approach was taken as the activity coordinators were able to identify, describe and report the benefits and pitfalls of the AMuSED toolkit based on their observation of how the session attendees (people living with dementia) interacted with the toolkit. Hence, although the user population could not articulate the benefits and pitfalls of AMuSED, enough information was still successfully collected from both the dementia experts at the ideation and prototyping stages, and the activity coordinators at the testing and evaluation stage.

This design thinking methodology also helped to identify the key ingredients of the AMuSED toolkit such as visually stimulating reminiscence images, multisensory elements, engaging and adaptable activities, and an attractive and easy-to-use packaging. The use of high-quality reminiscence images and printing on the panels gave the AMuSED toolkit a *"wow factor"* and promoted great first impressions at the evaluation sites. The attributes considered for the inclusion of elements and activities in the toolkit such as adaptability, affordability, portability, usability, accessibility, and personalisation also ensured that the AMuSED toolkit performed well during activity sessions when used with people living with dementia. Finally, the inclusion of the activity booklet and prompt questions made the planning of activity sessions easier for the activity coordinators and helped to organise smooth discussions during the sessions. Applying the design thinking approach to the development to ensure that non-pharmacological interventions meet the needs and requirements of people living with dementia and their caregivers or activity coordinators in different care surroundings can be considered an additional contribution to knowledge arising from this thesis.

8.5 The value of the user personas

As defined by (Cooper, 1999) personas are fictitious, specific, and concrete representation of target users, created with the goal of helping product designers better understand their target users and thus improve their products. They are a collection of realistic, representative information which usually include fictitious details for a more accurate characterisation (Cooper and Reimann, 2005). Personas are very valuable as they not only communicate the needs of the target users but can also provide flexibility and allow the occasional switching between the user perspective and the designer role which in turn promotes the orientation of an intervention design to the user experience (Qaed and Almurbati, 2021).

The personas created in chapter 4 – Ruby, Michael, Emilio, Angela, Emmanuel, and Rachael – were referred to at multiple stages of the research to ascertain how each adjustment would affect the different types of AMuSED users. For example, Rachael was referred to in the decision to design the AMuSED box as a collection of detachable panels, due to her role as a home caregiver who organises activities for individuals with dementia at home. The detachable panels were designed to not only improve mobility as her job required frequent travels between the homes of her care recipients, but also to prevent overstimulation during her one-to-one care activities. The different personas also influenced considerations regarding the shape, size, and weight of the AMuSED toolkit.

Furthermore, the personas influenced the elements that were included in the toolkit, especially in relation to the different locations of the users (personal homes, care homes and hospital). Consideration was given to the different environments where the toolkit would be used (single and multi-user environments), as well as the mode of use of the toolkit (personal sensory, personal activity, group activity). Also, decisions such as the inclusion of a clear plastic box to allow for easier movement between different locations or wards in the care home, the development of the activity booklet to help the activity coordinators understand and get started with the toolkit, and the type of prompt questions which were designed to be at an appropriate level of comprehension of a person with dementia were influenced by the personas.

Since this research did not involve direct interaction with people living with dementia, the personas were a useful tool in predicting how people would interact with the AMuSED toolkit during activity sessions. For example, the activity booklet contained activities such as trips to the seaside, cinema experience, and snowman activities, which the personas were most likely to interact with due to their interests. Also, since all the personas of people with dementia were situated within the United Kingdom, it was imperative that the reminiscence images inside and outside of the toolkit be relatable to life in the United Kingdom such as the Blackpool beach, Carter's Steam Fair, Wimbledon, and many other notable locations and activities within the United Kingdom.

The combination of the observation performed in Chapter 4 and the personas was also very beneficial in the design of the study. From the personas, it was clear that Angela, Emmanuel, and Rachael, caregivers in different care locations, might have other care duties outside of coordinating activities and may not have been able to conduct many sessions in a day. Therefore, the study proposed that the activity coordinators at the different evaluation sites had at least two weeks, and

often longer, to use the AMuSED toolkit to allow enough time for the use of the toolkit in multiple sessions. Also, the AMuSED toolkit was designed in such a way that a single activity session would provide multiple forms of stimulation to the attendees. This also influenced the design of the suggested activities proposed for the evaluation of the toolkit at the various locations.

Due to the COVID-19 pandemic, it was very difficult to observe real user interaction with the AMuSED toolkit. Hence, the personas were very valuable in helping to visualising the use of the toolkit by the end users. This, combined with the observation and feedback from dementia experts provided a good representation of the end users and helped to put them at the centre of the AMuSED design (Wang, 2014). Furthermore, testing each feature, adjustment, and improvement against the multiple personas allowed for key areas of improvement to be discovered such as the collapsible and more compact mode of storage of the AMuSED box to benefit the activity coordinators, or the incorporation of colourful Legos into the design to improve the outlook and add a playful element to the toolkit.

8.6 Summary

The results of the evaluation conducted in chapter 7 showed the AMuSED toolkit as a novel intervention relevant for providing engagement and stimulation to people living with dementia in various care provisions as well as adults with learning and physical disabilities. It also supported all the attributes considered in the development process of the toolkit in chapter 4 and identified flexibility as an additional attribute of the toolkit. The effects of COVID-19 on the evaluation were briefly discussed in this chapter but are detailed in the limitations section of chapter 9. This chapter also showed how well the AMuSED toolkit performed with adults with learning disabilities and chapter 9 recommends how future work can be conducted with this group and other similar groups.

Chapter 9: Conclusions and future work

Chapter 8 discussed the results of the research based on its evaluation at a range of different care locations as well as its relationship to the prior literature. This chapter concludes the thesis and showcases the achievements of this PhD. It summarises the rationale for the work, the research undertaken, the outcomes, and the novel contributions of the PhD to the field. It also explores the limitations of the research and provides recommendation for future work.

9.1 Rationale – the need for AMuSED

Chapters 1-3 established that the wellbeing of people living with dementia can be enhanced through the provision of meaningful activities in both formal and informal settings (Nyman and Szymczynska, 2016), with avenues for engagement including art therapy, exercise programmes, music therapy, aromatherapy, cognitive stimulation, multisensory stimulation, and reminiscence therapy (Dyer et al., 2018). As well as maintaining function and encouraging participation in activities outside of a person's daily routine, such activities can help them better cope with the consequences of the disease (Baker et al., 2001; Milte et al., 2016). These non-pharmacological interventions also provide safe, non-invasive ways of treating some of the behavioural and psychological symptoms often associated with dementia including apathy and aggression (Poulos et al., 2017), and help reduce social isolation and improve the quality of life of both people living with dementia and their caregivers (Zucchella et al., 2018; Buettner and Fitzsimmons, 2003).

In care homes, community and hospital settings, activities that aim to promote the health and wellbeing of those they are caring for are generally organised by care crew (Brooke and Herring, 2016; Evans et al., 2019) or activity co-ordinators (Guzmán et al., 2017) who deliver a range of activities such as such as music, reminiscence, art, puzzles, and games. Although there are many excellent and appropriate activities available on the market designed to engage and stimulate people living with dementia ranging from specialist multisensory rooms and environments such as the Snoezelen (Duchi et al., 2019; Lorusso and Bosch, 2018) and interactive gaming systems such as the Tovertafel (Anderiesen, 2017) to simple jigsaws and colouring books designed for adults with dementia, there is currently no single product that has all the qualities of being low-cost, portable, and adaptable to different stages of dementia, and which combines sensory and activity elements with physical and media artifacts through a strong reminiscence theme.

The focus of this PhD has thus been on developing in conjunction with a group of experts in dementia care, a multisensory toolkit, AMuSED (**A**ctive **Mu**lti-**S**ensory **E**nvironment for People Living with **D**ementia) that brings together different aspects of dementia therapy into a single portable box for use by carers, care teams and dementia activity coordinators to engage and stimulate people living with dementia physically, mentally, and socially through a combination of sensory elements and themed activities.

9.2 Research Objectives and Contributions

9.2.1 AMuSED Concept

This research was conducted using the Design Thinking methodology (Brown, 2008), a person-centred innovation process which has at its foundation the need to build an understanding of who the solution is being created for, followed by iterative development of prototypes that build towards the final solution with amendments based on user feedback. As such it incorporates observation, collaboration, fast learning, idea visualisation, prototyping and business analysis (Lockwood, 2010).

Understanding of the users grew from initial observations of the Care Crew working with dementia patients at the hospital and continued with co-design and co-creation activities with experts on the Dementia Friendly Reading Steering Group which resulted in the development of the AMusED concept and its requirements. AMuSED aims to fill the gap in the market and research for an affordable toolkit that brings together a range of proven activities for engaging people living with dementia as well as providing them with the visual and auditory effects of a sensory room. This combination is achieved in a manner that eliminates some of the drawbacks of dedicated sensory rooms, such as the high setup cost, use of expensive elements and the need for a dedicated room. The AMuSED concept makes use of low-cost, off-the-shelf materials to bring together and replicate the effects achieved by multisensory rooms, reminiscence kits and other proven activities such as art and music, in a form that is portable enough to be used independent of a dedicated location or room, the AMuSED toolkit. As such the work has met Research Objective 1 and resulted in Novel Contribution 1 as stated below and detailed in Chapter 4:

> ***Research Objective 1:*** *Work alongside dementia experts to co-create the requirements for a multisensory and multiactivity environment for people living with dementia.*

> ***Novel Contribution to Field 1:*** *The concept of an affordable, portable, and adaptable **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) toolkit, based on analysis of current state-of-the-art research and state-of-the-practice therapy, for use by caregivers and activity coordinators to provide engaging and stimulating multisensory and multiactivity sessions for people living with dementia.*

9.2.2 AMuSED Toolkit

The AMuSED toolkit development is underpinned by the current research and best practice in activity provision for dementia care according to experts. As such the toolkits are designed to be affordable and personalisable to an individual's or groups interests. Elements of the toolkit such as music, fragrances and essential oils for aromatherapy can also be personalised based on the mood or emotional requirements of a particular user or themed to encourage group social interaction and activity. For instance, games can be used to engage users and relieve passivity while a combination of music and the gentle stimulation from aromatherapy can be used to calm agitated users or to set the scene for reminiscence sessions. Items included in an AMuSED toolkit are a combination of physical and digital elements that can be downloaded from online sites subject to correct licence agreements or purchased through online stores. The images, contents and activities are linked to a set of reminiscence images printed on the inside and outside of the toolkit panels and designed to stimulate discussion and encourage people to 'revisit' and share their life experiences. An activity and question prompt booklet accompanies the toolkit to assist caregivers or give activity teams suggestions of how to use the contents of the toolkit in a coordinated manner. It is quick and easy to set up using colourful Lego brick tracks and can be used either as the complete toolkit or as a series of panels and activities that can be distributed around a room.

For durability, the toolkit is professionally printed on wipe-clean vinyl which is attached to high quality dense black foamboard. The toolkit comprises a lid, base and four sides which can be slotted together in under two minutes, and which is delivered with its multisensory and activity contents in a single plastic container for easy storage and portability. Use of low-cost items and its ability to be used independent of a room or location means it can be used to provide non-pharmacological interventions to a wide range of people or groups without the need to have a particular space dedicated to it. This is particularly useful for users who cannot afford dedicated or expensive multisensory stimulation set-ups as well as enabling the experience to be shared among multiple

groups. AMuSED toolkit themes developed for the PhD were Seaside, Countryside, Entertainment and Christmas Editions with Figure 9.1 showing an image of the Seaside themed AMuSED toolkit and some of its toolkit contents.

Figure 9.1. Example of an AMuSED toolkit

As such the work has met Research Objective 2 and resulted in Novel Contribution 2 as stated below and detailed in Chapter 5:

Research Objective 2: *Translate the co-created requirements into a series of prototypes that increasingly define the form of an **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) as an affordable, adaptable and portable toolkit that can be used by caregivers and activity coordinators to provide engaging and stimulating multisensory and multiactivity sessions to people living with dementia in a range of care provisions*

Novel Contribution to Field 2: *The AMuSED Toolkit, a multisensory and multiactivity toolkit that implements the AMuSED concept so that it can be used by caregivers and activity coordinators in different care settings such as individual homes, community spaces, care homes and hospitals to stimulate the physical, mental, and social wellbeing of people living with dementia.*

9.2.3 AMuSED Framework and Model

The need for a way of encapsulating and documenting the AMuSED Toolkit Concept (Research Objective 1 | Novel Contribution 1) and its tangible realisation as the AMuSED Toolkit (Research Objective 2 | Novel Contribution 2) has resulted in the AMuSED Framework (Research Objective 3 | Novel Contribution 3). The AMuSED Framework provides a way of specifying different versions of the AMuSED Toolkit to meet individual or group requirements or settings.
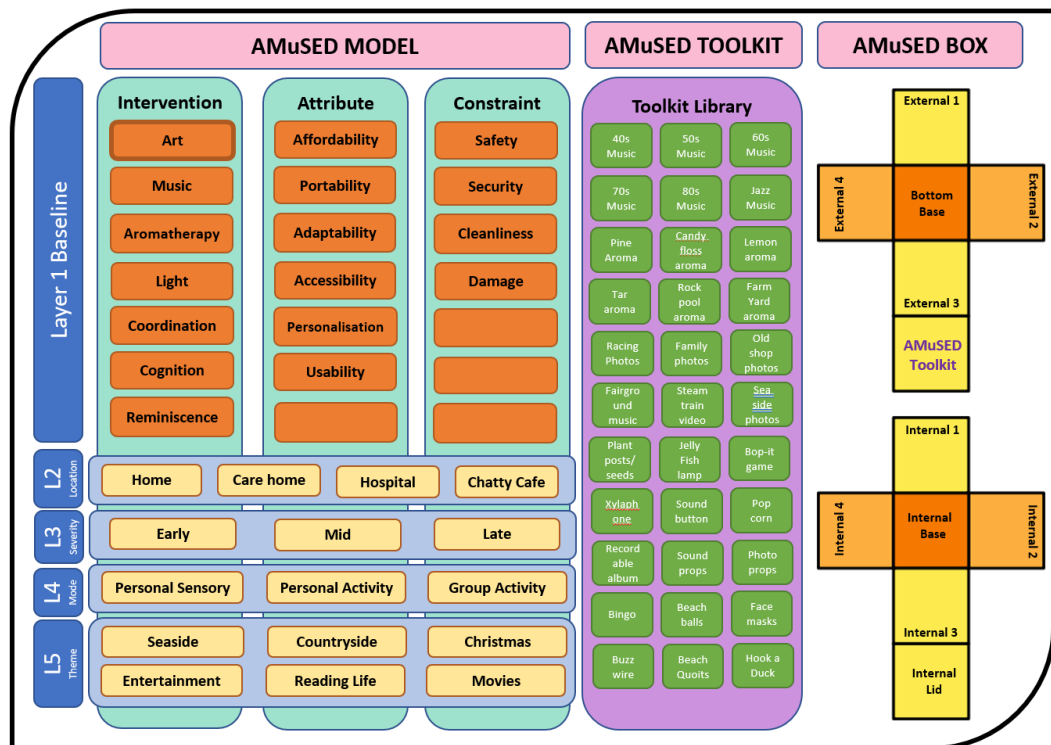
Figure 9.2: The AMuSED Framework and examples of items in the Toolkit Library

The AMuSED Framework as shown in Figure 9.2 consists of three core components (1) The AMuSED Model which incorporates the different interventions, parameters, considerations, and settings uncovered during the research process; (2) an AMuSED toolkit library which describes and documents the physical and digital multisensory components, elements, and activities that collectively form the AMuSED Toolkit and from which the contents of the individual AMuSED toolkits are selected and (3) the AMuSED Box itself which comprises six panels printed double-sided with themed or personalised reminiscence images that slot together to form the box.

The AMuSED Model is further represented by five interrelated layers: (1) Baseline that highlights different interventions, design attributes and constraints; (2) Location that considers where the AMuSED toolkit will be used; (3) Severity (and type) of dementia exhibited by an individual or group

228

of people who will use the AMuSED toolkit contents; (4) Type of Activity which considers how the AMuSED toolkit is intended to be used; and (5) Theme (or personalisation) of the AMuSED toolkit. By working through the above layers of the AMuSED Model, existing AMuSED toolkits can be modified to better suit individuals or specific care facilities, as well as new themes created. The model also allows for the AMuSED concept to be expanded from its current 10 prototype toolkits, as it provides a way for different individuals from various backgrounds to be able to understand, put together, tailor and use an AMuSED toolkit independent of a researcher. This means that the impact of AMuSED could, with the right funding model (see Future Work section), be spread to other care facilities in Reading, across Berkshire, throughout the UK and even globally.

By creating this AMuSED Framework, the work has met Research Objective 3 and resulted in Novel Contribution 3 as stated below and detailed in Chapter 6:

> ***Research Objective 3:*** *Based on the series of AMuSED prototype toolkits created, develop an AMuSED framework and model that enable different AMuSED toolkits to be defined for individuals, themes, and/or places of care including for example, individual homes, community settings, care homes and hospitals*

> ***Novel Contribution to Field 3:*** *The AMuSED Framework – a framework that formalised the ideas incorporated in the AMuSED Concept and AMuSED Toolkit Prototypes in order that AMuSED Toolkits can be specified and built based on individuals' preferences, requested themes, and/or places of care including for example, individual homes, community settings, care homes and hospitals. This Framework forms the basis for the continuation of the AMuSED work and its translation from research into mainstream social care provision*

9.2.4 AMuSED Evaluations

Evaluations (detailed in Chapter 7) of the AMuSED toolkits in a range of care provisions have shown the applicability of the PhD research to real-life practice with activity coordinators for people living with dementia giving highly positive feedback on the AMuSED toolkits. A further highly successful evaluation of the AMuSED toolkit with activity coordinators for adults with special learning needs has provided an additional novel contribution of the work related to its transferability into other care spaces.

> ***Research Objective 4:*** *Evaluate a range of AMuSED toolkits with care teams and activity co-ordinators in community and care facilities in Reading and Newbury*

9.2.5 Use of Design Thinking for Developing Non-Pharmacological Interventions

Following on from the success of the AMuSED Toolkit in different care locations and the demonstrated ability for AMuSED boxes to be specified and tailored for specific care scenarios largely through applying a Design Thinking approach to the work, a further contribution to the field of development of non-pharmacological interventions for people living with dementia has been identified from the thesis.

9.3 Limitations of the Research

The most significant limitation to this research was the COVID-19 pandemic which necessitated some changes within the research methodology. Ideally, focus groups involving individual people living with dementia and their caregivers would have been included in the research process to evaluate the AMuSED concept and the subsequent prototypes but the lockdowns and restrictions placed by the government across the UK due to the pandemic prevented any physical gatherings and led to the AMuSED concept being co-designed and co-developed by dementia experts using video conferencing software. These restrictions also prevented researchers from being physically present at most of the evaluation sites during the evaluations sessions which resulted in less detailed observations of the AMuSED toolkits in action than could have otherwise been made. Similarly, it was not possible to set up and test hypotheses related to the impact of the AMuSED toolkits on the activity coordinators or people living with dementia.

Lockdowns, restrictions on group gathering placed by the government, and multiple covid outbreaks across all the evaluation sites because of the COVID-19 pandemic also resulted in activity coordinators having to cancel or postpone their planned sessions with the AMuSED toolkits for as long as a month in some cases. This reduced the number of actual sessions in which the AMuSED toolkits were used compared with the activities that had been planned for their use. Lockdowns also affected the chatty café sessions at The MERL with them cancelled for some time and then people with dementia being very cautious of venturing out when restrictions ceased. Finally, the

lockdowns also meant that the Christmas AMuSED toolkits could not be delivered to some of the evaluation sites.

One minor limitation of the research was that some of the smell capsules used in the AMuSED toolkit, although purchased from one of top aroma scent makers, were considered by many of the activity coordinators and people with dementia to not smell of what they were intended to and were deemed to smell alike. Whilst the 'smells' were still one of the most eagerly anticipated and enjoyed activities, this poor distinction of smells did have an impact on the results, as some of the locations provided feedback that some attendees did not enjoy some of the olfactory stimulation provided by the capsules. Additionally, the Seaside AMuSED toolkit, initially included a Candy Floss maker for additional sensory experience, but following pre-delivery trials, this was removed on the grounds of safety due to the maker sometimes spitting boiling hot sugar whilst in operation!

Finally, the questionnaires used in the initial evaluations of the toolkit had the potential for bias due to the positively framed statements used. To rectify this and eliminate potential bias, an open-ended questionnaire was used for the 6-month survey, allowing the respondents to evaluate the AMuSED toolkit using their own words. A later questionnaire, to be used going forwards for any further evaluations, was also designed at the end of the research which not only contained both open and closed ended questions, but also incorporated balanced framed statements to reduce the possibility of bias.

9.4 Future Work

This PhD has many interesting directions in which it can be enhanced or extended. These include:

9.4.1 Expansion of AMuSED Themes and Toolkits.

The number of AMuSED toolkits can be readily expanded to include additional themes to add variety in general, as well as themes that will be beneficial to different user groups, gender, ethnicity, and location. Themes such as weddings, fashion, sports, festivals, and school years were some of the suggestions made by the activity coordinators.

Items within the toolkits can also be expanded with regards to both physical and digital elements. "What's in the box?" activities which combined physical objects with sound or music clues were particularly popular. Digital elements such as recordable photo albums, sound buttons, lamps, lights, and QR codes were used in this research as well as sustainable elements like aqua paints and

traditional games items. However, in times of lockdown it was the one-off use colouring and wordsearch sheets that were the easiest to use and distribute to residents as they could be thrown away after a single use. Further investigations can be made into the most popular items to include in each of the AMuSED toolkits as well as ways of balancing affordability, sustainability, and usability. Customisation of existing AMuSED themes, or expansion in the number of AMuSED toolkit themes, will be facilitated using the guiding steps of the AMuSED Framework and Model.

9.4.2 Further Studies with People with Dementia

This PhD has involved input from dementia experts and activity coordinators throughout the Design Thinking process, however the pandemic prevented any direct interaction between the researchers and people living with dementia and all feedback of how engaged people at different stages of dementia were with the AMuSED Toolkits was passed back via the activity coordinators. Additionally due to the pandemic, and although one evaluation site provided in-home care, the PhD study could not involve informal caregivers such as family members in private homes. Further research can be developed where, ethics permitting, people living with dementia in care facilities, as well caregivers and the people with dementia they are caring for in individual homes can be included directly in the study and their overall impressions of the AMuSED toolkits recorded.

The COVID-19 pandemic restricted the evaluation of the research and resulted in fewer evaluation sessions. However, a longer study with more frequent sessions may provide a deeper insight into the benefits of the AMuSED toolkit, especially with a researcher present to observe the sessions. The AMuSED toolkit can also be evaluated against hypotheses and with a control group to determine its advantage over other forms of technology or non-pharmacological interventions. A study can also be conducted to look at visual dominance, especially in relation to the olfactory elements (smell capsules) in the AMuSED toolkit. This can be conducted either by putting smells in containers shaped like the smell, having images of the smell on the smell capsules, or having a chart with or without distractors so that people can match the aroma cubes with the images. This study can be used to determine whether smells are perceived differently if people are aware of the smell beforehand and it will also be useful in seeing whether the smells are accepted better than they were in this PhD i.e., if people find the smells easier to recognise when visual cues are attached.

Currently, this research has determined that the AMuSED toolkit is appropriate and can provide engagement and stimulation to people living with dementia in different care locations. However, the long-term effects of the use of the AMuSED toolkit are currently unknown. Therefore, the

toolkit can be further studied via measurement and metrics to determine its long-term effect on the wellbeing and quality of life of people living with dementia in these different locations and whether there are any long-term benefits of the toolkit to them or their caregivers. These can be done through different study designs such as randomised controlled trials, non-randomised control studies, and before and after studies, considering different measures of outcome such as the following:

- Quality of life (QoL): adequately expressed as "the addition of life to years rather than years to life" (Clark, 1995), quality of life can be measured following the introduction of an intervention to evaluate its effectiveness. Many QoL measures such as Quality of Life for Dementia (QoL-D) (Terada et al., 2002), Quality of Life in Alzheimer's Disease (QoL-AD) (Logsdon et al., 1999), and Dementia Quality of Life Instrument (D-QoL) (Brod et al., 1999) adequately assess physical, psychological, and social variables, and could be used to measure the impact of AMuSED on the quality of life of people living with dementia (Logsdon et al., 2002).

- Engagement and emotion: defined as the act of being occupied or involved with an external stimulus (Perugia et al., 2018), engagement with the AMuSED toolkit could be measured in relation to social interaction (Jones, Sung and Moyle, 2015) or participation in activities (Sherratt, Thorton and Hatton, 2004) using tools such as the Observational Measure of Engagement (OME) (Cohen-Mansfield et al., 2011) and the Menorah Park Engagement Scale (Skrajner and Camp, 2007). Also, although people living with dementia have a reduced cognitive and communicative capacity, they still possess the ability to display preferences or aversions through emotional facial expressions (Hammar et al., 2011). Therefore, scales such as the Observed Emotion Rating Scale (OERS) (Lawton et al., 1999) could be used by caregivers to observe the emotions through the facial expressions of the attendees during the AMuSED sessions.

- Nursing Intervention Classification (NIC) (McCloskey and Bedechek, 1993): this defines an intervention as any treatment, based upon clinical judgement and knowledge, that a nurse performs to enhance patient/client outcomes (McCloskey and Bulechek, 2000). This classification organises interventions into seven domains (psychological: basic, psychological: complex, behavioural, safety, family, health systems, and community) and can be used in the identification of interventions that are useful to nursing practitioners (Haugsdal and Scherb, 2003). This could be used to evaluate the usefulness of the AMuSED

toolkit to patients or residents in care homes, hospitals and personal homes, in relation to the different domains.

- Physiological measures: the effect of the use of the AMuSED toolkit on parameters like stress can be measured using methods such as blood pressure measurements (Liang et al., 2017) or the measurement of the stress inducing hormone (cortisol) present in saliva (Adam et al., 2006). Other parameters such as movement and physical activity could also be measured using accelerometers (Rawashdeh et al., 2012).

- Video recordings and analysis: video recordings can be a useful tool in the observation of AMuSED sessions to give insight into the overall behaviour of the session attendees. This could be used in the observation of the behavioural and psychological symptoms of dementia and the effect of the AMuSED toolkit on some of these behaviours (Van Weert et al., 2005). The recordings could then be analysed for different outcome measures using behavioural scales such as the Cohen-Mansfield Agitation Inventory (CMAI) scale (Cohen-Mansfield, 1991) to measure the effect of the AMuSED toolkit on agitation, or the Behaviour Observation Scale for Psychogeriatric In-patients (BIP) (Theleritis et al., 2018), an extensive behavioural observation tool with subscales to measure behaviours such as apathy, anxiety, non-social behaviour, and restlessness before, during, and after the activity sessions.

The effectiveness of the AMuSED toolkit on different genders or ethnicities can also be studied, especially the impact of the different themes or toolkit elements. Studies of how to best use the AMuSED toolkit with people with different types of dementia such as Alzheimer's Dementia, Vascular dementia, frontotemporal dementia and dementia with Lewy bodies will also be beneficial in discovering its effects on these different groups of people and ways of developing the toolkit to be more suited to them. Studying people within all these different groups may lead to the development of more inclusive, diverse and useful AMuSED toolkit themes which can be specified and recorded using the AMuSED Framework.

9.4.3 Translation of AMuSED to different user groups

Following the success of the AMuSED toolkit at Evaluation Site 6, who offer activities for adults with specific learning needs, a separate study focused on the use of the AMuSED toolkit with groups other than people living with dementia including people with learning and cognitive impairments is recommended. The AMuSED toolkit performed well and provided significant engagement and

stimulation at sessions run with people with learning impairments and disabilities and showed positive results especially with the attendees with autism. Therefore, it will be beneficial to the development of AMuSED to build on this and determine how it can be further developed by different user groups and thereby recognise the wider potential benefits of the research. This can lead to the creation of specific themes or the use of specific elements more tailored to these groups as well as consider further groups who might benefit from the AMuSED concept.

9.4.4 Innovation pathway translating AMuSED from academia to social care provision

Feedback about the AMuSED toolkit has been universally positive throughout its development with experts and its evaluations, and some of the experts and managers at the evaluation sites have suggested different models in which the project can be progressed and made more widely available to users.

One of the implementation models considered was to have the toolkits on a subscription basis where people would sign up to receive a particular theme for a time frame e.g., a month, and then exchange their theme with that of another care facility on the subscription roster in the following month. This model meant that people could have access to different themes at different times. One of the evaluation sites is currently enrolled in a similar model for their reminiscence boxes which allows them to receive a different box containing different items every month. Although this model of implementation would mean that the care facilities can have access to different themed boxes without having to purchase them outright, it also means that each toolkit would have to be properly cleaned and sanitised before every exchange, especially due to the COVID-19 pandemic. This model also requires for money to be spent between exchanges to replace missing or damaged elements in the toolkit.

A discussion with the manager at one of the evaluation sites resulted in the consideration of the personnel or "one man" model where the toolkit would be delivered along with an activity coordinator to run the activity sessions. This model of implementation was suggested due to the short staffing issue often experienced in care facilities (Davidson and Szanton, 2020), which usually results in the staff being overwhelmed with other priorities and not having the time to organise or run activity sessions. Care facilities with this issue often rely on volunteers to serve as activity coordinators for their sessions and would largely benefit from having an activity coordinator deliver the sessions along with the toolkit at scheduled intervals. This would also be beneficial for care facilities who might not have the storage space for the AMuSED toolkit as the AMuSED coordinator

would bring the toolkit for the session and return with it after the session was completed. However, a deficiency of this model is that the facilities might not be able to readily access the toolkit when needed, especially in urgent situations such as in the case of trying to calm agitated residents or cheer people up when needed.

Another implementation model considered concerns people with dementia living in their personal homes (de Almeida et al., 2020). Organisations such as evaluation site 5 administer care to this group of people by providing them with care staff and activity coordinators at home. One of the ways in which the AMuSED toolkit can be used on a larger scale is to equip such organisations with the different themed toolkits to allow access to multisensory stimulation for people in their personal homes. This model also provides the opportunity for the AMuSED toolkit to be used and enjoyed with family members, as well as to be personalised with personal items like family photos and videos.

Innovation pathways to translate AMuSED from academia into social care provision by exploring various implementation models that will enable it to be made more readily available to people and groups where it will be beneficial can be explored through business models such as the APEASE (Affordability, Practicality, Effectiveness and cost-effectiveness, Acceptability, Side effects and Equity) framework (Atkins and Michie, 2015), and the Innovate UK Innovation Canvas (KTN, 2022).

9.5 Why AMuSED? (Dragon's Den Scenario)

By the year 2030, the number of people living with dementia globally is estimated to be 58 million (Alzheimer's Disease International, 2020), this large number also means that a very significant amount of money is spent globally on direct medical, social, and informal care, with the total costs expected to surpass $2.8 trillion in 2030 (World Health Organisation, 2021). One of the major challenges in dementia care is the provision of engagement and stimulation to these people who often experience apathy and sensory deprivation due to a lack of stimulation. Formal and informal caregivers, as well as activity coordinators are usually tasked with providing them with engaging and stimulating activities to not only relieve apathy, but also provide an avenue for communication and social interaction.

Studies have shown the need to provide meaningful activities in both formal and informal settings through pleasurable activities and therapies such as art, music, aromatherapy, reminiscence

therapy, and cognitive stimulation. However, although caregivers and activity coordinators deliver some of these activities and therapies through avenues such as memory boxes, twiddle muffs, sensory rooms and boxes, robotic pets, and some other non-pharmacological interventions used in practice, there is no single intervention on the market that has all the qualities of being portable, low-cost, combining sensory elements with activities, incorporating elements of digital technology, offering various exciting and relatable themes, and providing stimulation to all the senses.

The AMuSED toolkit is an **A**ctive **Mu**lti-**S**ensory **E**nvironment for people living with **D**ementia (AMuSED) that brings together different aspects of dementia therapy and themed activities into a single portable box for use by caregivers and dementia activity coordinators with people living with dementia to engage them physically, mentally, and socially through a combination of multisensory and multiactivity stimulation wrapped in a very strong reminiscence theme. This toolkit is an exciting and innovative non-pharmacological intervention which is currently available in four themes – Seaside, Countryside, Entertainment, and Christmas – and uses digital and traditional elements to promote reminiscence and social interaction among people living with dementia.

The four available themes of the AMuSED toolkit have all been evaluated in different care locations – care homes, sheltered housing facilities, dementia community, in-home care facility – around Reading and the Thames Valley area, with all the evaluations reporting highly positive results with an overall score of 4.8 out of 5 across all locations. The toolkits have also been used by different teams and in different ways during the activity sessions in (as a whole, and as an individual panel and selection of elements) and all the activity coordinators, care givers and care home managers have provided positive feedback on the affordability, portability, adaptability, accessibility and usability of the toolkit, with most locations celebrating the novelty of the AMuSED toolkit and mentioning how it contains something for everyone, which allows it to be successful in different care settings and with diverse groups of people living with dementia. This shows that AMuSED falls into the category of a market-pull innovation mentioned in Chapter 4 whereby innovations have clear market need and are designed to solve specific problems following analysis of customer needs.

There are currently about 74 care homes in Reading alone, with a total number of 1,127 people living with dementia, which has been projected to increase to 2,100 by the year 2030 (The Reading Chronicle, 2021). The feedback from putting the AMuSED toolkit in the field showed that not only will each of these care homes benefit from the use of an AMuSED toolkit for their residents, so will

the people living with dementia in their homes, assisted living facilities, the five geriatric wards of the Royal Berkshire Hospital in Reading, as well as other facilities in the Thames valley area. Currently, the development of an AMuSED toolkit for a location costs about £400 which includes the cost of printing the six reminiscence panels, sourcing for the Legos, and purchasing the multisensory and activity elements such as lamps, smells, aquapaints, and puzzles. This is a small price to pay considering the number of people who will benefit from a single AMuSED box especially considering that according to the Alzheimer's Society, the average annual cost of caring for someone with dementia is £32,250 per person and the lifetime cost falling between £100,000 - £500,000 per person. Going forward, if labour to put together the toolkit is added into the equation this brings the boxes to approximately £500 per box, although labour might well be provided on a voluntary basis. Although the process of creating new AMuSED boxes is prescribed through the AMuSED Framework and Model, design of newly themed boxes will incur a further cost of researching the images and elements needed to coherently implement the theme.

To produce AMuSED toolkits for the different care homes and facilities within and outside the Reading area thereby scaling up the impact of AMuSED, funding to support large scale expansion would be required from sources such as the Alzheimer's Society Project Grant scheme, National Institute for Health and Care Research funding, and the Alzheimer's Research UK's Pilot Projects grant. However, community funding opportunities are currently being explored, for example, through the process of showcasing the AMuSED toolkits to Rotary Clubs and asking them to sponsor a toolkit. The clubs are then matched and connected with an appropriate care home to foster a mutually beneficial relationship between both parties where the carehome gets an AMuSED toolkit to stimulate their residents and expand their activity sessions, and the club not only learns more about dementia, but also supports dementia care. As mentioned in Chapter 4, moving from small scale prototypes to large(r) scale distribution even on a social responsibility basis requires further consideration of areas such as IP, copyright, product support and maintenance, something that has been outside of the scope of the PhD, but which will be investigated further as more AMuSED boxes are produced. The learning that has occurred from undertaking the research and development of AMuSED to date will also form an important input to a larger roll-out.

The AMuSED toolkit was not just developed on a whim and made available to caregivers and activity coordinators for the engagement and stimulation of their residents with dementia, it is underpinned by extensive research of the non-pharmacological interventions available in literature and practice, as well as several stages of iterative prototyping, multiple evaluations, and extremely

positive testimonials from activity coordinators and carehome managers in dementia care. The positive feedback of the toolkit shown in this research also provides a strong case for why the AMuSED toolkit should be put into more care facilities to not only stimulate, but also promote communication and social engagement in people living with dementia.

9.6 Conclusion

This PhD has contributed new and unique knowledge to the field and addressed the gaps in literature and practice by creating an **A**ctive **Mu**lti-**S**ensory **E**nvironment for People Living with **D**ementia (AMuSED) in the form of themed multisensory and multiactivity toolkits that are portable, affordable, accessible, usable, adaptable and can be personalised, as well as the AMuSED Framework and Model which have been designed as a tool for the development of further, more personalised AMuSED toolkits by activity coordinators to use with people living with varying stages of dementia in different care locations.

Figure 9.3: The AMuSED toolkit

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263

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Appendices

Appendix A: Ethics I

University of Reading

ETHICS REVIEW APPLICATION FORM

To be used for School *or* University level review

Please append all relevant and supporting documentation to this project application form when submitting for School level (SREC) or University (UREC) review. Text boxes will expand as required and all language used to explain or justify the application should be comprehensible to a lay person.

Application form and all associated documents should be submitted electronically.

Submission deadline dates for UREC can be found on the UREC webpage.

Section 1: APPLICATION DETAILS

1.1 PROJECT AND DATES

Title	Creating an Active Multisensory Environment for People Living with Dementia
Date of submission	13/10/2020
Start date	20/10/2020
End date	30/09/2021

1.2 APPLICANT DETAILS

Chief Investigator	Prof. Rachel McCrindle

Please note that an undergraduate or postgraduate student cannot be a named Chief Investigator for research ethics purposes. The supervisor must be declared as Chief Investigator.

Is the project being carried out in whole or in part to support a student degree?

☒ Yes   ☐ Undergraduate   ☐ Masters   ☒ PhD

☐ No

School	School of Biological Sciences
Department	Biomedical Engineering
Email	r.j.mccrindle@reading.ac.uk
Telephone	01183786536

	Name:	School	Position	Email
All other Applicants	Esther Olorunda	SBS	PhD Student	e.o.olorunda@pgr.reading.ac.uk
	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.

1.3 WHAT REVIEW IS NEEDED?

Please tick the appropriate box below to confirm which review your ethics application requires.

Please tick all that apply.

☒ School Level Review (SREC)	☐ External (for example, HRA)
☐ University Research Ethics Committee Review (UREC)	

Projects expected to require review by the University Research Ethics Committee (for example; research involving NHS patients, research involving potential for distress to participants) must be reviewed by the Chair of the School Ethics Committee or the Head of School before submission to UREC. For further information see Section 16 of the UREC Guidance.

1.4 EXTERNAL RESEARCH ETHICS COMMITTEES

Please provide details of other external research ethics committees from whom a favourable ethics opinion will be required (for example; HRA REC)

Name of Committee	Date of submission / approval	Reference	Status
N/A	Click here to enter a date.	Click here to enter text.	Click here to enter text.

1.5 PROJECT SUBMISSION DECLARATION

On behalf of my co-applicants and myself,

- I confirm that to the best of my knowledge I have made known all information relevant to the appropriate Research Ethics Committee and I undertake to inform the Committee(s) of any such information which subsequently becomes available whether before or after the research has begun
- I understand that it is a legal requirement that both staff and students undergo Disclosure and Barring Service checks when in a position of trust (for example; when working with children or vulnerable adults)
- I confirm that if this project is an intervention study, a list of names and contact details of the participants in this project will be compiled and that this, together with a copy of the Consent Form, will be retained within the School for as long as necessary.
- I confirm that I have given due consideration to equality and diversity in the management, design and conduct of the research project.
- (For Chemistry, Food & Pharmacy (CFP) only) I confirm the Internal Review has been undertaken by Click here to enter text. and I have made the changes requested.
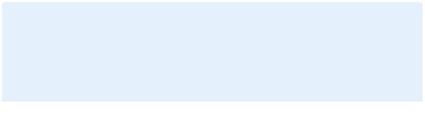
SIGNED, CHIEF INVESTIGATOR

28/08/2020

Where required by the School's Research Ethics Procedures, this ethics application should be signed off by the appropriate person to confirm the School Body are content for this application to be reviewed by UREC.

Chemistry, Food & Pharmacy – will require sign off from: Chair of SREC, Head of Department and School Ethics Administrator – insert rows below as required.

SIGNED, AUTHORISING SIGNATORY

Signature:	Position:	Date:
	Choose an item.	Click here to enter a date.

Section 2: PROJECT DETAILS

316

2.1 LAY SUMMARY

Please provide a summary of the project in plain English that can be understood by a non-specialist audience, which includes a description of the background of the study (existing knowledge), the questions the project will address, the methods to be used and the key ethical issues.

Please note the lay summary should not contain references and be no more than 500 words.

Dementia is the overall term used to represent a range of progressive disorders that involve damage to the brain and can affect the memory, thinking capability, mood, behaviour and lifestyle of people living with them. Many people living with dementia in homes and hospitals spend their days unoccupied and understimulated, which can lead to a low quality of life. Stimulating people living with dementia is a key factor in the improvement of their quality of life and one of the best ways to do this is through the use of games, recreational activities and therapies which may involve the use of technology or otherwise.

The use of multi-sensory environments (Snoezelen), therapies, multisensory kits and activities have been shown to have a positive impact in dealing with the behavioural issues (apathy, agitation, passivity and gerenal boredom) associated with people living with dementia. However, these are often expensive and cannot always be personalised to individuals' interests, as well as be adaptable to the different impacts of dementia as the disease progresses.

This study is aimed at developing a low-cost, technology-based kit that creates an active multisensory environment for people living with dementia in the form of a portable desktop-based toolkit – AMuSED (Active Multi-Sensory Environment for people living with Dementia). This kit combines multisensory activities with sensory room stimulation and caters to all stages of dementia. It can be used by an individual or in a group setting.

This stage of the study, for which ethics approval is being requested, involves speaking with a number of experts in dementia care from across a range of settings (e.g. care home, Reading Borough Council, Age UK), in order to ascertain their views on our proposed Toolkit to (1) gather further requirements, (2) adjust its design, and (3) ascertain any perceived barriers to the use of such a toolkit.

Using a brief Microsoft Teams call with a short set of structured questions provided in advance to participants together with a short video of the AMuSED prototype and it's features, we will get feedback from 5-8 experts recruited from the Dementia Friendly Reading Group with whom we already have contact.

We believe that this ethics application focused just on the discusson with experts can be considered at School Level, a separate application will be made to SBS/UREC in relation to involving people living with dementia and their carers, at a later date, dependent on the COVID-19 situation.

2.2 PRIMARY RESEARCH QUESTION

Please detail the primary research question this project will answer.

Can an affordable, portable, personalisable and adaptable toolkit be developed that will provide engagement and stimulation to people living with dementia?

This aim of this part of the study is to gain feedback from experts working in, or facilitating, a range of care-providing roles to people living with dementia.

2.3 SECONDARY RESEARCH QUESTION(S)

Please detail any secondary research question(s) this project will answer.

We will be discussing the following points with the experts within the context of their roles:
1. What is your job title and for which organisation do you work?
2. What are your overall views on having an affordable, portable, personalisable and adaptable multi-sensory toolkit available for engaging people living with dementia?
3. How do you envisage such a toolkit could be used to help support people living with dementia?
4. Do you think the elements included in the AMuSED toolkit are appropriate for what the kit is setting out to achieve?
5. What do you think will be the benefits of the AmuSED toolkit?
6. What do you think are the negatives of the AMuSED toolkit

7. What do you think will be the challenges of using/adopting the AMuSED toolkit?
8. Are you aware of any products/systems available on the market that already do what the AMuSED toolkit is set to do?
9. Are there any additional elements that you feel should be added to the AMuSED toolkit?
10. Are there any elements you feel should be removed from the AMuSED toolkit?

2.4 DESIGN AND PROCEDURE

Please describe concisely what the study will involve, how many times and in what order, for your participants and the procedures and methodology to be used.

Note: Any questionnaires or interview scripts should be appended to this application.

We will engage with dementia experts at 3 times during this stud: (1) at the early stage of prototype development, (2) at the mid stage, after amendment of the prototype based on their feedback and advice, and (3) at the end of the project. The study will involve talking to five (5) – eight (8) members from the Dementia Friendly Reading Organisation via Microsoft Team calls.

Emails containing details of the study will be sent to Dementia Friendly Reading along with the questionnaire and consent forms detailing that participants can opt out freely. A link to a short video will show the key features of the AMuSED toolkit.

All replies to the questionnaire will be anonymous and no participant will be identified by name. Results will also be published anonymously.

2.5 LOCATION

Please describe where the research will take place.

Online via Microsoft Teams

Please state whether an appropriate risk assessment/ local review has been undertaken.

☐ Yes
☐ No
☒ Not required

Notes:
- Ensure specific risk assessments have been undertaken for non-University locations (for example; schools or participant homes). Please consult either your School Ethics Contact or UREC for guidance.
- If the project is to take place in Hugh Sinclair Unit of Human Nutrition, it must be reviewed and approved by the Hugh Sinclair Manager.

2.6 FUNDING

Is the research supported by funding from a research council or other external source (for example; charities, businesses)?

☐ Yes
☒ No

If "yes", please,

    (a)   Give details of the funding body;

Click here to enter text.

318

(b)   Confirm if the funder specifically stipulates review by the University Research Ethics Committee.

☐ Yes
☐ No

2.7 ETHICAL ISSUES

Please summarise the main ethical issues, including harms and risks, arising from your study and explain how you have addressed them.

None identified; All activities are demonstrated via online calls.

2.8 DECEPTION

Will the research involve any element of intentional deception (for example; providing false or misleading information about the study)?

☐ Yes
☒ No

If "yes", please justify and append a description of the debriefing procedure.

Click here to enter text.

2.9 PAYMENT

Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

☐ Yes
☒ No

If "yes", please specify and justify the amount.

Click here to enter text.

2.10 DATA PROTECTION

What steps will be taken to ensure appropriate secure handling of personal data? Give comprehensive details on the collection, retention, sharing and disposal of participant personal data.

Personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

For guidance on data protection please, see the Data Protection for Researchers Guidance document.

319

Personal data will not be collected outside of the consent form. All ideas and feedback will be recorded anonymously. Quotes or ideas received might be added to future papers but will be done anonymously and will not be attributed to any person.

Will the research involve any activity that requires <u>a Data Protection Impact Assessment</u> (DPIA)?

☐ Yes
☒ No

If "yes", please append the "<u>DPIA Appendix A – Screening Questions</u>".

2.11 INFORMED CONSENT

    a.   Will you obtain informed consent from, or on behalf of, research participants?

☒ Yes   (go to question b)
☐ No   (go to question c)

    b.   If "yes", please describe the process by which they will be informed about the nature of the study and the process by which you will obtain consent.

    c.   If "no", you are not obtaining consent, please explain why (for example; 'opt-out' methodology without the acquisition of consent)?

Please append all relevant participant facing information documentation for participants, parents or guardians. Please note, age-appropriate information sheets must be supplied for all participants wherever possible, including children. Assent should be obtained from children, under 16 years, in addition to the consent required from parents, guardians or carers.

An email containing details of the study will be sent to Dementia Friendly Reading along with a consent form and an information sheet detailing that participants can opt out freely and without detriment.

2.12 GENOTYPING

Are you intending to genotype the participants?

☐ Yes
☒ No

If "yes", which genotypes will be determined?

Click here to enter text.

Section 3: PARTICIPANT DETAILS

3.1 PARTICIPANT NUMBER

How many participants do you plan to recruit?

Please briefly explain why the number is appropriate to answer the study's research question(s).

Between 5 and 8 experts from Dementia Friendly Reading working in different contexts of dementia care, support and advice. We believe that the breadth of expertise of our participants across dementia provision will be an appropriate number to receive a full critique on our initial prototype and it's relevance to supporting people living with dementia.

3.2 PARTICIPANT CHARACTERISATION

What age-range of participants will you recruit?

Unknown, and not relevant to the study, but they are likely to be between the ages 25 and 67

Please list the principal inclusion and exclusion criteria.

Inclusion: Must have a position of responsibility associated with dementia.

Exclusion: None

3.3 RECRUITMENT

Please describe the recruitment process and append any advertising if used.

Recruitment will take place through the Dementia Friendly Reading Group with which the project supervisor has a contact.

3.4 NHS AND SOCIAL SERVICES INVOLVEMENT

Will participants be recruited because of their status as NHS patients or Social Services clients, or identified through those services' records?

☐ Yes
☒ No

If "yes", please give details of current status of the HRA REC review.

Click here to enter text.

Will the study involve adult participants unable to consent for themselves as defined by the Mental Capacity Act 2005 or other vulnerable adults?

☐ Yes
☒ No

If "yes", please detail the associated procedures as set out in the HRA REC application.

Click here to enter text.

CHECKLIST

1. The Application form has the appropriate signatories	Yes

2. The Participant Information Sheet includes a statement to the effect that the project has been reviewed by the appropriate Research Ethics Committee and has been given a favourable ethical opinion for conduct.		Yes	
3. The Participant Information Sheet contains the relevant Data Protection information.		Yes	
4. EITHER	a) The proposed research will not generate any information about the health of participants;		☒
OR	b) If the research could reveal adverse information regarding the health of participants, their consent to pass information on to their GP will be included in the consent form and in this circumstance I will inform the participant and their GP, providing a copy of the relevant details to each and identifying by date of birth.		☐
OR	c) I have explained within the application why (b) above is not appropriate.		☐
5. EITHER	a) The proposed research does not involve children under the age of 5;		☒
OR	b) My Head of School (or authorised responsible person) has given details of the proposed research to the University's insurance officer.		☐
6. EITHER	a) The proposed research does not involve the taking of blood samples:		☒
OR	b) For anyone whose proximity to the blood samples brings a risk of Hepatitis B, documentary evidence of immunity prior to the risk of exposure will be retained by the Head of School or authorised responsible person.		☐
7. EITHER	a) The proposed research does not involve the storage of human tissue, as defined by the Human Tissue Act 2004;		☒
OR	b) I have explained within the application how the requirements of the Human Tissue Act 2004 will be met.		☐
8. EITHER	a) The proposed research does not involve the use of ionising radiation;		☒
OR	b) I am aware the proposed research will require HRA REC review.		☐

VERSION CONTROL

VERSION	KEEPER	REVIEWED	APPROVED BY	APPROVAL DATE
1.0	UREC	Annually	UREC	Sept 18

322

Appendix B: Ethics II

University Research Ethics Committee

ETHICS REVIEW APPLICATION FORM

To be used for School *or* University level review

Please append all relevant and supporting documentation to this project application form when submitting for School level (SREC) or University (UREC) review. Text boxes will expand as required and all language used to explain or justify the application should be comprehensible to a lay person.

Application form and all associated documents should be submitted electronically.

Submission deadline dates for UREC can be found on the UREC webpage.

Section 1: APPLICATION DETAILS

1.1 PROJECT AND DATES	
Title	AMuSED; Creating an Active Multisensory Environment for People Living with Dementia
Date of submission	13/10/2020
Start date	10/05/2021
End date	30/12/2021

1.2 APPLICANT DETAILS				
Chief Investigator	Prof. Rachel McCrindle			
Please note that an undergraduate or postgraduate student cannot be a named Chief Investigator for research ethics purposes. The supervisor must be declared as Chief Investigator.				
Is the project being carried out in whole or in part to support a student degree? ☒ Yes ☐ Undergraduate ☐ Masters ☒ PhD ☐ No				
School	School of Biological Sciences			
Department	Biomedical Engineering			
Email	r.j.mccrindle@reading.ac.uk			
Telephone	01183786536			
All other Applicants	Name:	School	Position	Email
	Esther Olorunda	SBS	PhD Student	e.o.olorunda@pgr.reading.ac.uk
	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.

1.3 WHAT REVIEW IS NEEDED?

Please tick the appropriate box below to confirm which review your ethics application requires.

Please tick all that apply.

☒ School Level Review (SREC)	☐ External (for example, HRA)
☐ University Research Ethics Committee Review (UREC)	

Projects expected to require review by the University Research Ethics Committee (for example; research involving NHS patients, research involving potential for distress to participants) must be reviewed by the Chair of the School Ethics Committee or the Head of School before submission to UREC. For further information see Section 16 of the UREC Guidance.

1.4 EXTERNAL RESEARCH ETHICS COMMITTEES

Please provide details of other external research ethics committees from whom a favourable ethics opinion will be required (for example; HRA REC)

Name of Committee	Date of submission / approval	Reference	Status
N/A	Click here to enter a date.	Click here to enter text.	Click here to enter text.

1.5 PROJECT SUBMISSION DECLARATION

On behalf of my co-applicants and myself,

- I confirm that to the best of my knowledge I have made known all information relevant to the appropriate Research Ethics Committee and I undertake to inform the Committee(s) of any such information which subsequently becomes available whether before or after the research has begun
- I understand that it is a legal requirement that both staff and students undergo Disclosure and Barring Service checks when in a position of trust (for example; when working with children or vulnerable adults)
- I confirm that if this project is an intervention study, a list of names and contact details of the participants in this project will be compiled and that this, together with a copy of the Consent Form, will be retained within the School for as long as necessary.
- I confirm that I have given due consideration to equality and diversity in the management, design and conduct of the research project.
- (For Chemistry, Food & Pharmacy (CFP) only) I confirm the Internal Review has been undertaken by Click here to enter text. and I have made the changes requested.

SIGNED, CHIEF INVESTIGATOR

06/05/2021

Where required by the School's Research Ethics Procedures, this ethics application should be signed off by the appropriate person to confirm the School Body are content for this application to be reviewed by UREC.

Chemistry, Food & Pharmacy – will require sign off from: Chair of SREC, Head of Department and School Ethics Administrator – insert rows below as required.

SIGNED, AUTHORISING SIGNATORY

Signature:	Position:	Date:
	Choose an item.	Click here to enter a date.

Section 2: PROJECT DETAILS

2.1 LAY SUMMARY

Please provide a summary of the project in plain English that can be understood by a non-specialist audience, which includes a description of the background of the study (existing knowledge), the questions the project will address, the methods to be used and the key ethical issues.

Please note the lay summary should not contain references and be no more than 500 words.

Dementia is the overall term used to represent a range of progressive disorders that involve damage to the brain and can affect the memory, thinking capability, mood, behaviour and lifestyle of people living with them. Many people living with dementia in homes and hospitals spend their days unoccupied and understimulated, which can lead to a low quality of life. Stimulating people living with dementia is a key factor in the improvement of their quality of life and one of the best ways to do this is through the use of games, recreational activities and therapies which may involve the use of technology or otherwise.

The use of multi-sensory environments (Snoezelen), therapies, multisensory kits and activities have been shown to have a positive impact in dealing with the behavioural issues (apathy, agitation, passivity and gerenal boredom) associated with people living with dementia. However, these are often expensive and cannot always be personalised to individuals' interests, as well as be adaptable to the different impacts of dementia as the disease progresses.

This study is aimed at developing a low-cost, technology-based kit that creates an active multisensory environment for people living with dementia in the form of a portable desktop-based toolkit – AMuSED (Active Multi-Sensory Environment for people living with Dementia). This kit combines multisensory activities with sensory room stimulation and caters to all stages of dementia. It can be used by an individual or in a group setting.

The initial stage involved speaking with a number of experts in dementia care from across a range of settings (e.g. care home, Reading Borough Council, Age UK), to ascertain their views on the proposed Toolkit to (1) gather further requirements, (2) adjust its design, and (3) ascertain any perceived barriers to the use of such a toolkit. This was achieved using Microsoft Teams and short sets of structured questions provided in advance to participants together with a short video of the AMuSED prototype and it's features.

This stage of the study, for which ethics approval is being requested, involves evaluating the AMuSED toolkit in care homes via an invite from the managers of the care homes. All components contained in the toolkit are off-the-shelf components available at stores like Amazon and meet the appropriate quality standards. None of the participants will be forced to engage in the activitiy sessions and the care team can select whatever components they see fit to use for their sessions from the box as it is not necessary to use all the items in the box.
Dementia pations will not be recruited and all evaluations will be done by proxy through the use of short questionnaires with open and close ended questions to be filled by the care team or activity co-ordinators of the care homes. The AMuSED box will be used in the same way as the activity boxes already used by the care team especially their memory/reminiscence boxes.
We will be asking for qualitative feedback from the care teams summarising their observations regarding the activity sessions; which of the activities were engaging, how well the residents enjoyed the sessions, etc.
For this evaluation, we will not be recruiting any of the residents living with dementia and all nteractions will be done as usual between the care team and the residents. We will also not be identifying anyone from the care team or any of the residents.

2.2 PRIMARY RESEARCH QUESTION

Please detail the primary research question this project will answer.

Can an affordable, portable, personalisable and adaptable toolkit be developed that will provide engagement and stimulation to people living with dementia?

This aim of this part of the study is to gain feedback from the care staff in selected care locations.

2.3 SECONDARY RESEARCH QUESTION(S)

Please detail any secondary research question(s) this project will answer.

325

We will be asking the members of the care team the following questions via a questionnaire:

1. What was the general mood of the partiipants before, during and after the sessions?
2. What elements from the box were used in the session?
3. Which elements or activities did the participants engage with the most?
4. Which elements or activities were not engaged with?
5. How well did the AMuSED toolkit engage participants?

2.4 DESIGN AND PROCEDURE

Please describe concisely what the study will involve, how many times and in what order, for your participants and the procedures and methodology to be used.

Note: Any questionnaires or interview scripts should be appended to this application.

We will drop off AMuSED toolkits at selected care homes to be used during their activity sessions. We will engage with the care team and care home managers regarding the sessions.
We will not be recruiting people with dementia and they have the choice of participating ot not in the activities as per any usual session run by the care team.
Each AMuSED box is to be used for two weeks, during which qualitative data will be collected via short questionnaires to be filled after each session by the members of the care team.

2.5 LOCATION

Please describe where the research will take place.

The research will take place in community situations where a care team is working with a group of people with dementia e.g care homes.

Please state whether an appropriate risk assessment/ local review has been undertaken.

☐ Yes
☐ No
☒ Not required

Notes:
- Ensure specific risk assessments have been undertaken for non-University locations (for example; schools or participant homes). Please consult either your School Ethics Contact or UREC for guidance.
- If the project is to take place in Hugh Sinclair Unit of Human Nutrition, it must be reviewed and approved by the Hugh Sinclair Manager.

2.6 FUNDING

Is the research supported by funding from a research council or other external source (for example; charities, businesses)?

☐ Yes
☒ No

If "yes", please,

(a) Give details of the funding body;

Click here to enter text.

(b) Confirm if the funder specifically stipulates review by the University Research Ethics Committee.

☐ Yes
☐ No

2.7 ETHICAL ISSUES

Please summarise the main ethical issues, including harms and risks, arising from your study and explain how you have addressed them.

None identified; No direct contact will be made with the care home residents or the care team.

2.8 DECEPTION

Will the research involve any element of intentional deception (for example; providing false or misleading information about the study)?

☐ Yes
☒ No

If "yes", please justify and append a description of the debriefing procedure.

Click here to enter text.

2.9 PAYMENT

Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

☐ Yes
☒ No

If "yes", please specify and justify the amount.

Click here to enter text.

2.10 DATA PROTECTION

What steps will be taken to ensure appropriate secure handling of personal data? Give comprehensive details on the collection, retention, sharing and disposal of participant personal data.

Personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

For guidance on data protection please, see the Data Protection for Researchers Guidance document.

Personal data will not be collected outside of the consent form. All ideas and feedback will be recorded anonymously. Quotes or ideas received might be added to future papers but will be done anonymously and will not be attributed to any person.

327

Will the research involve any activity that requires a Data Protection Impact Assessment (DPIA)?

☐ Yes
☒ No

If "yes", please append the "DPIA Appendix A – Screening Questions".

2.11 INFORMED CONSENT

a. Will you obtain informed consent from, or on behalf of, research participants?

☒ Yes   (go to question b)
☐ No   (go to question c)

b. If "yes", please describe the process by which they will be informed about the nature of the study and the process by which you will obtain consent.

c. If "no", you are not obtaining consent, please explain why (for example; 'opt-out' methodology without the acquisition of consent)?

Please append all relevant participant facing information documentation for participants, parents or guardians. Please note, age-appropriate information sheets must be supplied for all participants wherever possible, including children. Assent should be obtained from children, under 16 years, in addition to the consent required from parents, guardians or carers.

An information sheet containing the details of the study and a consent form will be sent to the managers of the care homes to obtain consent before the AMuSED toolkit is delivered. The information sheet will also detail that participants can opt out freely and without detriment.

2.12 GENOTYPING

Are you intending to genotype the participants?

☐ Yes
☒ No

If "yes", which genotypes will be determined?

Click here to enter text.

Section 3: PARTICIPANT DETAILS

3.1 PARTICIPANT NUMBER

How many participants do you plan to recruit?

Please briefly explain why the number is appropriate to answer the study's research question(s).

Between 5 and 8 experts from Dementia Friendly Reading working in different contexts of dementia care, support and advice. We believe that the breadth of expertise of our participants across dementia provision will be an appropriate number to receive a full critique on our initial prototype and it's relevance to supporting people living with dementia.

3.2 PARTICIPANT CHARACTERISATION

What age-range of participants will you recruit?

Unknown, and not relevant to the study, but they are likely to be between the ages 50 and 90		
Please list the principal inclusion and exclusion criteria.		
Inclusion: Must be a community situation where a care team is working with people living with dementia. *Exclusion: None*		

3.3 RECRUITMENT

Please describe the recruitment process and append any advertising if used.
Recruitment will take place through the Dementia Friendly Reading Group with which the project supervisor has a contact.

3.4 NHS AND SOCIAL SERVICES INVOLVEMENT

Will participants be recruited because of their status as NHS patients or Social Services clients, or identified through those services' records? ☐ Yes ☒ No If "yes", please give details of current status of the HRA REC review.
Click here to enter text.
Will the study involve adult participants unable to consent for themselves as defined by the Mental Capacity Act 2005 or other vulnerable adults? ☐ Yes ☒ No If "yes", please detail the associated procedures as set out in the HRA REC application.
Click here to enter text.

CHECKLIST

1. The Application form has the appropriate signatories		Yes	
2.The Participant Information Sheet includes a statement to the effect that the project has been reviewed by the appropriate Research Ethics Committee and has been given a favourable ethical opinion for conduct.		Yes	
3. The Participant Information Sheet contains the relevant Data Protection information.		Yes	
4. EITHER	a) The proposed research will not generate any information about the health of participants;		☒
OR	b) If the research could reveal adverse information regarding the health of participants, their consent to pass information on to their GP will be included in the consent form and in this circumstance I will inform the participant and their GP, providing a copy of the relevant details to each and identifying by date of birth.		☐

329

OR	c) I have explained within the application why (b) above is not appropriate.	☐
5. EITHER	a) The proposed research does not involve children under the age of 5;	☒
OR	b) My Head of School (or authorised responsible person) has given details of the proposed research to the University's insurance officer.	☐
6. EITHER	a) The proposed research does not involve the taking of blood samples;	☒
OR	b) For anyone whose proximity to the blood samples brings a risk of Hepatitis B, documentary evidence of immunity prior to the risk of exposure will be retained by the Head of School or authorised responsible person.	☐
7. EITHER	a) The proposed research does not involve the storage of human tissue, as defined by the Human Tissue Act 2004;	☒
OR	b) I have explained within the application how the requirements of the Human Tissue Act 2004 will be met.	☐
8. EITHER	a) The proposed research does not involve the use of ionising radiation;	☒
OR	b) I am aware the proposed research will require HRA REC review.	☐

VERSION CONTROL

VERSION	KEEPER	REVIEWED	APPROVED BY	APPROVAL DATE
1.0	UREC	Annually	UREC	Sept 18

330

University of Reading

School of Biological Sciences
University of Reading,
Whiteknights,
Reading, UK RG6 6AY

QUESTIONS FOR DISCUSSION

My name is Esther Olorunda and I am currently undertaking a PhD in the School of Biological Sciences at the University of Reading. My PhD involves developing a developing a low-cost, technology-based toolkit that creates an active multisensory environment for people living with dementia in the form of a portable desktop-based toolkit – AMuSED (Active Multi-Sensory Environment for people living with Dementia). This kit combines multisensory activities with sensory room stimulation and caters for all stages of dementia. It can be used by an individual or in a group setting.

We have designed the toolkit elements based on extensive literature review of products and therapies available to assist people living with dementia, however we are keen to make sure that what we develop is appropriate for 'real-world' application. Based on your expertise in the provision of dementia care we would very much welcome your feedback on our proposed toolkit so that we can (1) gather further requirements, (2) adjust its design, and (3) ascertain any perceived barriers to the use of such a toolkit.

We would like to set-up a brief Microsoft Teams call with you at your convenience to discuss your views on this toolkit and feed any advice from you into our next prototype. We are suggesting that the following questions might be a useful guide to this discussion, though a flexible conversation focussing in more detail on one of two elements would be just as valuable.

1. What is your job title and for which organisation do you work?
2. What are your overall views on having an affordable, portable, personalisable and adaptable multi-sensory toolkit available for engaging people living with dementia?
3. How do you envisage such a toolkit could be used to help support people living with dementia?
4. Do you think the elements included in the AMuSED toolkit are appropriate for what the kit is setting out to achieve?
5. What do you think will be the benefits of the AmuSED toolkit?
6. What do you think are the negatives of the AMuSED toolkit
7. What do you think will be the challenges of using/adopting the AMuSED toolkit?
8. Are you aware of any products/systems available on the market that already do what the AMuSED toolkit is set to do?
9. Are there any additional elements that you feel should be added to the AMuSED toolkit?
10. Are there any elements you feel should be removed from the AMuSED toolkit?

Many thanks for your participation in this study

Esther Olorunda (PhD student)   Professor Rachel McCrindle (Supervisor)

Appendix D: Information sheet

University of Reading

School of Biological Sciences
University of Reading,
Whiteknights,
Reading, UK RG6 6AY

INFORMATION SHEET

Project Title: Creating a Personal Environment for People Living with Dementia

What is the purpose of this study?

This study is aimed at developing a low-cost, technology-based kit that creates an active multisensory environment for people living with dementia. This kit combines multisensory activities with sensory room stimulation and caters to all stages of dementia.

Using a brief Microsoft Teams call with a short set of structured discussions provided in advance to participants, we would like to get feedback from a number of dementia experts on the prototype of our sensory multimedia toolkit (AMuSED) developed for people living with dementia.

How are the participants selected?

Participants are selected through Dementia Friendly Reading based on the inclusion criteria that they have a position of responsibility associated with provision, advice, or guidance on dementia care.

What will I be asked to do?

You will be asked to attend a Microsoft Teams call where you will be shown a prototype that is being developed to stimulate people living with dementia. You will be asked to provide feedback on the idea and prototype.

What data will be collected, and how will it be used?

Personal data will not be collected outside of the consent form. All feedback will be recorded anonymously. Some quotes and feedback collected will be used in future papers but will be done anonymously and will not be personally attributed to any individual.

Where will the studies take place?

The study will take place online via Microsoft Teams.

What if I do not wish to complete the study?

Participants can opt out at any point without detriment.

Will my data be kept anonymous?

1

332

University of Reading

School of Biological Sciences
University of Reading,
Whiteknights,
Reading, UK RG6 6AY

PURPOSE OF EVALUATION

My name is Esther Olorunda and I am currently undertaking a PhD in the School of Biological Sciences at the University of Reading. My PhD involves developing a developing a low-cost, traditional/technology-based toolkit that creates an active multisensory environment for people living with dementia in the form of a portable desktop-based toolkit – AMuSED (Active Multi-Sensory Environment for people living with Dementia). This kit combines multisensory activities with sensory room stimulation and caters for all stages of dementia. It can be used by an individual or in a group setting.

We have designed the toolkit elements based on extensive literature review of products and therapies available to assist people living with dementia as well as from experts in the dementia field recruited via the Reading Dementia Friendly Steering Group, however we are keen to make sure that what we develop is appropriate for 'real-world' application. Based on your expertise in the provision of dementia care we would very much welcome your feedback on our proposed toolkit so that we can (1) gather further requirements, (2) adjust its design, and (3) ascertain any perceived barriers to the use of such a toolkit.

As part of the care team or activities co-ordination team we would like you to use the AMuSED toolkit at your convenience over a two-week period as part of, or instead of, your usual activity sessions and to complete a short questionnaire after each session to give us some feedback on how well people living with dementia engaged with its contents. You may use some or all of the toolkit contents as per your wish. We would also appreciate it is you could complete a questionnaire about your impressions of the AMuSED toolkit prior to your use of it, as well as a final summary questionnaire at the end of the two-week usage period.

Many thanks for your participation in this study.

Esther Olorunda (PhD student)   Professor Rachel McCrindle (Supervisor)

University of Reading

School of Biological Sciences
University of Reading,
Whiteknights,
Reading, UK RG6 6AY

CONSENT FORM

Please use tick box after each statement to confirm it has been read and agreed to.

1. I have read and had explained to me by Professor Rachel McCrindle/Esther Olorunda the accompanying Information Sheet relating to the project on: Creating a Personal Environment for People Living with Dementia ☐

2. I have had explained to me the purposes of the project and what will be required of me, and any questions I have had have been answered to my satisfaction. I agree to the arrangements described in the Information Sheet in so far as they relate to my participation. ☐

3. I have had explained to me what information will be collected about me, what it will be used for, who it may be shared with, how it will be kept safe, and my rights in relation to my data. ☐

4. I understand that participation is entirely voluntary and that I have the right to withdraw from the project any time, and that this will be without detriment. ☐

5. I understand that the data collected from me in this study will be preserved and made available in anonymised form, so that they can be consulted and re-used by others. ☐

6. This project has been reviewed by the School Research Ethics Committee and has been given a favourable ethical opinion for conduct.

7. I have received a copy of this Consent Form and of the accompanying Information Sheet. ☐

Name: ……………………………………………………………………………
Date of birth: ……………………………………………………………………
Signed: ……………………………………………………………………………
Date: ………………………………………………………….…………………

I am happy to be included on a register of research participants for the purposes of being contacted about further studies by……………………………………………………. Please tick   ☐
(optional)

1

Appendix G: Manager questionnaire

AMuSED Box - Manager Questionnaire

So that we can assess the appropriateness of our AMuSED boxes for people at different stages of dementia, and different forms of dementia, please let us know the general characteristics of the residents of your care home or other location where organised activities for people with dementia take place.

Care Location:	
Your Role:	
Date:	

How many residents in your care provision take part in organised activities?

Have the residents in your care home been clinically diagnosed with dementia? (Please tick as appropriate)

Yes – all		Yes - some		No		Unsure	

In general, what forms of dementia do your residents most commonly have (Please give as a percentage)

Alzheimer's	
Vascular dementia	
Dementia with Lewy Bodies	
Other forms of dementia	
Not clearly diagnosed	

In general, what is the most prevalent stage of dementia in your residents? (Please give as a percentage)

Early (mild) stages of dementia	
Mid (moderate) stages of dementia	
Late (severe) stages of dementia	
Not easy to categorise	

Thank you for setting the scene regarding your residents.

Appendix H: Pre session questionnaire

Carer/Care Team - Pre-Evaluation Questionnaire for the AMuSED Box

So that we can assess the appropriateness of our AMuSED boxes to help you run your activities for people with dementia, please let us know your initial impression of the box prior to using it for the first time. We are interested in getting as many views as possible.

Care Location:	
Your Role:	
Date:	

Section 1 – Your Current Activities

How many days a week do you typically run activity sessions?	
How many activity sessions do you typically run in a day?	
How many people with dementia are typically in each of your sessions?	
Are you aware of the type/stage of dementia that your attendees have in a particular session?	
What current activities do you run in your sessions? Please give some examples.	

Section 2 – First Impressions of the AMuSED Box

Please state how much you agree or disagree with the following statements about the AMuSED Box (tick appropriately)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The box is well made					
The box is an appropriate size					
The box is easy to open					
The box is easy to put back together again					
The construction of the box is sturdy enough					
The box when placed on a table will immediately stimulate interest					
The images are of good quality					
Images on the outside of the box are of an appropriate size					
Images will prompt reminiscence and communication					
The larger images on the inside of the box are useful for further discussion					
The larger images on the inside of the box link to activities inside the box					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The question prompt cards are helpful (use is optional)					
The activity card suggestions are helpful (use is optional)					
Having themed boxes is useful					
The theme of the box is coherent					
The box contains an appropriate number of elements and activities					
Having a mix of sensory elements, reminiscence prompts and activities is a good idea					
The box and its contents will engage and stimulate people with dementia					
The box contains elements that are relevant to people at different stages of dementia					
I am keen to try out the box and its contents in my activity sessions					

Section 3 – AMuSED box contents and use

Have you used, or do you currently use any of the elements in the AMuSED box in your activity sessions? Please state which ones below
Are there any elements you are particularly looking forward to using? Please state which ones below
Are there any elements that you don't think you will use or which you have concerns about? Please state which ones below
How do you think you will use this box with your care home residents living with dementia?

Section 4 – Final thoughts on your first impressions

From your first impressions what three words would you use to describe the AMuSED box?
Do you have any suggestions for how the first impression of the AMuSED box can be improved?

Thank you for giving us your first impressions of the AMuSED box – we hope you enjoy using it and your residents find it fun and engaging.

Appendix I: During session questionnaire

Please tell us how your AMuSED session went!

Location:	

Date:		Start time:		End time:	

Number of male participants:		Number of female participants:	

Please circle the general mood of the participants:

Before the session:	During the session:	After the session:

What was the theme of your box?	

Which elements did you use from the box in this session? Tick all that apply

Reminiscence images		Sand box/mini spades		Postcards and pens	
Holiday/travel brochure		Candy floss maker		Photo props	
Seaside nostalgia jigsaw		Sound buttons		Beach quoits	
Seashells		Sea fragrances		Beach balls	
Sea creatures		Aqua paints		Bubble blowers	
Jellyfish lamp		Colouring/word search		Windmills	

Did you make use of the prompt questions or suggested activity sheets?

Which elements or activities from this session did the participants engage with or enjoy the most?

Were there any elements or activities that the participants did not engage with or enjoy?

Based on your session today how well did the AMuSED toolkit engage participants with:

	Not at all	A little	On and off	Quite a bit	Very much	N/A
Early dementia						
Mid dementia						
Late dementia						

Is there anything else you would like to tell us about your AMuSED session today?
e.g. general comments, things you liked, suggestions for improvements, new themes or elements etc.

Thank you for using AMuSED today and for giving us your feedback.

Carer/Care Team Post-Evaluation Questionnaire

So that we can assess the appropriateness of our AMuSED boxes to help you run your activities for people with dementia, please let us know your impressions of the box now that you have used it for a couple of weeks. We are interested in getting as many views as possible.

Care Location:	
Your Role:	
Date:	

Section 1 – Your AMuSED Box Activities

How many days a week did you typically use AMuSED in activity sessions?
How many activity sessions did you typically use AMuSED in a day?
How many people with dementia were typically in each of your sessions?
Were you aware of the type/stage of dementia that your attendees have in a particular session?
Did you continue to run any of your 'normal' activities in addition to the AMuSED box activities?

Section 2 – Overall Impressions of the AMuSED Box after 2 weeks

Please state how much you agree or disagree with the following statements about the AMuSED Box (tick appropriately)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The box is well made					
The box is an appropriate size					
The box is easy to open					
The box is easy to put back together again					
The construction of the box is sturdy enough					
The box when placed on a table immediately stimulates interest					
The images are of good quality					
Images on the outside of the box are of an appropriate size					
Images prompt reminiscence					
The larger images on the inside of the box are useful for further discussion					
The larger images on the inside of the box link to activities inside the box					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The question prompt cards are helpful (use is optional)					
The activity card suggestions are helpful (use is optional)					
Having themed boxes is useful					
The theme of the box is coherent					
The box contains an appropriate number of elements and activities					
Having a mix of sensory elements, reminiscence prompts and activities is a good idea					
The box and its contents will engage and stimulate people with dementia					
The box contains elements that are relevant to people at different stages of dementia					
I would be keen to try out this box (or another theme) and its contents in future activity sessions					

Section 3 – Your use of the AMuSED Box

Across the 2 weeks how often did you use the elements from the AMuSED box in your sessions. For each element below please write 'F' for frequently; 'O' for occasionally; 'N' for never

Reminiscence images		Sand box/mini spades		Postcards and pens	
Holiday/travel brochure		Candy floss maker		Photo props	
Seaside nostalgia jigsaw		Sound buttons		Beach quoits	
Seashells		Sea fragrances		Beach balls	
Sea creatures		Aqua paints		Bubble blowers	
Jellyfish lamp		Colouring/word search		Windmills	

Did you make use of the prompt questions or suggested activity sheets?

Which elements or activities did your participants engage with or enjoy the most?

Were there any elements or activities that your participants did not engage with or enjoy or which you were worried about using? Please let us know below.

Did you create your own activities with the AMuSED box other than those suggested in the activity sheet? Please share what you did below.

Based on your sessions over the 2 weeks how well did the AMuSED toolkit engage participants with:						
	Not at all	A little	On and off	Quite a bit	Very much	N/A
Early dementia						
Mid dementia						
Late dementia						

Section 4 – Your overall impressions of the AMuSED Box

Did the AMuSED box help you plan or run activity sessions?

What do your think are the best features about a multi-sensory/multiactivity AMuSED box?

Overall what were your favourite elements/activities within the box?

Overall, which elements or activities did the group enjoy the most?

Overall, which were your least favourite elements/activities in the AMuSED box?

Can you suggest any other elements/activities to include in the AMuSED box?

Would you be interested in trying a different themed box? ('Y' for yes; 'N' for no)							
Entertainment		Movie Night		Countryside		Life Activities	

Are there any other themes you would like to suggest?

Section 5 – Final thoughts on your impressions having used AMuSED

After 2 weeks what three words would you use to describe the AMuSED box?

Do you have any suggestions for how the AMuSED box can be improved?

Is there anything else you would like to tell us about experiences with using the AMuSED box?

Thank you for giving us your impressions of the AMuSED box – we hope you enjoyed using it and that your residents find it fun and engaging.

A Day Out in the Country

Do you consider yourself a Town or Country person? Do you prefer one to the other and why?

What do you associate most with the countryside?

How important was the countryside to you when growing up?

Would you ever visit the countryside and why?

Where would you go? Who would you go with?

How did you travel there?

What did you do while you were there?

Did you have a favourite place to visit?

Have you lived or do you live in the countryside?

Have you ever worked in the countryside? What did that work involve?

Has the countryside changed over the years in your experience? If so, how?

What's your most memorable countryside moment?

Appendix L: Seaside edition activity booklet

AMuSED Toolkit

Seaside Edition

Welcome to AMuSED

Our AMuSED (Active Multi-Sensory Environment for people living with Dementia) toolkits are part of a PhD at the University of Reading investigating the development of themed low-cost portable toolkits for people living with dementia that combine multisensory elements with reminiscence prompts and activities that can be enjoyed by people at all stages of dementia.

We have designed the toolkit elements based on extensive review of products and therapies available to assist people living with dementia as well as from experts in the dementia field recruited via the Reading Dementia Friendly Steering Group, however we are keen to make sure that what we develop is appropriate for the people that you care for. Based on your expertise we would very much welcome your feedback on our proposed toolkit so that we can (1) gather further requirements, (2) adjust its design, and (3) ascertain any perceived barriers to the use of such a toolkit.

We would like you to use the AMuSED toolkit at your convenience over a two-week period as part of, or instead of, your usual activity sessions and to complete a short questionnaire after each session to give us some feedback on how well people living with dementia engaged with its contents. You may use some or all the toolkit contents as per your wish. We would also appreciate it is you could complete a questionnaire about your impressions of the AMuSED toolkit prior to your use of it, as well as a final summary questionnaire at the end of the two-week usage period.

Many thanks for your participation in this study.

University of Reading

AMuSED – Seaside Edition
What's in the Box?

The seaside box is filled with images, sounds, objects and activities to remind people of the times they spent at the beach encouraging discussion and social engagement

Images associated with the seaside
Old holiday and travel brochures
Postcards and pens
Beach photo props
Scents of the sea
Sounds of the sea
Jelly fish illuminated lamp
Message in a bottle
Sand and mini spades
Plastic and plushy sea creatures
Large and small seashells
Beach balls, bubble blowers and windmills
Beach Quoits
Beach related aqua paints and jigsaws
Beach themed colouring sheets and wordsearches

relish.
Beach Holiday
Aquapaint™

Please feel free to use the box however you wish, use our example Activity suggestions and Question prompts or create you own set of exciting activities.

AMuSED – Seaside Edition
Your Box at a Glance

AMuSED Images

Jellyfish lamp

Smells of the sea

Sound buttons

Sand boxes
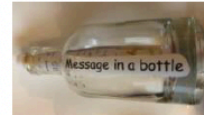
Message in a bottle

Holiday camps

Postcards
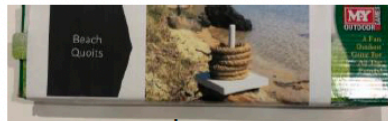
Beach quoits

Wordsearch

Aqua paints
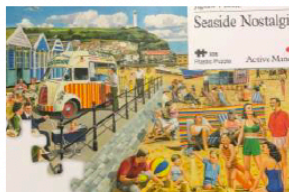
35-piece jigsaw

12-piece jigsaw

Colouring

Sea creatures

Seashells
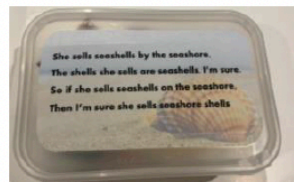
Tongue twister

Fishing game
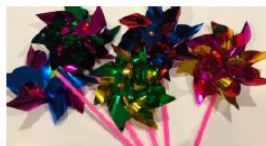
Windmills
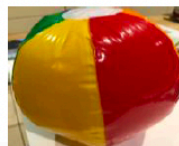
Beachballs

Bubbles

Photo props

Example Activity
Trips to the Seaside

Set the scene for your session using the images on the insides and outsides of the cube, the sound buttons of the seagulls and the waves and the scents of the sea. Use the question prompts if you want some starter questions.

Let people tell their stories and reminisce about the times they spent at the beach. The photos on the inside and outsides of the box provide great discussion points. Have the whole box as a central point or encourage conversation by distributing the different sides of the box around the table so that people can discuss the pictures. Add the brochures of Prestatyn and entertainment posters for more directed discussion. Have a knobbly knees competition!

Press the buttons to play the sounds of the seagulls and the waves, read the message in the bottle (from the Police song 'Message in a Bottle) and ask people to say what messages they would put in the bottle. Send postcards!

Ask people to sniff the scent cubes and try to identify the smells of the sea, extending this into reminiscence about the smells of the sea they remember.
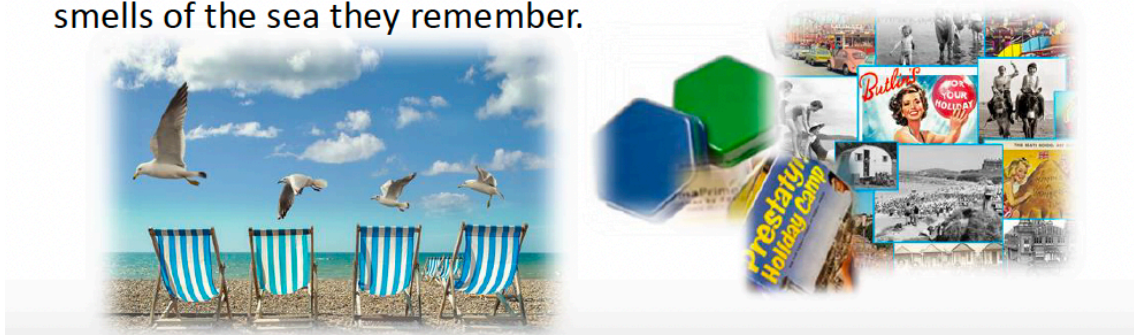
Example Activity
On the Beach

Use items such as the kinetic sand, seashells, beachballs and quoits to encourage activity and social engagement.

Have people recreate their times at the beach by playing with the sand. For example, let them feel the sand between their fingers, bury and find shells buried in the sand and build sandcastles. Have a sandcastle building competition for the more competitive residents! Take a photo of the sandcastles.

Get people to guess 'What's in the Shell Box' by shaking the box and from hint questions. Take the shells out of the box and explore their shapes and colours. Move the discussion onwards to what people used to collect on the seashore. Have fun trying to say the tongue twister. What other tongue twisters do people know.

Discuss beach games. Play a ball game by having people pass round the beachball, throw it to each other or throw it the furthest. Set up the beach quoits and have a game with these as well.

Example Activity
Sea Creatures

Alongside the shells, use the jelly fish lamp and the plastic and plushy sea creatures to consider the animals that live in the sea or that can be found on the beach. Name as many of them as possible.

Have people reminisce about the activities they used to do at the seaside involving animals such as riding donkeys, fishing with nets in rock pools or using fishing lines to catch crabs whilst sitting on the harbour walls. Use the images on the box and the iSpy as reminders of the things they used to find on the beach. See who remembers having iSpy books and which ones.

Empty the fish out of the tin and use the magnetic rods to catch the wooden fish – see who catches the most fish in a given time.

Move the conversation into different directions such as favourite fish to eat; fish and chips at the seaside; other seaside food such as ice creams and sticks of rock; places visited and modes of transport.
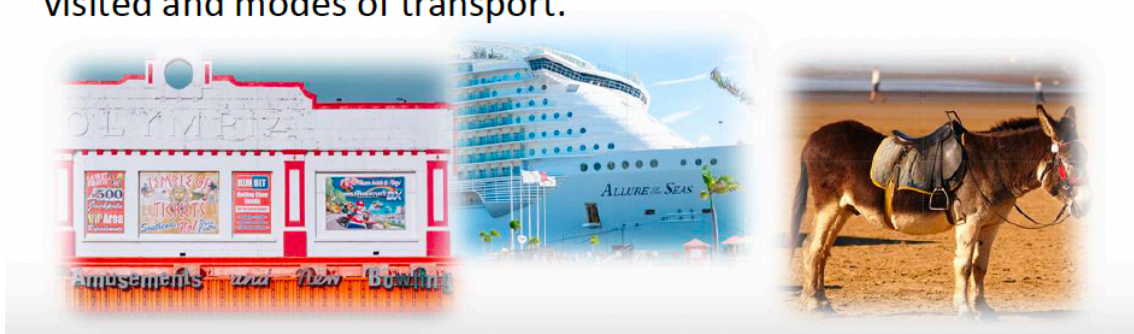
Example Prompt Questions

- Have you ever been to the seaside? Where did you go?
- How did you travel there?
- Where did you stay?
- What activities did you do while you were there?
- Did you ever ride on a donkey?
- Did you collect seashells?
- Did you have a favourite beach to visit?
- What is your most memorable moment at the seaside?
- If you were writing a message in a bottle to put into the sea, what would you write?
- Have you ever been on a cruise? Where did you go?
- What's your favourite seafood or fish?
- Who would you send a postcard to?
- Did you enjoy swimming or sailing?

Need Help? Things Mended or More Materials?

We hope you are enjoying using the AMuSED Seaside Box. Should anything break, or you would like more of your favourite resources, or you would like further ideas about how to use the AMuSED Box, just get in touch with us:

Esther – e.o.olorunda@pgr.reading.ac.uk
Rachel – r.j.mccrindle@reading.ac.uk
Fred – fjemcc@gmail.com

Thank you once again for your feedback, it is much appreciated.

Appendix M: Christmas edition activity booklet

AMuSED Toolkit

Christmas Edition

Welcome to AMuSED

Our AMuSED (Active Multi-Sensory Environment for people living with Dementia) toolkits are part of a PhD at the University of Reading investigating the development of themed low-cost portable toolkits for people living with dementia that combine multisensory elements with reminiscence prompts and activities that can be enjoyed by people at all stages of dementia.

We have designed the toolkit elements based on extensive review of products and therapies available to assist people living with dementia as well as from experts in the dementia|field recruited via the Reading Dementia Friendly Steering Group, however we are keen to make sure that what we develop is appropriate for the people that you care for. Based on your expertise we would very much welcome your feedback on our proposed toolkit so that we can (1) gather further requirements, (2) adjust its design, and (3) ascertain any perceived barriers to the use of such a toolkit.

We would like you to use the AMuSED toolkit at your convenience over a period of time as part of, or instead of, your usual activity sessions and to complete a short questionnaire after each session to give us some feedback on how well people living with dementia engaged with its contents. You may use some or all the toolkit contents as per your wish. We would also appreciate it if you could complete a questionnaire about your impressions of the AMuSED toolkit prior to your use of it, as well as a final summary questionnaire at the end of the evaluation period.

Many thanks for your participation in this study.

University of Reading

AMuSED – Christmas Edition
What's in the Box?

The Christmas AMuSED box is filled with images, sounds, objects and activities to remind people of the times they spent at Christmas encouraging discussion and social engagement. The panels of the box may be used individually or put together to form a centre piece of discussion.

Setting up the AMuSED box is easy! There is a top and bottom panel edged in Lego and four slightly smaller side panels. Lay the bottom panel on a flat surface so that the Littlewoods image is facing upwards. Take one side panel and with the small images facing outwards slot this panel into the Lego guides. Make sure that you push it right to the edge so that a small gap is left just at one end. Take the next panel and slot it into the base so that it fills up the small gap that was left and creates one of its own. Continue with the other two sides. When all sides are in place the lid can be gently placed on top to secure the AMuSED box.

AMuSED – Christmas Edition
Your Box at a Glance

AMuSED images

Singing snow globe

Xmas aromas

Sound buttons

1950s childhood

Christmas bingo
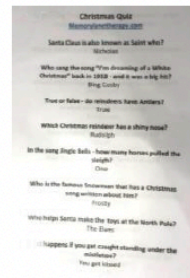
Quiz
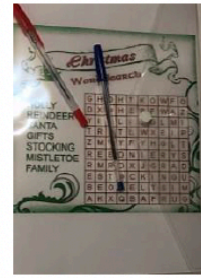
Wordsearch

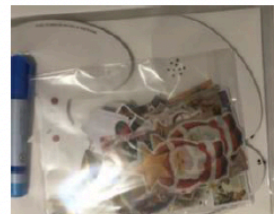Vintage Xmas

35-piece jigsaw

12-piece jigsaw

Colouring

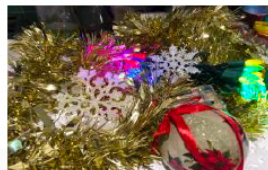Pomanders

Xmas chains

Talking collages

Wreath decorations

Headbands

Tinsel and lights

Santa hoopla

Magic tree

Example Activity
Set the Scene for Christmas

Set the scene for Christmas with your tinsel, traditional fairy lights, bauble, snowflakes and Christmas stocking.

Press the square sound button to hear a message from Father Christmas and the small round button to hear the bells of his sleigh. Add the scents of Christmas and turn on the music and lights of the snow globe for extra yuletide cheer.

Get further into the Christmas mood by wearing the headbands and glasses. Take some images on a phone for printing later as a memento of the session.

Ask everyone to sniff the scent cubes and try to identify the smells Christmas, extending this into reminiscence about the smells of Christmas they remember.

Let people tell their Christmas stories and reminisce about how they spent their Christmas holidays. The photos on the inside and outsides of the box provide great discussion points. Have the whole box as a central point or encourage conversation by distributing the different sides of the box around the table so that people can discuss the pictures. See who remembers snow and the river Thames freezing over. Use the question prompts if you want some starter questions.

Add one of the reminiscence packs for more directed discussion about Christmas traditions, favourite toys, pantomimes, television programmes etc. Look out for the reference to Reading's Huntly and Palmer's biscuits and see who remembers these (as well as the other Reading 'Bs' of beer (Simonds brewery then Courage) and bulbs (Sutton's Seeds) and for some the 4th 'B' of bricks (S & E Collier).

Discuss what food people ate at Christmas and where they shopped for their food and presents – look at the images of Heelas, Woolworths and Littlewoods taken in Reading.

Broaden the discussion using the other reminiscence pack to consider who was a brownie, cub, girl guide or a boy scout and where they went to school etc.

Example Activity
Christmas Crafts

Get everyone to create home-made decorations using the wreath making kit and the paper chain making kit. Use the vintage stickers to create a collage on the foam board or use them to decorate the speech bubbles and then record a Christmas message for family or friends.

Invoke the activities and aromas of Christmas past by using oranges, ribbon and cloves to make pomanders and hang them in the room to dry and for everyone to smell. Wrap a ribbon round the orange, pierce the orange skin in patterns no more than ½ cm apart and push a clove into each hole. Hang and leave to dry over a few weeks.

Water the magic tree in one session and show how it has grown into a mini tree by the next session. Decorate the mini tree.

Example Activity
Games & Activities

Encourage social interaction and competition with the Santa hoop throwing game, Christmas bingo, and a Christmas Quiz. Have people reminisce about the games that they used to play at Christmas.

Using the image on the AMuSED box as a guide get everyone to sing the 12 days of Christmas. Consider other well-known songs that could be sung such as Jingle Bells, and We Wish you a Merry Christmas and Rudolf the Red Nosed Reindeer.

For those who prefer the quieter activities there are colouring sheets, word searches, spot the difference and 35 and 12-piece jigsaws.

Example Prompt Questions

- Do you enjoy Christmas?
- How did you spend your Christmas holidays?
- Did you travel or stay at home?
- What are your favourite Christmas activities?
- Did you ever write a letter to Santa?
- What reminds you of Christmas?
- How did you decorate your house for Christmas?
- Did you have a Christmas tree? Real or artificial?
- How did you decorate it?
- Did you play games during Christmas?
- What games did you play?
- What was your favourite Christmas gift?
- Do you remember it snowing at Christmas?
- Did you ever build a snowman?
- What is your favourite Christmas food?
- Did you go to the pantomime?

Need Help? Things Mended or More Materials?

We hope you are enjoying using the AMuSED Christmas Box. Should anything break, or you would like more of your favourite resources, or you would like further ideas about how to use the AMuSED Box, just get in touch with us:

Esther – e.o.olorunda@pgr.reading.ac.uk
Rachel – r.j.mccrindle@reading.ac.uk
Fred – fjemcc@gmail.com

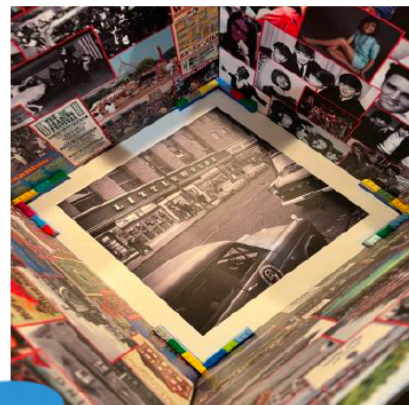Thank you once again for your feedback, it is much appreciated.

Appendix N: Entertainment edition activity booklet

AMuSED Toolkit

Entertainment Edition

Welcome to AMuSED

Our AMuSED (Active Multi-Sensory Environment for people living with Dementia) toolkits are part of a PhD at the University of Reading investigating the development of themed low-cost portable toolkits for people living with dementia that combine multisensory elements with reminiscence prompts and activities that can be enjoyed by people at all stages of dementia.

We have designed the toolkit elements based on extensive review of products and therapies available to assist people living with dementia as well as from experts in the dementia field recruited via the Reading Dementia Friendly Steering Group, however we are keen to make sure that what we develop is appropriate for the people that you care for. Based on your expertise we would very much welcome your feedback on our proposed toolkit so that we can (1) gather further requirements, (2) adjust its design, and (3) ascertain any perceived barriers to the use of such a toolkit.

We would like you to use the AMuSED toolkit at your convenience over a period of time as part of, or instead of, your usual activity sessions and to complete a short questionnaire after each session to give us some feedback on how well people living with dementia engaged with its contents. You may use some or all the toolkit contents as per your wish. We would also appreciate it if you could complete a questionnaire about your impressions of the AMuSED toolkit prior to your use of it, as well as a final summary questionnaire at the end of the evaluation period.

Many thanks for your participation in this study.

University of Reading

AMuSED – Entertainment Edition Setting Up your Box

The Entertainment AMuSED box is filled with images, sounds, objects and activities to remind people of the times they spent undertaking different hobbies or attending different types of entertainment to encourage discussion and social engagement. The panels of the box may be used individually or put together to form a centre piece of discussion. The panels are interchangeable and includes a special 'Newbury' themed panel that can be used if desired.

Setting up the AMuSED box is easy! There is a top and bottom panel edged in Lego and four slightly smaller side panels. Lay the bottom panel on a flat surface so that the Lego strips are facing upwards. Take one side panel and slot this panel into the Lego guides. Make sure that you push it right to the edge so that a small gap is left just at one end. Take the next panel and slot it into the base so that it fills up the small gap that was left and creates one of its own. Continue with the other two sides. When all sides are in place the lid can be gently placed on top to secure the AMuSED box.
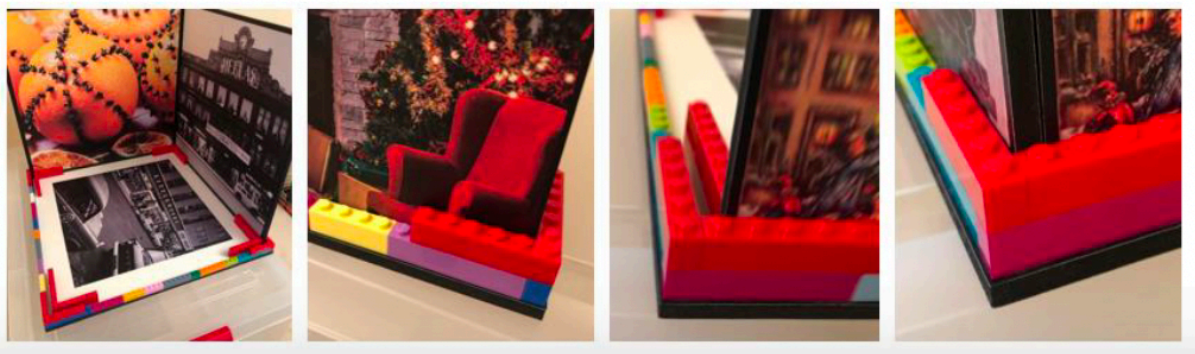
AMuSED – Entertainment Edition
Your Box at a Glance
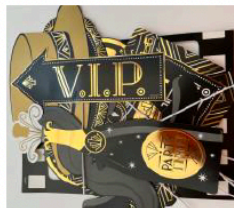

AMuSED images

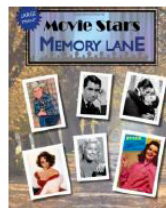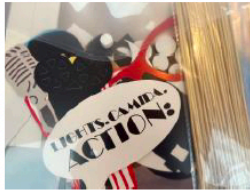Popcorn maker

Light box

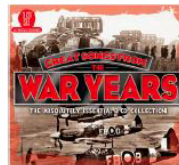
Clapper board

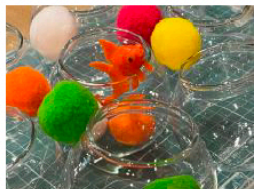Sound effects

Movie stars

Song cube

Famous masks
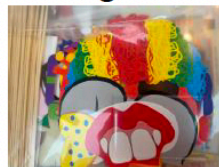

1950s childhood
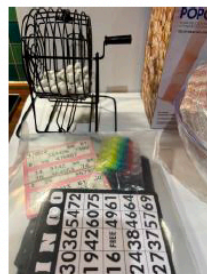

Movie props large

Sing to CD

Red carpet

Aromas

1960s childhood

Movie props small

Circus props
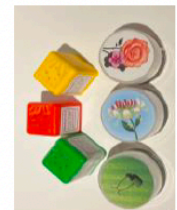
Bingo

Colouring

Win a goldfish

Hook a duck

Buzz wire
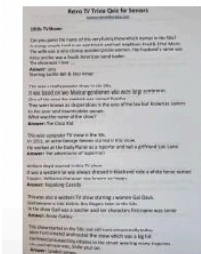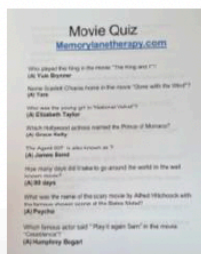

Retro TV Quiz

Movie Quiz

Aqua paints

Plant flowers

Word search

Example Activity
Recreate that Cinema Experience

Set the scene for those glamourous days of the 'silver screen' with your AMuSED box images of old cinemas, lightbox, clapper board, popcorn maker, photo props, red carpet backdrop, sound effect box, famous masks, movie star book and movie song cube

Reminisce about the cinemas your residents used to go to and the experiences they had – intervals, smoking and no smoking areas, usherettes and ice creams, and the National Anthem being played at the end of the film!

Get further into the Movie spirit by wearing the famous face masks and using the photo props – have photos taken in front of the red carpet backdrop using a phone for printing later as a memento of the session. Make a collage from the smaller props if you prefer.

Try out the sound effects box – see if everyone can guess what the sound is. Make some popcorn (be careful the spout gets hot) and sing along to the cube (download a free QR code reader and the CD of old time songs from the war years.

Example Activity Reminiscence

Let people tell their stories and reminisce about how they used to spend their time. The photos on the inside and outsides of the box provide great discussion points. Have the whole box as a central point or encourage conversation by distributing the different sides of the box around the table so that people can discuss the pictures. See who remembers the 4Bs of Reading (Huntly and Palmer's biscuits), beer (Simonds brewery then Courage) and bulbs (Sutton's Seeds) and for some the 4th 'B' of bricks (S & E Collier); and who remembers the Greenham Common or the Newbury Bypass protests.

Add one of the reminiscence packs for more directed discussion about, favourite toys (look at the bottom of the AMuSED box as well), favourite singers, dancehalls and bingo venues. Discuss where people shopped in Reading and Newbury and the sporting venues they used to frequent to watch or participate in.

Broaden the discussion using the other reminiscence pack to consider who was a brownie, cub, girl guide or a boy scout and where they went to school etc.

For those who like to garden – grow the seed packs

Example Activity
Go to the Funfair

Look at the AMuSED panels – and let people reminisce about the times they visited the funfair; when the circus came to town; and all the events at the Newbury show.

Discuss fairground games and prizes. Have the people reminisce about the games they played at the fairground and how they were played. The prompt questions act as a great guide to steer the conversation. Let people say what types of prizes they won at the fairground and the games they played to win the prizes.

Set up your own fairground arcade with the hook a duck – your ducks can swim in the plastic box they come in or be on dry land); throw the balls into the bowls to win a goldfish; and see who can beat the buzz wire!

Become circus performers with the photo props and try and identify the smells of toffee apples, cinder toffee and candy floss (waft the cubs around a bit before smelling closely to get the best experience).

For those who prefer a quieter time – the colouring sheets have big tops and circus performers.

Example Prompt Questions

- Have you ever been to the cinema? Which one?
- What movies did you go to see? Who did you go with?
- What is your favourite movie?
- Who is your favourite movie star?
- If you could make a movie, what will the title be?
- What will your movie be about?
- What was your favourite thing to eat at the cinema?
- Have you ever been to the fairgrounds?
- Who did you go with?
- What rides did you go on when you visited the fairgrounds?
- Where did you visit?
- What was your favourite ride to go on?
- What games did you play?
- Did you ever win a goldfish at the fair?
- What other prizes did you win?
- What foods did you eat at the fairground?
- Were you a brownie or a cub scout? Did you gain any badges?
- Do you remember the Newbury bypass being built
- Did you go to the Newbury show?
- What is your favourite sport?
- Do you follow a football team?
- What were your favourite toys?
- Do you enjoy gardening?

Need Help? Things Mended or More Materials?

We hope you are enjoying using the AMuSED Entertainment Box. Should anything break, or you would like more of your favourite resources, or you would like further ideas about how to use the AMuSED Box, just get in touch with us:

Esther – e.o.olorunda@pgr.reading.ac.uk
Rachel – r.j.mccrindle@reading.ac.uk
Fred – fjemcc@gmail.com

Thank you once again for your feedback, it is much appreciated.

Appendix M: 6-Month Follow Up Questionnaire

University of Reading

AMuSED Toolkit

Dear Manager or Activity Coordinator, we hope that you have enjoyed using your AMuSED boxes over the past few months. Please complete the questions below – or if you prefer just to send us an email with your own set of thoughts. Many thanks.

1. How often have you used your AMuSED toolkit(s) over the past 6 months?	
2. In what ways have you incorporated AMuSED into your activity sessions?	
3. What have you like most about the AMuSED Toolkit?	
4. What have been your favourite elements? If possible, please tell us why.	
5. Is there anything you have disliked about the AMuSED toolkit? Anything annoying?	
6. What have been your least favourite elements? If possible, please tell us why.	
7. Are there any other elements would you like to see included in AMuSED? Please specify.	
8. Are there any elements you would like to see removed or changed? Please specify, and if possible, tell us why.	
9. How well do you think the AMuSED box has stood up to use over time?	
10. In what ways do you think AMuSED is different from other products on the market?	
11. Are there any ways in which you think AMuSED could be improved? We would love to learn from your experience.	
12. Do you have any suggestions for other themes that your residents would enjoy?	
13. How likely are you to recommend AMuSED to others?	
14. Is there anything else you would like to say about AMuSED?	

Final Questionnaire for the AMuSED Box

Dear Manager or Activity Coordinator, we hope that you have enjoyed using your AMuSED box(es) over the past months. We know you are very busy, but we would be really appreciative if you could answer this final questionnaire about your experience of using the AMuSED box(es) and send it back to us Many thanks for your time 😊.

Section 1 – Overall Impressions of the AMuSED Box

Please state how much you agree or disagree with the following statements about the AMuSED Box (tick appropriately)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The images on the AMuSED box are of good quality					
The AMuSED box is too large					
We are keen to continue using the AMuSED box (or other themes) and its contents in future activity sessions					
There are not enough elements and activities included in an AMuSED box					
The AMuSED box is not sturdy enough					
The AMuSED box contains an appropriate number of elements and activities					
It is a bad idea to mix sensory elements, reminiscence prompts and activities within a single AMuSED box					
The size of the images on the outside of the AMuSED box are not appropriate					
The elements in the AMuSED box are relevant to people at different stages of dementia					
The AMuSED box and its contents do not engage people with dementia					
The AMuSED box is an appropriate size					
The images on the inside of the AMuSED box are not well related to the theme or its activities					
The AMuSED box images do not prompt reminiscence					
The theme of the AMuSED box is coherent					
The construction of the AMuSED box is sturdy enough					
It would be better not to have specific themes for the AMuSED boxes					
The images on the AMuSED box prompt reminiscence					
The AMuSED box is easy to put together from its individual panels					
The images on the AMuSED box are of poor quality					
Having an Activity Booklet is useful					

Please state how much you agree or disagree with the following statements about the AMuSED Box (tick appropriately)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The AMuSED box and its contents engage people with dementia					
Having different themes for the AMuSED boxes is useful					
We do not wish to continue to use the AMuSED box (or other themes) and their contents in our future sessions					
The images on the outside of the AMuSED box are of an appropriate size					
The AMuSED box is difficult to put together from its individual panels					
The AMuSED box when placed on a table immediately stimulates interest					
Having a mix of sensory elements, reminiscence prompts and activities in a single box is a good idea					
It is not necessary to include an Activity Booklet in the AMuSED box					
The AMuSED box is well made					
The theme of the box is not clear					
The images on the inside of the box do not help to generate further discussions					
Having question prompts included in the Activity Booklet is helpful					
The AMuSED box has does not stimulate interest when placed on a table					
The box is easy to open and use as separate panels					
The elements in the AMuSED box are not relevant to people at different stages of dementia					
The images on the inside of the AMuSED box link to the theme of the box and/or its activities					
The AMuSED box is poorly made					
Having example questions within the Activity Booklet is not useful					
The images on the inside of the box are useful for stimulating further discussion					
The AMuSED box is difficult to split into its separate panels					

Section 2 – Use by Activity Coordinator

How did you choose the activities for your sessions?	
Did you combine the AMuSED box with other activities?	
If yes above, what activities did you combine the box with?	
Did the AMuSED box help you plan or run activity sessions?	
What element or activity did you enjoy working with the most?	
What element or activity did you not enjoy?	

Section 3 – Use by participants

Did your participants with dementia engage with the box?	
What elements of the box were your participants most excited about?	
Were there any elements or activities that your participants did not engage with or enjoy?	
Were there any participants that could not participate in the AMuSED sessions due to impairments or other reasons?	

Section 4 – Interpretation of the AMuSED Box

Based on your sessions, how well did the AMuSED toolkit engage participants with:					
	Not at all	A little	On and off	Quite a bit	Very much
Early dementia					
Mid dementia					
Late dementia					

Do you believe the AMuSED box helps people to reminisce?	
Is there a difference between the AMuSED box and other tools or activities you normally use? Please state the difference.	

Do you believe the AMuSED box provides the right amount of stimulation to your session participants?	
If no, please explain why. (e.g too advanced, too childish, not enough stimulation etc.)	

Thank you for giving us your final impressions of the AMuSED box – we hope you enjoyed using it and your residents found it fun and engaging.