

THE IMPACT OF ENGAGEMENT WITH THE ARTS ON THE HEALTH AND  
WELLBEING OF HOSPITAL INPATIENTS WITH DEMENTIA

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## ABSTRACT

The global rise of dementia has provoked a multidimensional response from research, policy, and practice sectors. Care for dementia in hospital settings is of particular concern given the outsized lengths of stay and readmission rates. To respond to the resulting care needs, arts in health programmes are increasingly implemented in hospitals, with a central focus on supporting those with dementia. This PhD aimed to explore patterns of engagement with the arts and their psychosocial effects on hospital inpatients with dementia, with a particular focus on the differences in psychological impact between traditional and digital modes of engagement.

The study used a sequential mixed methods design organised across three inter-related studies. Study 1, a cross-sectional study of 123 inpatients, used a questionnaire battery consisting of validated measures for loneliness, quality of life, and depression alongside questions regarding current, past-year, and life course engagement with different art forms and cultural activities. High rates of loneliness and depression were measured among participants, but current individual engagement with the arts was associated with less loneliness and increased quality of life. Notably, passive and solitary activities such as reading and watching television were associated with lower levels of loneliness. Study 2, a focused ethnographic study of 43 participants, focused on digital and traditional arts and music programmes at an acute care NHS trust. This study found that the novelty of digital art led to focused individual engagement while traditional art groups were more likely to engage socially. Additionally, this study presented a model for patient experience of hospital art groups describing the discrete and interactive effects of arts engagement, social interaction, and environment. Study 3, a 3-arm controlled study with 90 participants, compared validated before and after measures of anxiety and wellbeing for traditional art, digital art, and control activities. This study found short term improvements in wellbeing in both digital and traditional art groups and lowered anxiety in the traditional art group compared with a control group.

The thesis triangulates data from the studies to explicate patterns of arts engagement and their effects. A methodological contribution is made by using both qualitative and quantitative methods to connect intra-activity data with outcome measures. Theoretical contributions include considerations of the balance between novelty and familiarity in arts engagement, the roles of the environment and social engagement in a hospital setting, and the use of art for both reminiscence and expression in dementia.

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## INTRODUCTION

Dementia is an age-associated syndrome that affects individuals on a global scale. As populations age, policymakers, researchers, and healthcare practitioners have begun organising efforts to combat the rise of dementia and the effects of its symptoms. While research into the development of pharmacological treatments and preventions are ongoing, we must simultaneously turn attention to ways in which people can live well with dementia. This calls for exploration of the lived experience of dementia, which should take into consideration the perspective and experiences of the researcher.

My educational and professional backgrounds are in public health and health communication. My undergraduate studies emphasised environmental health, and I have worked for a time with the United States National Center for Environmental Health as a health communication specialist. This work highlighted and developed my interest in health perceptions, education, and their influence on health behaviours. Through this work, I have gained an appreciation for the environment's impact on health and health behaviours. From this perspective, I have seen that unusual built environments have the potential to influence health and wellbeing in unusual ways. I therefore approached my PhD research with the presumption that the unfamiliar acute care environment has the potential to influence the health and wellbeing of patients.

My MSc Public Health project focused on knee replacement surgeries in the National Health Service (NHS), bringing my attention to the ageing population and the challenges it brings to the NHS. Additionally, I came into my PhD research having read newspaper headlines focused on budget and staffing cuts alongside general turmoil at high levels in the NHS. With this background, I anticipated a certain amount of stress and harried behaviour among clinical staff, which I expected to demonstrate the need for additional support in the care for dementia in hospital.

In addition to my background in public health and health communication, I also have spent much of my life involved in a broad range of pursuits in music and performance. I began classical piano lessons at age 5, and I have sung in choirs since age 9. This exposure to music has included experiences conducting choirs, directing music for local theatre productions, and teaching music to young people. Through these experiences, I have steadily gained a broad perspective on the different ways and reasons people engage with music and the arts and the effects this can have on their lives. Many important relationships in my life have come from and

developed through engagement with the arts, and I have observed and experienced the power of the arts to, for instance, facilitate social interaction, develop mutual understanding, nurture spiritual health, and improve mood. I embarked on my PhD research acutely aware that my own experience and background are not generalisable, especially to specific vulnerable populations such as hospital inpatients with dementia. Therefore, I began my studies broadly, aiming to explicate the experience of dementia in hospital environments before exploring how arts activities might fit in and provide support to individuals and healthcare institutions.

The undertaking of this PhD involved research on both the biomedical model and social care perspectives on dementia. My background in health communication was defined by a similar pragmatic orientation that constantly negotiated the boundary between the top-down belief in the power of messaging and education, mixing with a bottom-up perspective emphasising the power of individual perceptions, experiences, and environments. By focusing this research on the mental health and wellbeing of hospital inpatients with dementia, I accepted the inherent tension of bringing a person-centred social perspective to a mainly biomedical setting. This perspective allowed me to view the hospital as a complex organisational setting that houses activities normally undertaken in community and social settings. By embracing perspectives with inherent tensions, this thesis aims to provide a nuanced characterisation of the setting and activities studied.

### **The Policy Context for Dementia Care and Research**

This PhD research has taken place in a single NHS trust across two hospitals in London. The challenge of care for dementia, however, is a global issue. Policymakers, researchers, and charities around the world have recognised the challenges faced by dementia as well as the potential for engagement with the arts to improve the lived experience of dementia. Following this recognition is a series of policy recommendations and actions taken in health services practices and non-pharmacological interventions at international, national, regional, and local levels.

**International dementia policy.** The World Health Organization (WHO), the international health arm of the United Nations, called dementia “one of the greatest societal challenges for the 21<sup>st</sup> century” and has taken note of the range of challenges presented by dementia across the world. In 2012, it published its strategy in the report *Dementia: A Public*

*Health Priority*. This seminal document outlined the epidemiology, policy, care landscape, and public perception of dementia, aiming to provide meaningful data and strategies for the range of challenges that affect countries with different populations and healthcare systems. Firstly, it urged that all countries should consider dementia as a central concern in their public health strategies. It then acknowledged the personal nature of the disease by recognising that “people with dementia and their caregivers often have unique insights to their condition and life” and therefore “should be involved in formulating the policies, plans, laws and services that relate to them” (World Health Organisation & Alzheimer’s Disease International, 2012). Furthermore, this report acknowledged the levels of action that must be taken to address dementia, including “internationally, nationally and locally, as well as at family and personal levels.” The WHO concluded the report by calling for research, stating that “evidence should underpin all actions and is a critical element of the overall package of international dementia efforts.”

Following the report’s publication, the WHO has since released the *Global Action Plan on The Public Health Response to Dementia: 2017 – 2025* (WHO, 2017). It called for the development of “strategies and interventions for dementia...care that are person-centred, cost-effective, sustainable and affordable” as well as the improvement of “care and support for people with dementia” and “innovative models of care.” It also emphasised the importance of “continuity of health and social care,” a particular challenge for people with dementia admitted to acute care facilities. This report acknowledged the challenge of acute care settings by recommending that United Nations member states “systematically shift the locus of care away from hospitals.” Further to its emphasis on person-centred care for dementia, it also recommended that member states “foster the development of technological innovations that, in terms of design and evaluation, respond to the physical, psychological and social needs of people with dementia” (WHO, 2017).

**UK dementia and wellbeing policy.** Although few countries have risen to the WHO’s challenge to create a national dementia plan (WHO | Dementia, 2018), the United Kingdom has led the way in national-level efforts to address dementia. In 2009, a national strategy, *Living Well with Dementia*, was launched. It is a comprehensive outline for the ways in which research and care practice might approach the issue. “Improved quality of care for people with dementia in general hospitals” was listed as a key objective. Identified under this objective was the need for “specialist liaison older people’s mental health teams.” While this report suggested that teams be

made up of clinical staff, there was scope for arts activities to aid in the care of dementia, especially in concert with therapy teams. In addition to awareness and early diagnosis, a major feature of the national dementia strategy focused on living well with dementia. The emphasis on care and treatment was a recognition of the lived experience of dementia and the importance of researching care strategies alongside research in dementia prevention and treatment (Banerjee and Owen, 2009).

More tangible, concrete policy was published in 2015, when the Department of Health released the *Prime Minister's Challenge on Dementia 2020* and its associated *Implementation Plan* in 2016. It promised increased government funding for dementia research, which is now over £60m per year. A major element of future plans included the establishment of the Dementia Research Institute, whose hub was later given residency at University College London in July 2018. The *Prime Minister's Challenge on Dementia 2020* featured a focus on hospital care, including quality of care and the creation of dementia-friendly settings (Department of Health, 2016). Reducing unnecessary increases in lengths of stay was a specific challenge cited. Also, in 2015, the WHO established the Global Dementia Observatory, a surveillance system for comparing dementia epidemiology and service data between countries. England was among the initial group of countries selected to pilot this system.

Alongside the calls for focused dementia care has been a UK call for a focus on wellbeing across the country. The UK government white paper *Healthy Lives Healthy People* articulated the government's emphasis on wellbeing in addition to the elimination and treatment of disease (Department of Health, 2010). This document set out the vision for the government agency Public Health England, later established in 2013. A broad report addressing broad public health concerns throughout the UK, it included a section titled "Health and wellbeing throughout life." This signaled an important shift in thinking for the Department of Health, which called the broad definition of wellbeing a "radical shift in the way we tackle public health challenges." Ageing healthfully, according to this document, includes "maintaining social networks, being part of a community and staying active." The white paper identified barriers to these goals, including ageist attitudes which impact older people in myriad ways. Feeding these attitudes is the "taboo about discussing death and dying," which can complicate end-of-life care and planning for both older people and their loved ones. The experience of people with dementia

who are admitted to hospital presents further challenges to the goals of this white paper due to a range of symptoms affecting their health and wellbeing (Boaden, 2016; Timmons et al., 2016).

**NHS dementia policy.** The *Prime Minister's Challenge on Dementia 2020* served as a response to the *National Health Service Five Year Forward View*, published in 2014. It was written to be a general rallying cry for the NHS. While it was aimed at the entire range of NHS care, it identified three main gaps that cut to the core of dementia care concerns: the health and wellbeing gap, the care and quality gap, and the funding and efficiency gap. NHS England responded with the *Implementation Guide and Resource Pack for Dementia Care* in 2017. This document outlined the standards of support for NHS Commissioners and Providers. Its mission was as a practical document, beginning by defining simply “what good dementia care looks like” from a health systems perspective. The implementation guide drew from and supplemented work already being done in localised academia and practice, featuring case studies including Stockport CCG’s shared care pathway and memory services in Enfield, Stockton and Devon (NHS England, 2017). In a review commissioned by the Department of Health, the Centre for Policy on Ageing reported an agreement among researchers and policymakers that mental health services available for older hospital inpatients are insufficient. The paper recommended a liaison service model characterised by collaboration between general practitioners and psychiatric specialists without making a formal referral (Livesey, 2009). The overhaul was recommended in the context of intractable issues such as age discrimination in acute and community care settings as described by Livesley (2009). These service models have been addressed alongside built environmental overhauls. The Department of Health’s Dementia Capital Investment Fund has focused on environmental renovations, funding 42 NHS and 74 Social Care Pilot projects in 2013-14 (Price, Pantartzis, & Pascale, 2015). These projects were chosen to encompass a variety of care home and acute care settings and a variety of spaces within those establishments including public lounges, bathrooms and bedrooms.

All of these policy shifts are monitored by the *NHS Outcomes Framework*, which outlines 5 broad domains:

- Preventing people from dying prematurely,
- Enhancing quality of life for people with long-term conditions,
- Helping people to recover from episodes of ill health or following injury,

- Ensuring that people have a positive experience of care,
- Treating and caring for people in a safe environment and protecting them from avoidable harm.

While the NHS is often associated with medical interventions, these framework domains reflect priorities in person-centred care. Applied to research fields in dementia, the first domain leaves scope for drug discovery and dementia prevention and reversal. However, the subsequent four domains are potentially best addressed through psychosocial care.

**National Institute for Health and Care Excellence.** As the NHS's branch dedicated to providing guidance across England and Wales, the National Institute for Health and Clinical Excellence (NICE) has power in shaping the way dementia is cared for across NHS trusts. Person-centred care is an “overarching principle of care and support during transition” (NICE, 2015), according to their guidelines examining the transition between inpatient hospital settings and community or care home settings. However, reports from NHS England found consistently rising delays in transfers out of acute care due to lack of social support upon discharge (NHS England, 2017). For people with dementia, these rising rates include people whose independence worsened during their time in hospital. The Alzheimer's Society reported that only 36% of people with dementia who come from their own homes are then returned home upon discharge (Boaden, 2016). The resulting increased lengths of stay as hospital inpatients point to a need for sustained and institutionalised person-centred care.

To address this, NICE guidelines recommend efficient data sharing as a means of achieving consistent care across clinicians and settings. It emphasises the person-centred approach to care for dementia (NICE, 2006). This has been adopted as a philosophy in hospitals across the NHS, but person-centred care is difficult to define and recognise consistently in practice in an acute setting. As defined by the Health Innovation Network, person-centred care is a holistic approach to healthcare that puts “people and their families at the centre of decisions and seeing them as experts, working alongside professionals” (Health Innovation Network, 2018). Along with addressing “personal and social care needs,” NICE recommends that health and social care are integrated through primary care, home, and acute care among other settings (2006).

## Arts, Health, and Wellbeing

The NICE guidance on dementia care comes at a time when the health and wellbeing benefits of arts engagement are receiving attention from governmental agencies. This comes after a surge in research interest regarding the effects of cultural engagement on health outcomes as wide ranging as psychological wellbeing (Hankir, Kirkcaldy, Carrick, Sadiq, & Zaman, 2017), biomarkers for stress such as cortisol (Fancourt et al., 2016), and mortality (Väänänen et al., 2009).

The WHO has recognised the importance of cultural context and activity in the promotion of health. It has called for research on cultural influence on health perceptions, and the European health policy framework, Health 2020, prioritises research in cultural impact on subjective wellbeing (WHO - Regional Office for Europe, 2013). In January 2015, the WHO European office convened 21 experts in health and cultural fields who began a project addressing advocacy, research, and reporting on cultural contexts of public health issues including the measurement of overall wellbeing.

The turn of the 20<sup>th</sup> century saw the beginning of national-level initiatives demonstrating a commitment to development of arts and culture for wellbeing. The Arts Council of Ireland led the way in coordinating a national-level effort to fund arts in health programmes (Fancourt, 2017). Since the 1990s, it has supported projects such as *The Picture of Health* (Brown et al., 2004), *Mapping the Arts in Healthcare Contexts in the Republic of Ireland* (O Cuiv, 2001), *The Public and the Arts 2006* (Drury, 2006), and *Arts and Health Policy and Strategy* (Kildare County Council, 2009).

Scandinavia has also acknowledged the importance of cultural engagement for health. Sweden did this through a report issued by the Swedish Governmental Commission on Public Health (Östlin, Diderichsen, & Organization, 2001), which was then followed by the establishment of a Society for Culture and Health in 2007. Other Scandinavian countries have established similar governmental organisations with the Norwegian National Institute for Culture, Health and Care in 2014 and the Arts Promotion Centre Finland (Fancourt, 2017). Other prominent publications outside Europe include the Australian *National Arts and Health Framework* (2014), the white paper *Arts, Health and Wellbeing across the Military Continuum*

(2013) and *Why Healthcare Institutions Invest in the Arts* (2008) from the not-for-profit organization Americans for the Arts.

The UK has demonstrated its own interest in the potential for the arts to influence health. In 1998, the Nuffield Trust for Research and Policy Studies in Health Services organised *The Role of Humanities in Medicine: Beyond the Millennium*, a conference with the purpose of reviewing the landscape of arts in health activities across the world and future directions (Philipp, Baum, Mawson, & Calman, 1999). Closely following this conference was the publication by the Health Development Agency of *Art for Health: a review of good practice in community-based arts projects and initiatives which impact on health and wellbeing* (2000). This paper in particular introduced the idea that arts are a vehicle for social capital, a term that captures interpersonal concepts including “trust, reciprocity, local democracy, citizenship, civic engagement, social relationships and social support.” By improving social capital, this paper argues that public health and health promotion can be improved in turn.

In 2014, the All-Party Parliamentary Group on Arts, Health and Wellbeing (APPG) was formed, releasing a ground-breaking report *Creative Health: The Arts for Health and Wellbeing* in 2017. This report was notable for its breadth, encompassing research, practice, and policy across the UK and international arts in health communities. It drew connections between different forms of engagement with the arts, health, wellbeing, and their relationship to social determinants of health, including the role of the arts in marginalised communities. Further to its breadth included broad summaries of research evidence, international policy, and funding streams. It also described how engagement with the arts can be impacted by environments, outlining the role of the arts in natural and built environments, with a focus on healthcare environments and the importance of place-based commissioning.

The APPG report identified populations that may benefit from engagement with the arts. Sections were dedicated to evidence and practice focused on people with dementia, pregnant women and new mothers, and those with various chronic conditions. An entire section was devoted to the arts in older age, outlining the ways engagement with the arts can help, including benefits to mental health and wellbeing, combatting social isolation, and practical benefits from dance for prevention of falls. This report recommended ambitious interventions for the arts, including the incorporation of arts on prescription in commissioning plans.

Many UK charities have now taken up the mantle of research and policy recommendations for dementia care, focused on providing specific implementation strategies for the broader goals set by the WHO, UK government, and NHS reports. This includes the importance of the care environment and the value of arts in health activities for people with dementia. In 2004, Arts Council England funded the first review of scientific literature of health benefits of engagement in the arts across artforms and patient groups (Staricoff, 2004). Based at Chelsea & Westminster Hospital, Staricoff reviewed studies performed between 1990 and 2004, demonstrating the sizeable growth of the research field in recent decades. Charity work has also focused on activities and environments for older people and people with dementia. The King's Fund, in a report focused on hospital continuity of care, recommended a "complete transformation in hospital organisation and culture," citing the growing consensus that elder care in hospitals is insufficient (Cornwell, Levenson, Sonola, & Poteliakhoff, 2012). The Baring Foundation has published reports on the care of older people, including how the arts can be used as a tool for social and artistic fulfilment in older age (Cutler, 2009), strategies for addressing loneliness (Cutler, 2009), and how digital technologies might be used in arts activities for older people (Randall, 2012). The recognition by diverse organisations including charities, healthcare institutions, and governments of the power of the arts to benefit health and wellbeing indicates the political relevance and timeliness of further research into the role the arts have to play within healthcare.

### **The Need for the Study**

As the UK population ages, it faces a growing burden of dementia, and hospital settings present particular challenges to the care of patients with dementia. The Care Quality Commission (2011) has reported that 65% percent of hospital inpatients in the UK are aged 65 or older, and 30% of these patients have dementia. This comes at a time when NHS trusts face increasing financial pressures which may impact on patient care, especially for older populations (Robertson, Wenzel, Thompson, & Charles, 2017).

Governmental and charitable organisations have acknowledged the growing evidence base regarding the effectiveness of engagement with the arts for health and wellbeing (All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017). Arts in health activities are seen as particularly beneficial for people with dementia, and research has demonstrated that this is especially true for community-based arts activities (Young, Camic, & Tischler, 2016). Little is

known, however, about the effect of engagement with the arts by patients with dementia in hospital settings.

## CHAPTER 1 REVIEW OF THE LITERATURE

### 1.1 Background to dementia

#### 1.1.1 Clinical Description of Dementia

Dementia is a broad term describing the cluster of conditions characterised by the deterioration of neurons and neural functioning. This deterioration may occur through a variety of aetiologies by which dementias are classified (Edhag et al., 2008). Alzheimer's disease, frontotemporal dementia, and dementia with Lewy Bodies are all examples of degenerative dementias, while vascular dementias are caused by disruptions of the flow of blood to certain areas of the brain, often through stroke (Cooper and Greene, 2005). These classifications may be useful for understanding symptoms and treatment, however there is often overlap between degenerative and vascular dementias (Kalaria and Ballard, 1999), creating a category often referred to as mixed dementia (Zekry, Hauw, and Gold, 2002).

#### 1.1.2 Epidemiology of Dementia

In 2010, an estimated 35.6 million people worldwide had dementia, and an additional 7.7 million new cases are expected each year. Fifty-eight per cent of current dementia cases are thought to occur in low and middle-income countries, and this proportion is projected to grow to 71% by 2050 (WHO, 2015). Alzheimer's disease is the most prevalent dementia, accounting for 60-70% of all dementia cases (WHO, 2015). Vascular dementia is the second most common form, comprising between 5 and 20% of all dementia cases (Tampi, 2015).

The risk for dementia climbs with increasing age, and dementia is often classified as either late onset for those developing dementia after age 65 and young onset for those developing dementia before age 65 (Edhag et al., 2008). Young onset dementia is much less prevalent than late onset, accounting for between 2% and 9% of all cases. Of these, 68% of young onset cases occur in people age 55 and older. As the global population ages and medical advances increase longevity, dementia incidence and prevalence are expected to rise considerably (WHO, 2015).

### 1.2 Symptoms of Dementia

Dementia onset and progression are characterised by a wide range of symptoms that are experienced by most patients but experienced uniquely by each patient. While it is helpful to organise symptoms of dementia into categories such as cognitive, functional, and psychological, the lines between these distinctions may be blurred. Furthermore, a secondary symptom of one

classification of dementia may be considered a primary symptom of another (Edhag et al., 2008). The wide range of aetiologies and personal patient histories lead to the wide range of type and severity of dementia symptoms. Dementia is primarily understood as a neurodegenerative condition, however it is a condition influenced by psychological, social, and cultural factors. These human factors will be discussed at greater length in Section 1.3 called “Challenges in Dementia”.

### **1.2.1 Cognitive Impairment**

Cognitive impairment progresses at variable rates that cannot be predicted based on the type of dementia (Ballard et al., 2001). Cognitive impairment from dementia may affect different cognitive functions, but it is most commonly associated with memory loss, especially episodic (the sequence of events in time) and semantic (accumulated knowledge about language and the world) (Cooper and Greene, 2005). Anterograde memory loss involves forgetting occurrences after onset of dementia, and retrograde memory loss involves forgetting events that occurred before onset of dementia (Cooper and Greene, 2005). Alzheimer’s disease is characterised by slow onset and progression, thus making conclusive early diagnosis difficult (Edhag et al., 2008). In early stages, memory loss is usually characterised as being anterograde episodic (Cooper and Greene, 2005). While it invariably ends with severe cognitive deterioration and death, the rate of progression is variable, with death usually occurring in a 2-20 year window from onset (Edhag et al., 2008).

Semantic dementia is characterised by the loss of meaning-based memory, often manifested in a loss of language communication capability (Snowden, Goulding, and Neary 1989). It may also be known as primary progressive aphasia, a dementia characterised by language loss rather than memory problems (Mesulam 2003; Wicklund, Johnson, and Weintraub, 2004). Semantic dementias are distinct from Alzheimer’s disease by the nature of cerebral degeneration, with temporal regions of the brain more affected than frontal regions (Snowden, Goulding, and Neary; 1989). Multilingualism is often lost with progression of dementia (Hyltenstam and Obler, 1989).

While problems with memory are often considered a normal part of ageing, they may become severe enough to be classified as a mild cognitive impairment or dementia (Tampi,

2015). The distinction between normal and abnormal cognitive ageing is a subject of some debate (Edhag et al., 2008), thus making early diagnosis of mild dementia a challenge.

Cognitive reasoning may also be affected by dementia. A 2006 study found that patients with the frontal variant of frontotemporal dementia had preserved knowledge of social rules, but moral reasoning was impaired due to lessened empathy (Lough et al., 2006). Reasoning is thought to be cognitively unrelated to language because it is often preserved in patients with primary progressive aphasia (Wicklund, Johnson, and Weintraub, 2004). This progressive impairment of reasoning in patients with dementia presents important ethical issues regarding consent and decision-making in clinical matters (Moye et al., 2004).

Finally, orientation in time and space is often impaired in patients with dementia, starting with mild impairment all the way through total dissociation in the later stages of dementia (Booth et al., 2016; Sulkava and Amberla, 1982).

Despite the variety of cognitive symptoms in dementia, cognitive assessments are often focused on memory, especially episodic memory. Dementia is often diagnosed using tools such as the Mini-Mental State Examination (MMSE) (Cooper and Greene, 2005). However, the evaluation of these tools is limited (Edhag et al., 2008). While developing brain-imaging technology is producing more accurate diagnoses, dementia cannot be conclusively diagnosed until brain tissue is analysed post mortem.

Given the multidimensionality of dementia, a number of scales have been developed to address progression based on different symptoms. The commonly used MMSE divides cognitive progression into mild, moderate, and severe stages while the Global Deterioration Scale focuses on progression of functional symptoms of dementia. Early stages of Alzheimer's disease are characterised mostly subjectively and are not often examined clinically (Edhag et al., 2008). Overall functioning can be measured by the Clinical Dementia Rating (CDR) scales, which use a structured interview to measure functioning in "memory, orientation, judgement & problem solving, community affairs, home & hobbies, and personal care." Additionally, the CDR scales have been validated for identifying stages of dementia (O'Bryant et al., 2008).

### **1.2.2 Functional Impairment**

Cognitive symptoms of dementia lead to functional impairments in daily living, and people with even mild cognitive impairment have been found to have trouble completing tasks involving complex reasoning (Pernecky et al., 2006). Functional impairment has been examined by teasing out differences between types of dementia. Gure et al. (2010) examined three groups of people with different dementias: Alzheimer’s disease, vascular dementia, and other aetiologies. Using the ADAMS scale to measure functional impairment, they found that those with vascular dementia have significantly more problems completing daily activities than those with Alzheimer’s disease (Gure et al., 2010). Another study found that dementia with Lewy Bodies is associated with more functional impairment than Alzheimer’s disease (McKeith et al., 2006), although slight dysphagia and dysgraphia (trouble speaking and writing) are known to occur in Alzheimer’s disease (Edhag et al., 2008).

Early diagnoses of mild cognitive impairment were based on cognitive measures only, but there has recently been a push for functional measures to be prioritised criteria in diagnosing mild cognitive impairment and dementia (Sheehan, 2012). Bombin et al. (2012) found functional impairment to be a more sensitive predictor of multi-domain mild cognitive impairment from single-domain mild cognitive impairment than cognitive tests.

### **1.2.3 Neuropsychiatric Symptoms – Behavioural and Psychological Manifestations**

Different dementias are generally associated with different behavioural and psychological symptoms of dementia (BPSD). This has been attributed to different areas of the brain being affected by vascular and degenerative dementias. BPSD, similarly to cognitive and functional symptoms, tend to worsen as dementia progresses (Kales, Gitlin, and Lyketsos, 2015).

First order cognitive impairment effects of dementia include “emotions, mood, perception, thought, motor activity, and personality traits” (Cerejeira, Lagarto, and Mukaetova-Ladinska, 2012). As second-order symptoms, they are not currently used as diagnostic criteria. However, because these BPSD are associated with distress and other morbidities in both patients and carers, they are considered important targets for health interventions (Cerejeira, Lagarto, and Mukaetova-Ladinska, 2012).

Delusions may occur as symptoms of dementia. However, in dementia, delusions tend to be more fleeting, less complex and less organised than in psychosis. While hallucinations may occur with any type of dementia, visual hallucinations are most commonly associated with dementia with Lewy Bodies (Cerejeira, Lagarto, and Mukaetova-Ladinska, 2012). In later stages of Alzheimer's disease, delusions and hallucinations are features of about half of cases (Edhag et al., 2008).

Motor function is often affected through motor retardation in which the patient may speak, move, or complete dextrous tasks more slowly. Motor hyperactivity may also occur. Abnormal motor functioning is broadly referred to as agitation, a term that refers to a range of behaviours from pacing to wandering to repetitive motions to antisocial or inappropriate behaviours which can range from wandering to sexual disinhibition (Cerejeira, Lagarto, and Mukaetova-Ladinska, 2012).

People with dementia also exhibit changes to sleep patterns including both insomnia and hypersomnia. Related physiological issues include needing to urinate and side-effects from new medications taken for dementia or co-morbidities. Appetite changes, including over or under appetite and change in preferred foods, are also common among persons with dementia (Cerejeira, Lagarto, and Mukaetova-Ladinska, 2012).

### **1.3 Challenges in Dementia**

While the distinctions between symptoms of dementia may be blurred, challenges in dementia are further confused by their interaction with social and societal factors. In addition to their role as symptoms of dementia, the following challenges in dementia are considered by this thesis as broad issues that affect psychosocial health, wellbeing, and quality of life of people with dementia. These challenges have been researched to varying degrees and may be particularly amenable to arts in health or other non-pharmacological interventions.

#### **1.3.1 Wellbeing**

Wellbeing has been set as a governmental priority through a number of reports including *Healthy Lives Healthy People* (2010), the Stiglitz-Amartya-Fitoussi report (2011), and the UK Office of National Statistics (Hicks, 2011). By exploring the wellbeing of hospital inpatients

with dementia, this thesis addresses health challenges in general. Indeed, the first WHO principle of health is defined as “a state of complete physical, mental and social wellbeing.”

The United States Centers for Disease Control and Prevention acknowledges that wellbeing has no single definition, however there is a consensus that wellbeing describes “the presence of positive emotions and moods, the absence of negative emotions, satisfaction with life, fulfilment and positive functioning” (CDC, 2018). The UK Government white paper *Healthy Lives Healthy People* defines wellbeing as “a positive physical, social and mental state.” These slightly different definitions have led to the investigation of wellbeing in dementia from a variety of perspectives, including mental wellbeing (Allward, Dunn, Forshaw, Rewston, & Wass, 2017), emotional wellbeing (Kolanowski, Litaker, & Catalano, 2002), and psychological wellbeing (Farrand, Matthews, Dickens, Anderson, & Woodford, 2016).

Encompassing these sub-definitions of wellbeing is the general concept of subjective wellbeing. Seligman (2011), an influential thinker in the domains wellbeing and positive psychology, hypothesised the PERMA model of wellbeing. The anagram outlines *positive emotion, engagement, relationships, meaning, and accomplishment* as the tenets of wellbeing. The PERMA model of wellbeing has proven especially useful for “institutional leadership and culture change” (Slavin, Schindler, Chibnall, Fendell, & Shoss, 2012) and has been applied to environments including foster care (Jee & Simms, 2006), employee wellbeing (Kern, Waters, Adler, & White, 2014), tourism (Filep, 2014), social media use (Schwartz et al., 2015), and dementia care (Clarke & Wolverson, 2016; Peacock, Danger, & Nicol, 2017). The PERMA model is also useful for considering the health and wellbeing of healthcare providers (Penwell-Waines, Ward, Kirkpatrick, Smith, & Abouljoud, 2018). By being considered both in its broadest sense and through its sub-definitions, wellbeing is a useful concept for approach care for dementia. While dementia carries with it individual cognitive, functional and neuropsychiatric symptoms, it is experienced broadly. Wellbeing has led thinking in care for dementia from national-level strategy (NICE, 2013) to pilot project research (O’Rourke, Tobin, O’Callaghan, Sowman, & Collins, 2011).

### **1.3.2 Depression**

Depression is a mood disorder whose high prevalence gives it broad categories and definitions. It is generally characterised by persistent unhappiness and hopelessness, including

lost interest in activities that were once pleasurable (NHS, 2017). There are many subcategories of depression, including persistent depressive disorder, postpartum depression, psychotic depression, and seasonal affective disorder (National Institute of Mental Health, 2018).

Depression is often concealed by dementia because of changes in expressive capacity in dementia. Therefore, symptoms of depression may often be mistaken for BPSD. In identifying depression, it is useful to distinguish it from apathy, a state of lack of caring but importantly free from psychological distress and anxiety. Behaviourally, depression in dementia may be recognised through “apprehension, panic, worry”, and physical signs of tension (Cerejeira, Lagarto, and Mukaetova-Ladinska, 2012).

Research has rarely co-analysed depression and dementia in the older population (Korczyn and Halperin, 2009). However, some research has examined the relationship between coexisting depression and dementia as a risk factor for aggressive behaviour in patients living in a nursing home community. It suggested that treating persons with dementia for depression could reduce aggressive behaviour, thereby making a safer environment for other residents, staff, and the patients themselves (Lyketsos et al., 1999).

Both depression and dementia occur with considerable prevalence, but their occurrence as co-morbidities is largely unmeasured (Korczyn and Halperin, 2009). Because they share many symptoms, their overlap has even led to the term “pseudodementia”, a term whose loose definition accurately reflects the ambiguous distinction between depression and dementia (Korczyn and Halperin, 2009). A number of studies have, however, taken coexisting dementia and depression as a syndrome in its own right (Cohen, Hyland, and Kimhy, 2003).

Tekin and Cummings (2001) suggested that depression, bringing about its own cognitive decline, may be responsible for a syndrome known as dementia syndrome of depression. The relationship between dementia and depression is complex given that depression may exist as a risk factor, comorbidity, or result of dementia. There has been little research examining associations between the two, and even less research addressing a causal relationship between depression and dementia (Tekin and Cummings, 2001), although it was found that late-life depression co-occurs with – but does not precede - MCI as a precursor to dementia (Richard et al., 2013). The comorbidity of dementia and depression has implications for health services.

Kales et al. (1999) found significantly higher usage of inpatient services among those with coexisting dementia and depression than those with either dementia or depression alone.

Research into early-life depression has been more conclusive, finding risk for developing dementia increases more than twofold in those with early-life depression or depressive symptoms. Late-life depression has less conclusive links to the development of dementia (Byers and Yaffe, 2011).

### **1.3.3 Quality of Life**

Quality of life is a holistic concept defined by measures both intrinsic (affect, emotions, interest) and extrinsic (activities of daily living) factors. It is considered an important outcome measure in evaluating the effectiveness of both pharmacological and non-pharmacological treatments for dementia (Whitehouse and Rabins, 1992). The understanding of the complex relationship between dementia and quality of life is still being studied. A cross-sectional study in London and Nottingham found no relationship between level of cognition and quality of life (Banerjee et al., 2006). This was confirmed by a longitudinal study of 60 persons with dementia, finding no association between cognition and quality of life over a one-year period (Selwood, Thorgrimsen, and Orrell, 2005). Factors positively associated with quality of life include age of person with dementia and mental health of the carer (Banerjee et al., 2006). Quality of life was found to be negatively associated with severity of behavioural and psychological symptoms of dementia (Banerjee et al., 2006). This was confirmed by a questionnaire survey of 46 persons with dementia and 166 carers, where Hurt et al. (2008) found that depression and irritability, as rated by the carer, were negatively associated with quality of life. For the persons with dementia, higher amounts of delusion and apathy are associated with lower quality of life. Selwood et al. (2005) also found that depression and anxiety were associated with lower quality of life among people with dementia, a finding that is shared in research on adult populations (Brenes, 2007; Demyttenaere, De Fruyt, & Huygens, 2002) While the negative correlation between depression and quality of life is strong, a systematic review pointed out the low proportion of variance, suggesting that they are importantly different constructs (Banerjee et al., 2009).

### **1.3.4 Loneliness**

Loneliness is the subjective feeling of isolation (Hawkley and Cacioppo, 2010) and therefore may be felt with or without objective aloneness. As such, is often measured by asking

questions such as “how many people do you feel you can talk to?” and “do you feel part of a group of friends?” Both dementia pathology and cultural factors such as stigma may contribute to subjective feelings of loneliness and social isolation (Savikko, Routasalo, Tilvis, Strandberg, & Pitkälä, 2005). This loneliness may be exacerbated by the isolation that results from people with dementia withdrawing from work, social clubs, and public in general (Singleton, Mukadam, Livingston, & Sommerlad, 2017).

The relationship between loneliness and cognition has been researched from many angles. A cohort study of the English Longitudinal Study of Ageing found that baseline isolation was associated with decreased cognition after a 4-year follow-up. This study found that participants with low levels of education were more likely to have poor recall and higher levels of loneliness (Shankar, Hamer, McMunn, & Steptoe, 2013). Loneliness has also been shown to have strong links to depression and psychosis, worsening over time (Lim and Gleeson, 2014). These depressive symptoms are further associated with stress, fear of negative evaluation, anxiety, and anger, which are all exacerbated by loneliness.

Growing bodies of research have focused on the all-cause mortality risk presented by loneliness, with a recent meta-analysis finding that loneliness has a comparable mortality risk to smoking and obesity (Holt-Lunstad et al. 2015). Cacioppo and Hawkley (2009) described the myriad ways loneliness might contribute to this effect, including “poorer overall cognitive performance, faster cognitive decline, poorer executive functioning, increased negativity and depressive cognition, heightened sensitivity to social threats, a confirmatory bias in social cognition that is self-protective and paradoxically self-defeating, heightened anthropomorphism and contagion that threatens social cohesion.” By including internal experience, physical and cognitive impacts, and social structures, this description presents a holistic argument for the impact of loneliness on mortality. More targeted studies have found loneliness increases cardiovascular risk, even when controlled for often co-occurring depression (Hawkley and Cacioppo 2010). In an earlier paper, Hawkley and Cacioppo (2003) described this mortality risk as “a phenomenon that arguably reflects the social essence of our species.”

Loneliness has also been investigated as a risk factor for dementia. A longitudinal cohort study of 823 people in the United States found double the risk for Alzheimer’s disease in those who reported perceived social isolation (loneliness) than those who did not (Wilson et al., 2007).

A longitudinal cohort study of 2173 people in the Netherlands also found an increased risk for dementia in those who felt lonely (OR 1.64, 95% CI 1.05 to 2.56). This study controlled for objective social isolation, focusing instead on subjective loneliness (Holwerda et al., 2014). This study clarifies the distinction between loneliness and social isolation, finding that subjective experiences impact on the onset and progression of dementia.

### **1.3.5 Apathy and Engagement in Dementia**

Apathy, defined by diminished interest and energy, is a common comorbidity of dementia and occurs in 70% percent of those with Alzheimer's disease. While its symptoms have overlaps with depression, apathy is identified as a separate syndrome that merits dedicated consideration (Mortby, Maercker, and Forstmeier, 2012). In a cross-sectional study, Starkstein et al. (2005) identified apathy as being associated with cognitive deficits while depression was not. Furthermore, that study found no relationship between apathy and depression severity. It has been linked to irritability (Clarke et al., 2008), carer stress, agitation, and accelerated cognitive decline in dementia (Cerejeira, Lagarto, and Mukaetova-Ladinska, 2012). Important to the acute care setting is the impact of apathy on doctor-patient relationships. By not being engaged in their own care and recovery, apathetic patients are more likely to have longer lengths-of-stay (Chinman, Weingarten, Stayner, & Davidson, 2001; Keller & Chand, 2017)

Engagement, as an act of focus on a stimulus, has been used as an outcome measure indicating lowered apathy (Holmes et al., 2006). Several competing models for engagement in dementia have been developed (Cohen-Mansfield, Dakheel-Ali, and Marx, 2009) with no clear standard of use in long-term care, community, or acute care settings. Cohen-Mansfield et al. (2009) modelled an engagement framework as being composed of environmental attributes, person attributes, and stimulus attributes. These three attributes influence and contextualise one another in the dimensions of engagement included: *rate of refusal*, *duration of time engaged with stimulus*, *level of attention towards stimulus*, *attitude towards stimulus*, and *type of action towards stimulus* (Cohen-Mansfield, Dakheel-Ali, and Marx, 2009). While results are encouraging, more work needs to be done in interventions and evaluations for lowering apathy. Systematic reviews for both pharmacological (Berman et al., 2012) and non-pharmacological (Brodaty and Burns, 2012) treatments for apathy in persons with dementia called for further

inquiry, although Brodaty and Burns (2012) emphasised that non-pharmacological interventions have strong potential to reduce apathy.

### **1.3.6 Anxiety in Dementia**

Defining anxiety is not straightforward, according to Munday (1973), despite the calls for the importance of its study. It has been described as “vague fear” (Scovel, 1978), “an uncontrollable disposition to worry” (Akiskal, 2007), and “a reaction to a stimulus which is recognised introspectively by the subject as anxiety and which produces a pattern of behaviour, both physiological and psychological, that is observable by the subject or other people.” (Munday, 1973). Munday’s complex definition may be a reflection of the personal, intimate nature of anxiety. Despite this, anxiety is recognised as a challenge in dementia and its care. It has been linked with lower quality of life in studies that controlled for depression (Harwood, Sultzer, & Wheatley, 2000; Orrell & Bebbington, 1996). The differentiation between dementia and anxiety complicates the situation further, as they share symptoms. Dementia may cause disruption to emotional regulation, leading to higher prevalence of anxiety among people with dementia (Seignourel et al., 2008). People with mild-to-moderate progression of dementia may be most likely to have anxiety, as indicated by studies showing decline in anxiety in severe dementia (Lyketsos et al., 2000; Shankar, Walker, Frost, & Orrell, 1999). Lowered anxiety in severe dementia may be linked to decreased awareness and insight, (Shankar, Walker, Frost, & Orrell, 1999) suggesting that if a person with dementia is functional enough to engage with the arts, he or she is more likely to have high anxiety. Seignourel et al. (2008) pointed out the environmental and social elements influencing anxiety in dementia, including “lack of daytime activities, psychological distress, lack of company, and memory and communication problems.” Optimal treatment options for anxiety in dementia have not been agreed upon (Kwak, Yang, & Koo, 2017), however Orrell and Bebbington (1996) suggested considering social interventions as effective tools for easing anxiety in hospital inpatients with dementia.

### **1.3.7 Self-identity and Personhood in Dementia**

The conceptual importance of self-identity and personhood has been highlighted by addressing these multifactorial challenges in dementia. In building a social-psychological theory of dementia care, Kitwood argued that the “key psychological task in dementia care is that of keeping the sufferer’s personhood in being” (Kitwood and Bredin, 1992). By elevating

personhood, Kitwood argued that the experience of dementia should be seen as a combination of personal, environmental, social, and biological factors. This perspective may be seen as a reaction against the medicalisation of the person into a patient (Green, Carrillo, & Betancourt, 2002; Sillars, 2015). O'Connor et al. (2007) described personhood as lying at the intersection between the lived/subjective experience, the interactional environment, and the socio-cultural context. Each discipline frames the concept of personhood differently and gives different importance to each of its dimensions. Dewing (2008) pointed out that Western values emphasize cognitive ability for “rationality, informed choice, decision-making, and responsible action, with attributes such as expressiveness or the ability to feel and express emotion and spirituality having less value.” She also pointed out that in defining frameworks for humanity and personhood, a hierarchy inevitably follows, and some people are inevitably excluded from personhood at all (Dewing, 2008). Because personhood is defined so loosely, exclusion from personhood could include a range of marginalised populations from enslaved people to those who are stigmatised. While these criticisms of personhood are worth consideration, its definition has been critical to the development of person-centred care approaches (Mitchell and Agnelli, 2015). The widely used person-centred approach addresses the loss of personhood associated with progressing dementia, considering it to be somewhat responsible for comorbidities and social symptoms of dementia.

The way in which the personhood of those with dementia is recognised by others interacts with the self-conceptions of those with dementia themselves. In a systematic review on the impact of dementia on the self and identity, Caddell and Clare (2010) pointed out the range of study on the persistence of self in dementia. This systematic review found a variety of dimensions of self-identity including autobiographical memory, role identities, self-recognition, and self-knowledge, informed by a variety of models to describe the lived experience of dementia. Of the 33 studies reviewed, the majority found the persistence of self-identity in dementia, although it may often be diminished or changed as dementia progresses. Overall, this review found a pattern in the specific, model-focused nature of the quantitative studies. This involved different conceptions of self that have underpinned different studies of self-identity in dementia. While it noted the difficulty in drawing broader conclusions from a meta-analysis, the range of models used to conceptualise self and identity point to a multifaceted experience of dementia that might benefit from studies using triangulated methods (Caddell and Clare, 2010).

The preservation of self-identity in dementia has been described through both personal and social lenses. As a cognitive syndrome, dementia is subject to anosognosia, or lack of insight or awareness of one's own health status. Sabat (2002) identified three factors influencing the level anosognosia in Alzheimer's patients, two of which are socially influenced:

- (a) the person's reaction to the disease's effects; (b) the behavior and reactions of others; and (c) the reactions of the person with AD to the behavior of others in his or her social world.*

### **1.3.8 Additional Risk and Protective Factors for Dementia**

Challenges outlined above such as depression and loneliness act as risk factors for dementia in addition to being caused or exacerbated by dementia. Additional to these psychological and social risk factors are genetic, demographic, and behavioural risk factors for dementia.

Genetic factors have been widely researched as risk factors for dementia. Corder et al. (1993) first identified the apolipoprotein E type 4 allele (APOE-epsilon 4) as a risk factor for Alzheimer's disease. The calculated risk was significant, with an increase from 20% to 90% risk in those with APOE-epsilon 4. Accompanying this increased risk is a mean onset age of 68 years in those with APOE-epsilon 4 as opposed to 84 years in those without. Since Corder et al. (1993) first identified its importance, several studies have investigated its effect. In 2007, Bertram et al. introduced the AlzGene database, which serves as a repository for studies investigating APOE-epsilon 4 and other identified potential genetic risk factors for Alzheimer's disease. Evidence for the genetic impact on dementia risk is supported by different levels of APOE-epsilon 4 among different ethnicities, both within countries (Anderson, Bulatao, & Cohen, 2004; Midorikawa et al., 2016) and on an international scale (Ganguli et al., 2000). Further evidence for the genetic impact on risk for dementia comes from a Swedish twin study. In an analysis of 14,435 twins, 59% of genetically identical twins developed concordant Alzheimer's disease compared with 32% of heterozygous same-sex twins and 24% of heterozygous unlike-sex twins (Gatz et al., 2005).

The effect of sex on risk for dementia varies by type of dementia. There is some evidence that women are at higher risk for Alzheimer's disease in older age. A Dutch prospective cohort study found significantly higher incidence of Alzheimer's disease for females after age 85, but

no increased incidence was calculated for vascular dementia (Andersen et al., 1999). A similar finding was reported in a study with Spanish participants in which females were found to have a relative risk of 1.8 (95% CI = 1.0-3.4) for Alzheimer's disease (López-Pousa, Vilalta-Franch, Llinàs-Regla, Garre-Olmo, & Román, 2004). However, the prevalence of vascular dementia is higher in older men, a finding which has been attributed to the higher incidence of stroke in men (Appelros, Stegmayr, & Terént, 2009).

Although there is very little research conclusively identifying modifiable risk factors for dementia, many demographic and lifestyle factors have been linked to the development of dementia. Among the most prominent risk factors include cardiovascular risks such as smoking, diabetes, and hypertension. Cohort studies have suggested that a sedentary lifestyle may be a risk factor for developing late onset dementia, a finding that may link risk for dementia development and overall cardiovascular risk (Rosness, Strand, Bergem, Engedal, & Bjertness, 2014; Streber, Abu-Omar, Hentschke, & Rütten, 2017). These findings are related to the evidence finding the protective effect of physical exercise on the development of dementia. Physical exercise may also be beneficial for people who have already developed dementia. A meta-analysis of 30 randomised controlled trials found that exercise improved cognitive function in people over age 65 with cognitive impairment (Heyn, Abreu, & Ottenbacher, 2004). A prospective cohort study with 3,375 participants age 65 years and older found a relative risk of dementia of .51 (95% CI = .33-.79) in participants who engaged in over 4 separate physical activities compared with those who participated in 1 or none (Podewils et al., 2005). However, this study reported no protective effect of physical activity among participants with the APOE-epsilon 4 gene, indicating the power of the genetic risk factor for dementia.

Higher educational attainment and literacy have been found to be protective factors against dementia in several studies in developed countries ('WHO | Dementia: A Public Health Priority, 2015). However, others have investigated level of education as a risk factor for dementia (Cobb, Wolf, Au, White, & D'Agostino, 1995), but its correlations with socioeconomic status, life course behaviours, and sex have been cited as potentially confounding any significant associations (Chen, Lin, & Chen, 2009). An American study examined race alongside level of educational attainment, finding that poorly educated black participants had five times the risk of dementia as highly educated white participants. Highly educated black participants had a similar risk of dementia as poorly educated white participants (Shadlen et al., 2006).

Individual personality and experiences throughout life can influence risk for and experience of dementia and its progression (Edhag et al., 2008). While all experiences of dementia are unique, few are considered reversible. In a meta-analysis, Clarfield (2003) found that only 9% of dementia cases are thought to be potentially reversible, and only 0.6% of cases were actually reversed. Many risk factors such as smoking, alcohol consumption, and sedentary lifestyle are modifiable. However, significant demographic factors such as age, sex, and genetic factors can not be modified. Therefore, interventions to reduce the risk of onset, slow progression, or improve care must consider their context. The effects of these interventions are individually experienced and will be dependent on the individuals they engage with.

### **1.3.9 Conclusion – Challenges in Dementia**

Cognitive, functional, behavioural, and psychological symptoms of dementia converge and interact in ways that produce complex challenges to the lived experience of dementia. These challenges are multifactorial and are therefore not likely to be solved by pharmacological interventions. For most forms of dementia, there are no current treatments that prevent, slow, or reverse progression (Tampi, 2015). According to NICE, all treatments should “promote independence, maintain function, and manage symptoms of dementia” (NICE, 2019). However, there is little generalisable evidence of the efficacy of drugs on cognitive (Wang et al., 2015; Russ & Morling, 2012) and psychotic (Schneider, Dagerman, & Insel, 2006) symptoms. Additionally, they introduce significant side effects including agitation, (O’Brien et al., 2017) sleepiness and extrapyramidal symptoms (Lee et al., 2004). Considering this context, environmental optimisation and non-pharmacological treatments are being explored as more humane alternatives for social engagement, symptom treatment, and the slowing of dementia progression (Ayalon L et al., 2006).

### **1.4 How Dementia is Affected by Environments**

Many symptoms and challenges related to dementia are affected by the care environment of persons with dementia. Activities of daily living (ADL) is a key measure of interest due to the functional and behavioural symptoms of dementia impacting on quality of life. It can be improved by optimising the home environment of people living with dementia (Gitlin et al., 2001). By implementing changes suggested by the competence-environmental press framework, Gitlin et al. (2001) found that simplifying the environment can help alleviate disorientation as

mental health declines in dementia. Relatedly, Hoppes, Davis, and Thompson (2003) found that people with dementia are less able to adapt to environmental changes (Hoppes, Davis, and Thompson 2003). Using the Structured Assessment of Independent Living Skills with 12 participants, they found better performance on motor tasks in a familiar home setting than in a clinical setting. Furthermore, research has suggested that the care environment can impact carers of persons with dementia, affecting work-related stress and quality of care (Lyman, 1989). The interaction between the physical environment and the activities within them has been studied. Studies on care home environments found that design features such as wayfinding aids, safety measures, open visibility and accessible resources improved the living space for people with dementia (Fleming & Purandare, 2010; Innes, Kelly, & Dincarslan, 2011).

The most comprehensive efforts to create friendly environments for dementia care are so-called dementia villages populated residents with dementia. Built upon the idea of “taking the community into the home,” dementia villages aim to provide housing and daily activities tailored to the lifestyles of their residents (Notter, Spijker, and Stomp, 2004). This model is especially focused on minimising challenges stemming from mental and physical disability to maximise wellbeing (Jenkins and Smythe, 2013). The first dementia village is Hogewey in Weesp, Netherlands, just outside of Amsterdam. Interest in this model has risen, with researchers beginning to analyse how a Hogewey-inspired dementia village might work in their own countries and health systems (Jenkins and Smythe, 2013).

#### **1.4.1 Acute Care Settings**

Acute care environments represent a unique challenge in dementia care. Because people are rarely hospitalised for dementia itself, hospital inpatients with dementia must contend with their dementia in addition to their reason for admission. This challenge has been recognised by clinicians caring for patients with dementia, as reported in an ethnographic study (Tadd et al., 2011). It found that acute hospitals are not the “right place” for older people because of the lack of dignity available to them. The report also emphasises the “untenable staffing levels” of NHS trusts observed, leading to the deprioritisation of patient needs in order to satisfy organisational targets (Tadd et al., 2011).

Acute care settings pose important practical challenges for need identification, delivery, and evaluation of arts in health programmes. Depending on the reason for hospitalisation, the

patient may be admitted for a few hours, a few days, or a few months. Fast-paced care environments face challenges with frequent clinical rotations, and some hospital staff may not know if a patient has dementia (Alzheimer's Society, 2017). A qualitative study examining person-centred approaches in acute settings found "little evidence that the professionals supported a sense of identity, occupation, and comfort" towards patients with dementia (Clissett et al. 2013). A qualitative report presented results from interviews with acute care health providers who described hospitals as "strange", "unsafe", and even "dangerous" environments for patients with dementia. Some of this is reportedly due to the unfamiliar and unintuitive layout of many hospital wards, especially at night (Borbasi et al., 2006).

Environmental change also occurs within acute care settings, after patients have been admitted. The King's Fund reported that 36% of patients have been transferred between wards during their hospital stay (Cornwell, Levenson, Sonola, & Poteliakhoff, 2012). Resource restrictions may force patients to be moved to a new bay with new staff and schedules. Disorientation increases with changing staff shifts and bed bay neighbours, and the noisy hospital environment often interferes with restful sleep, increasing daytime agitation and anxiety (Dewing, 2009). Discharge of hospital inpatients with dementia presents another challenge because no objective scale measures full patient capacity for discharge. Relying on patients being deemed "medically fit," discharge is made more complex for patients with dementia as an array of psychosocial and cognitive symptoms will impact quality of life after discharge (Alzheimer's Society, 2019). The ideal measurement of capacity for discharge would be a combination of mental capacity, available social support, and a deeper knowledge of the patient's quality of life than any short assessment would provide (Brindle and Holmes, 2004). An exploratory study investigated moral and ethical issues regarding decisions to discharge patients with dementia to home or to an institution. It highlighted the lack of standardised practice, recommending advocacy for people with dementia (Emmett, Poole, Bond, & Hughes, 2013; Poole et al., 2014). Young, Camic, and Tischler (2016) highlighted the importance of the delivery environment for arts in health programmes, suggesting that welcoming spaces could have an important impact on the reception of the intervention.

Hospitals often face challenges providing these types of welcoming spaces, therefore many recommendations have been made for the improvement of the hospital environment for persons with dementia. Common recommendations involve targeting problematic aspects of the

acute setting, such as harsh lights and sounds. A systematic review of the arts and environment in healthcare found lower stress among hospital patients who were exposed to natural elements such as sunlight or views onto trees (Daykin et al., 2008). Wayfinding and patient environment have recently received particular scrutiny in hospital dementia wards as inexpensive, effective solutions to immediate problems of orientation, safety, and comfort. McCloskey (2004) wrote about special considerations for caring for patients with dementia in a hospital environment. This article identified the changing environment as one of the key stressors that may accelerate baseline functioning decline to anxiety and dysfunctional behaviour. Fluorescent lights may cause a glare on shiny surfaces that cause disorientation, and patients often benefit from being close to a window with plentiful natural light. Deteriorating eyesight may call for extra light, so for those without access to natural light, Heath et al. (2010) called for personal lights that can be used and moved at the patient's discretion. Delivering care becomes more difficult in an acute setting due to myriad factors that may be difficult to identify quickly. One broad strategy is to minimise distractions by eliminating noise, excessive movement, and using simple language (McCloskey, 2004).

Environmental considerations of acute care settings are intertwined with care systems, protocols, and culture. Older hospital patients, especially those with dementia, are at risk for cascade iatrogenesis (Butcher, 2018), a concept that refers to a sequence of adverse events set off by a single medical or nursing intervention (Thornlow, Anderson, & Oddone, 2009). Inciting interventions might be environmental, medical, or activity-based. For instance, acute hospital patients are likely to experience chronic poor sleep, due to pain and lack of control over environment including disturbances by patient and medical noise during the night (Little, Ethier, Tirgari, Jiang, & Mehta, 2010). Because people with dementia are more prone to falls (Härlein, Dassen, Halfens, & Heinze, 2009), physical injury in hospital could lead to cascade iatrogenesis. The difficulty of clinical management might also contribute to the risk of cascade iatrogenesis as patient information loss may increase with medical and nursing changes, both within wards and between wards (Tsilimingras, Rosen, & Berlowitz, 2003). Furthermore, the interplay between cognitive, psychological, behavioural, and functional symptoms of dementia could increase the possible routes cascade iatrogenesis might take. For instance, an adverse emotional reaction to a clinical encounter could lead to physical or psychological distress, thereby affecting functioning and cognition in varying measures depending on the individual.

In addition to environmental change, changing care personnel presents a challenge in the acute care setting. The shifting assignments of ward staff members may be an impediment to development of familiar care relationships (Clissett et al., 2013). Constantly shifting environments and care staff lead to an unstable overall patient experience. Attitudes among clinicians toward dementia care might also contribute to poorer outcomes for hospital inpatients with dementia. A model for cascade iatrogenesis was developed by Thornlow, Anderson, and Oddone (2009), who considered how nursing care might play a role in identifying and preventing the initial event. George, Long, and Vincent (2013) modelled the spiral of negative outcomes specifically for hospital inpatients with dementia. They cited “poor attitudes, discrimination, inadequate training, poor leadership, inadequate resources” as contributors to chronic increased burden of frailty and vulnerability. The discriminatory culture was illustrated by continued use of terms such as “acopia” and “social admission.” Oliver (2008) wrote about consultants casually using derogatory terms such as “bed-blocker” and “crumbly.” Studies into the “prestige” of disease treatment among physicians ranked mental illness and age-related patients towards the bottom (Dobson, 2007; Oliver, 2008). Low on this list was the pejoratively referenced “social service medicine” which may describe the complex presentation of multiple morbidities in frail patients. A realist review including literature reviews and stakeholder meetings found that educational interventions, simply by focusing on staff awareness of the experience of dementia, can be helpful in attenuating these attitudes (Handley, Bunn, & Goodman, 2017). These interventions might be especially effective considering challenges presented in the training and screening for dementia-related assessments in hospitals (Timmons et al., 2016).

All models of cascade iatrogenesis refer to the unique nature of each case (Butcher, 2018; George, Long, & Vincent, 2013; Thornlow, Anderson, & Oddone, 2009), leading to difficulty in creating models which are both precise and generalisable. The difficulty in isolating a specific solution to the problem of cascade iatrogenesis demands a flexible, scalable intervention that can include participation by patients, therapy and medical staff, and carers. Oliver (2008) recommended consideration of more areas for evaluation in addition to standard medical evaluation. These include assessments of functioning, psychology, socialisation, and environment. Addressing these elements might occur for interventions at any level from the patient-level through to organisational context, as recommended by George, Long, and Vincent (2013).

Technological advancements might aid in addressing these issues. Coordination between care settings, for instance, has been identified as a challenge this can address (Mason et al., 2013). The use of technology been investigated for communication among clinicians in a hospital setting (Popovici et al., 2015) and between primary and secondary care settings (La Rocca & Hoholm, 2017).

#### **1.4.2 King’s Fund Enhancing the Healing Environment**

Environmental design efforts have sprung up to address the challenge of creating dementia-friendly spaces. A particularly prominent and successful example is the King’s Fund Enhancing the Healing Environment (EHE) Programme. Launched in 2000, it has coordinated across acute and community settings and a variety of types of spaces (The King’s Fund, 2016). Its expansion has pointed to the need to improve acute care environments, particularly in end-of-life settings for care and bereavement. In 2009, the EHE programme was expanded to focus on care settings for patients with dementia. Soon after, in 2011, the Royal College of Psychiatrists released the first *Report of the National Audit of Dementia Care in General Hospitals*, identifying the need to examine, evaluate, and improve hospital environments specifically for patients with dementia (Young et al., 2011).

A number of evaluations have also added to our understanding of design principles and effects of the EHE programme. A qualitative study of the EHE programme in a psychiatric intensive care unit found that staff and patients preferred the new environment, feeling it to be friendlier, more open, and natural (Payne and May, 2009). In 2010, the University of Nottingham released an evaluation commissioned by the King’s Fund. The research focused on case studies across 6 acute care setting in its qualitative analysis including North Bristol, Southmead, Newham, Salisbury, Cambridge and York hospitals. After a mixed-methods evaluation using interviews, focus groups and questionnaires, carers were found to feel empowered over their environment and the humane feeling of “caring for” patients rather than “processing” them (Arthur et al., 2010).

#### **1.4.3 Conclusion**

Acute care environments present a range of challenges for the care of dementia. Patients with dementia are prone to confusion, falls, and poor sleep in an unfamiliar clinical environment (George, Long, & Vincent, 2013). Furthermore, the attitudes of clinical staff members may

present challenges to person-centred care (Kada, Nygaard, Mukesh, & Geitung, 2009). While the efforts of the King's Fund EHE and the National Audit of Dementia place due focus on the acute care setting environments, more active elements of dementia care, such as social and artistic engagement, must also be taken into consideration. Non-pharmacological interventions, especially arts in health programmes, have been given increased attention in recent years due to evidence of improved wellbeing, person-centred care, and clinical outcomes (McCormack, Dewing, and McCance, 2011; Staricoff, 2004). Currently, there is no coordinated effort to coordinate arts in health programming at the same level as King's Fund EHE.

### **1.5 Non-pharmacological Interventions for Dementia**

Non-pharmacological interventions for dementia have shown great potential to slow cognitive decline and other symptoms of dementia, as well as improving quality of life, psychological health, and wellbeing. While a variety of risk factors have been identified for the development of dementia, no single risk factor is said to cause dementia. Relatedly, no single activity or demographic factors has been identified as effective in preventing dementia (Daviglius et al., 2011). Pharmacological treatments for dementia have been criticised for being expensive, ineffective, or prone to severe side effects (Casey, Antimisiaris, & O'Brien, 2010). In 2018, Pfizer withdrew from its drug discovery research for Alzheimer's and Parkinson's in a strong signal of the slowing enthusiasm for pharmacological solutions to dementia (Whipple, 2018). In lieu of any single prevention or treatment of dementia, research and care efforts have focused on improving the experience of dementia through non-pharmacological interventions.

#### **1.5.1 Psychosocial Interventions**

Forming a broad category, psychosocial interventions describe non-pharmacological interventions used "to support people to overcome challenges and maintain good mental health" (O'Shea, Watkins, & Farrand, 2017). A variety of psychosocial interventions have been used to address mood, anxiety, and quality of life in dementia by considering and adapting to cognitive change in dementia (Guss et al., 2014). In a Cochrane systematic review, 6 randomised controlled trials for psychological interventions for dementia were analysed. All studies took place in a care home or community setting and found improved outcomes for depression and clinician-rated anxiety. However, no change was found in patient- and carer-related anxieties (Orgeta et al., 2014). Another Cochrane review of psychosocial methods identified multi-

sensory stimulation and behaviour therapy as promising areas of study for improvement in wellbeing and reduction of depression, apathy, and aggression in dementia (Verkaik, van Weert, and Francke, 2005).

A common psychological intervention, Cognitive Behavioural Therapy (CBT) is a personalised process of working with a trained therapist to identify problems that can be addressed through behavioural modification (Guss et al., 2014). Pilot studies have shown its potential to reduce anxiety in dementia (Kraus et al., 2008; Spector et al., 2015), but it has not been studied as thoroughly as the more bespoke Cognitive Stimulation Therapy (CST). A therapy designed more specifically for persons with dementia, CST aims to improve communication and memory. As a broad approach, CST may include individual or group games, music, arts, and reminiscence (Guss et al. 2014). In an experimental study of 61 nursing home residents with dementia, Hsieh et al. (2010) reported lowered depression and apathy after 12 sessions of reminiscence group therapy. Part of the efficacy of CST may derive from its group socialisation aspect (Spector, Gardner, and Orrell, 2011). It was also shown to be a more effective alternative to drug treatments for improving cognition and quality of life after a 7-week programme in a randomised controlled trial (Spector et al., 2003). Longer-term quality of life improvements were also measured after 6 months of CST maintenance programme attendance (Orrell et al., 2014). Despite the promise of the efficacy of CST, it must be carried out to specific standards by trained CST therapists, limiting flexibility and range of potential facilitators (Guss et al., 2014).

**1.5.1.1 Reality orientation and validation approaches.** Developed by Naomi Feil, Validation is a therapy and care approach for people with dementia (Feil, 2012). Spurred by the stripping of dignity she observed in many people with dementia, Feil developed Validation with the goal to “restore dignity and avoid deteriorating into a vegetative state.” Its tenets reflect Kitwood’s vision of person-centred care in which the individual is approached as valuable, despite the severity of cognitive impairment. Feil also emphasises the holistic effect of dementia, recognising the “physical, social, and psychological” dimensions (Feil, 2012).

Validation positions itself in opposition to reality-orientation, or cognitive stimulation, techniques (Holden, 1995). It assumes that there is a reason for every behaviour in dementia, therefore every behaviour must be accepted without judgement. If this is done, Feil argued, a

trust will form between the person with dementia and his or her carer, leading to more communication within the bounds of a safe relationship. In a pilot study focused on validation therapy, Morton and Bleathman (1991) found increased interaction among five people with dementia in a community setting. Tondi et al. (2007) found reduced agitation, apathy, and irritability in a case control study with 50 participants, 27 of whom underwent validation therapy. The validation approach depends on a long-term relationship between the person with dementia and his or her carer. While this type of relationship might seldom occur in an acute-care setting, the validation approach can inform how carers interact with patients with dementia. Validation perspective can potentially translate to smaller relational settings and philosophically inform acute care practices through its emphasis on positive communication and engagement with the present.

### **1.5.2 Arts in Healthcare**

As part of a holistic view of health and healthcare, arts in health interventions aim to improve health and wellbeing. A variety of arts in health efforts have been established over the last century, from the Music in Hospitals charity in 1948 (Music in Hospitals, 2017) to Arts for Health in the 1970s (MMU | Arts for Health Archive, 2017) to the Centre for Arts and Humanities in Health and Medicine in 2000 (Clift et al., 2009). Across the UK, key institutions such as Arts Council England, The King's Fund, Nuffield Trust, and the Wellcome Trust have promoted awareness of the links between arts and health over the past 15 years (Clift et al., 2009). Many other countries have also seen a push towards arts in health programming and research in the 21<sup>st</sup> century (Cox et al., 2010; Lane, 2006; Sonke et al., 2009). In a report commissioned by the Arts Council of England, Staricoff (2004) performed a literature review including 385 studies examining the impact of arts in health programming on medical outcomes, demonstrating the renewed surge of interest and research in the evidence base for arts in health.

The term "arts in health" is broad, potentially encompassing such disparate interventions as passively installed hung wall art to active engagement such as singing groups to crafts at the bedside. Eakin (2003) asserted that all art promotes health at individual, community, and spiritual levels. However, in studying the health effects of arts in health programmes, it is generally useful to examine three factors: the type of art or arts in health programme, the patient group, and the setting for the art. Both active and passive arts in health interventions are used

across different settings and populations, and art can even be used as a research method in a range of health research by using visual art, performance, and literary arts to communicate the experience of health states and processes (Fraser and Sayah, 2011).

There is some debate about the distinction between the terms *arts in health therapy* and *arts in health programmes* or *arts in health activities*. Therapy is a more regulated term, only referring to activities performed by certified therapists with therapeutic aims. “Arts in health” refers to a broader array of programmes and has been described as any artistic activity or intervention that relates to health (Moss, 2016). Beard (2011) made the distinction between “therapy” and “art activity,” which she defined as “the process of art as a leisure activity.” This definition allows for consideration of the holistic engagement with the arts and culture, positioning the study of engagement with the arts within the remits of governmental priorities in the study of cultural engagement (Philipp, Baum, Mawson, & Calman, 1999; WHO - Regional Office for Europe, 2013). Within an acute care setting, this can address the psychosocial needs of patients who already have focus placed on their biomedical care needs (Hirsch & Meckes, 2000).

While several systematic reviews of arts in health have pointed out a range of clinical and quality of life benefits, they have called for more detailed investigation into more narrowly defined arts in health programmes, patient populations, and settings (Beard, 2011; Staricoff, 2004; Young, Camic, and Tischler, 2016).

**1.5.2.1 Music.** Music interventions have been widely studied across a variety of patient groups. A randomised experimental study of 236 pregnant women found significant decreases in perceived stress, anxiety, and postnatal depression after two weeks of music therapy (Chang, Chen, and Huang, 2008). More broadly, music has been found to lower anxiety in a variety of settings including intensive care units, cancer care, pain management, surgery, and pre- and post-natal care (Staricoff, 2004). Music therapy for pain management has also been extensively studied. A systematic review of 42 randomised control trials found considerable evidence for the positive effect of music in relieving pain and anxiety (Nilsson, 2008).

**1.5.2.2 Visual art.** Staricoff (2004) pointed out that visual art provides an opportunity for others to gain a point-of-view insight into the patient’s subjective experience. The mere presence of visual art in healthcare settings has been linked with increased patient dignity, therapeutic benefits, and improved staff morale. In the same study, Daykin et al. (2008) also

found broad qualitative consensus from clinical staff and patients of the value of having art in clinical settings.

**1.5.2.3 Dance and movement.** Used across age and patient groups, dance and movement activities hold potential for creative expression that can help physically and psychologically. A meta-analysis of dance and movement therapies found improved effects on categories of body-awareness, movement analysis, and psychological change such as anxiety (Ritter and Low, 1996).

**1.5.2.4: Other arts in health and cultural activities.** In addition to the broad categories detailed above, a range of other arts in health programmes have been implemented and studied. Creative writing has been explored as an instrument to improve mental wellbeing in adult users of mental health services (Jensen, 1997). The narrative capacity of photography has also been used in an ongoing project called Photovoice, which uses photography as a qualitative method for engaging with the perspectives of vulnerable populations (Budig et al., 2018). Collaborative theatre is another narrative medium that has been explored by the TimeSlips project in the United States (Fritsch et al., 2009).

### **1.5.3 Arts in Health Programmes for Dementia**

In 2016, Young, Camic, and Tischler performed a systematic literature review of arts-based interventions for dementia in community settings, encompassing most places for senior care outside of hospitals and other outpatient mental healthcare settings. The earliest study reviewed was published in by Rentz in 2002 – a finding which highlights the early stages of the field of arts in health as a whole. Young, Camic, and Tischler (2016) excluded research focused on music therapy conducted by trained musical therapists as part of a broader arts in health focus. Across the 17 studies reviewed, all types of interventions yielded positive effects on cognition and communication. There was also evidence for improved memory in the storytelling and group singing programmes reviewed (Young, Camic, and Tischler, 2016). Of the 17 studies reviewed, only 1 used a randomised controlled trial design with over 50 participants (Särkämö et al., 2014). Most others were framed as pilot or exploratory studies. Some quantitative studies made no use of control groups, and some qualitative studies lacked full explanations of methods used (Young, Camic, and Tischler, 2016). Overall, Young, Camic, and Tischler found broad benefits from arts in health programmes for dementia in community settings for psychological and social outcomes.

Further studies of arts in health programmes for dementia are detailed below, organised by type of arts intervention. This overview of findings includes community and long-term care settings but omits acute care settings. A systematic review of arts in health programmes for hospital inpatients with dementia can be found in Section 1.6.

**1.5.3.1 Music.** Music activities have been studied extensively for addressing various symptoms of dementia. Music has been shown to decrease behavioural and psychiatric symptoms of dementia (Raglio et al., 2008) and increase alert responses in those with late-stage dementia (Clair, 1996). Holmes et al. (2006) found significant levels of engagement with live music, but not with recorded music. A systematic review of arts therapies in dementia care found that music therapy is linked to reductions across behavioural and psychological symptoms of dementia, although sustained effects were not found. This review, however, did call for more “person-centred” outcomes to be measured, noting an emphasis on narrower clinical and symptomatic outcomes (Beard, 2011).

**1.5.3.2 Visual art.** In contrast to musical therapies for dementia, a 2011 systematic review found that art therapies were generally viewed to be more person-centred, focusing less on biomedical outcomes. Art was also found to lend itself to validation of the lived experience of the person with dementia rather than steering towards an objective normative reality (Beard, 2011). Compared to other activities in a care home, Kinney and Rentz (2005) found “significantly more interest, sustained attention, pleasure, self-esteem, and normalcy” in persons with dementia participating in a group art programme.

**1.5.3.3 Dance and movement.** The research base for dance and movement therapies for persons with dementia has emphasised empowerment through creative expression rather than discrete biomedical outcomes (Nyström and Lauritzen, 2005). This focus on process over outcome has implications for quality of life and wellbeing through its ability to facilitate reminiscence (Arakawa-Davies, 1997).

**1.5.3.4 Other arts in health and cultural activities.** Combinations of arts in health interventions have also been explored. For example, the joint use of art and music has been implemented to reduce social isolation and anxiety in persons with Alzheimer’s disease (Wald, 1983). Doll therapy, as an intervention targeting behavioural and psychological symptoms of dementia, has been found to increase positive communication and lower agitation (James,

Mackenzie, and Mukaetova-Ladinska, 2006; Schaefer, 2003). The interactive, social, and communicative element of art has often been highlighted as a key factor to arts in health programming. For persons with dementia, it has been identified as a route to self-efficacy by reminding them of their ability to create and learn new things (Kelly et al., 2015).

#### **1.5.4 The Effect of Environments on Art and Artmaking**

Environments and social contexts have an enormous subjective impact on the way art is produced and experienced. A study of university students in Austria found that viewing time and interest in artworks was higher in a museum than in a laboratory context (Brieber, Nadal, Leder, & Rosenberg, 2014). This suggests that purpose-built spaces prime the viewer for a richer, more reflective experience. This effect extends to the realms of the digital versus physical. A study measuring fMRI data found that neural activity and aesthetic judgements were significantly higher for “gallery” images compared to “computer generated” images. This study attributed the results to expectations and priming rather than inherent aesthetic content in the images (Kirk, Skov, Hulme, Christensen, & Zeki, 2009). A study comparing image display options, demonstrated that aesthetic judgements follow tradition. When comparing original artworks with slide projections and tablet-reproductions of the same artworks, the original artworks were consistently rated more aesthetically pleasing (Locher, Smith, & Smith, 2001).

## **1.6 Systematic Literature Review – Arts in Health for People with Dementia in an Acute Care Setting**

While previous systematic reviews have provided a needed analysis of arts in health programmes for dementia, none have included studies focusing on acute care settings. Given the environmental and care idiosyncrasies outlined above, arts in health programmes in an acute hospital setting would need to take considerations not applicable to community settings. In a noisy environment filled with bustling staff, machinery, and unfamiliar neighbours, arts in health programmes present a unique opportunity for hospital inpatients with dementia to focus on an activity, commune with other patients, and try something new.

### **1.6.1 Method**

In order to assess the current state of research on arts programmes for dementia care in a variety of settings, systematic database searches were conducted of PubMed, Web of Science, Cochrane, and Google Scholar. These sources were chosen because they give a broad overview of research in the fields of psychology, ageing, and arts in health. Searches were made by combining search terms in three domains: intervention, setting, and study population. Intervention keywords were “music”, “art”, “dance”, “reminiscence”, and “museum”. Setting keywords were “hospital”, “acute setting”, “clinical setting”, “inpatient”, “outpatient”, “assessment unit”, “hospice”, “nursing home”, and “care home”. Study population keywords were “dementia”, “Alzheimer”, “older adults”, “elderly”, “third age”, “fourth age”, and “senior”. This search strategy was designed to capture as broad a range of studies as possible in order to review abstracts and papers before making final judgments regarding inclusion. The searches returned 3,814 articles published between 1975 and January 2018, of which 1,802 duplicate, irrelevant, and non-English language articles were removed. After reviewing the remaining 2,012 abstracts, a further 1,927 articles not meeting the criteria were removed. Eighty-five full articles were reviewed, and 66 were excluded for failing to meet inclusion criteria. This review includes articles that were new studies, studied only patients with dementia, and used only non-pharmacological therapies. Systematic literature review reference sections were scanned for additional new studies, but the reviews themselves were not included. Figure 1 provides a diagram of studies reviewed.

After a full review, 19 studies were included. Extracted study results include date, country of origin, intervention details, methods used, outcome measures, and general findings. Due to the wide variety among these parameters, a meta-analysis of the data would show very little; therefore, a qualitative approach was used to assess general trends in the field of arts in health research for dementia care. Informed by Greenhalgh's (2001) principles of literature review, this review aimed to extract data including sample size, participant population, method, measure and results

Randomised controlled trials (Higgins et al., 2011) and qualitative studies (Hannes, 2011) were evaluated based on Cochrane Collaboration guidelines. Randomised controlled trials were assessed for bias by examining *sequence generation, allocation concealment, participant blinding, outcome assessment blinding, completeness of outcome data* and *selective reporting*. Qualitative study evaluation was based on Hannes's (2011) criteria including *credibility, transferability, dependability* and *confirmability*. Non-randomised quantitative studies were assessed for risk of bias using the ROBINS-I tool (Sterne et al., 2016). This tool examines bias due to *confounding, participant selection, intervention classification, missing data, outcome measurement* and *reporting selection*. Mixed methods studies were evaluated according to their constituent methods and the strength of their integration. According to Hannes's guidelines, studies were rated as "low" or "high" quality based on fulfilment of elements assessed.

### 1.6.2 Results

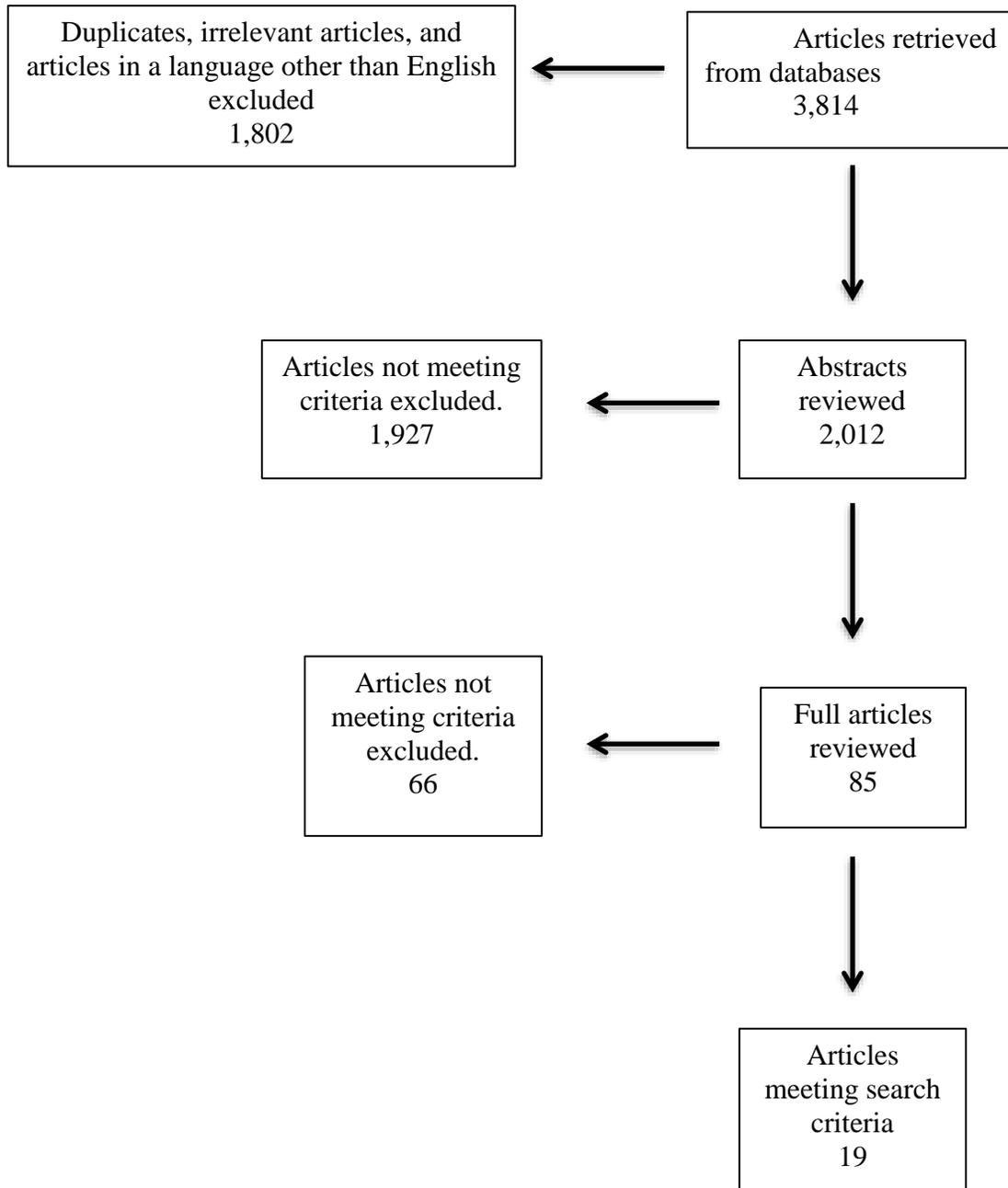


Figure 1. Flowchart of the systematic search process.

Review of the included studies shows the growing interest in researching arts in health programmes in hospital settings. While the earliest study reviewed was performed in 1999, the second was not published until 2002. From 2015 – 2017, eight studies were published. More information can be found in Figure 2.

These studies were mostly performed in developed countries with ageing populations such as the UK, Japan, and the United States. While this reflects the priorities of societies expecting higher burdens of diseases of ageing, healthcare providers in developing countries might consider ways in which this research could be applied to acute care, especially as prevalence of dementia is expected to rise in the developing world.

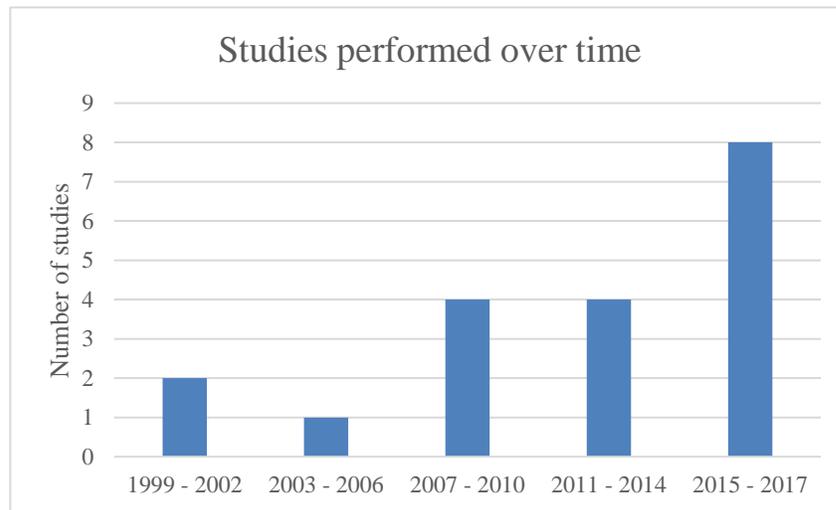


Figure 2. The number of studies of non-pharmacological therapies for hospital inpatients with dementia over time

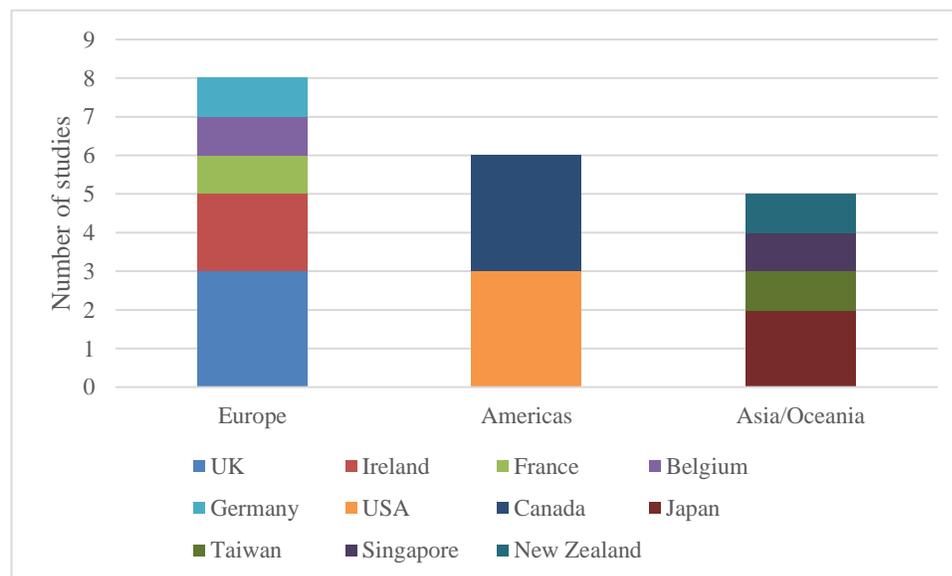


Figure 3. Regions and countries where studies of non-pharmacological interventions for hospital inpatients with dementia were performed.

Table 1.

## Music-based Programmes

Author/Date/Country	Sample Details	Intervention	Method	Measures	Reported Findings	Quality Rating H/L
Berger et al. (2004) Germany	Thirty-six PWD, 36 carers	Weekly one-hour programmes for 24 months. Two activity groups: memory training and music therapy. Intervention groups were self-selected based on interest in weekly group activities.	Quasi-experimental design using rating scales completed by caregivers	Mini-Mental State Exam (MMSE), Syndrom-Kurz-Test (SKT), Global Deterioration Scale (GDS), Brief Cognitive Rating Scale (BCRS), Behavioral Abnormalities in Alzheimer's Disease Rating Scale (BEHAVE-AD), Instrumental Activities of Daily Living Scale (IADL), Physical Self Maintenance Scale (PSMS), Nurses Observation Scale for Geriatric Patients (NOSGER), Zarit Caregiver Burden Interview, Geriatric Depression Scale (GDS), Beck's Depression Inventory (BDI)	This study found no significant difference between intervention and control groups over 2 years. However, the intervention group showed consistently poorer cognitive, disease progression, activities of daily living, and carer burden after 24 months.	H
Bruer, Spitznagel, and Cloninger (2007) Canada	Seventeen PWD	Weekly group music sessions for 8 weeks. Music was based on a reality-orientation methodology, choosing songs made popular when participants were about 25 years old. Singalongs, props, and joke telling were all employed during the sessions.	Randomised controlled trial with a cross-over design	Mini-Mental State Exam (MMSE), activity attendance	This study found an MMSE score difference of 3.46 between intervention and control groups the day after the music group. Participants in the music group experienced an average rise in MMSE score of 1.46 immediately after the programme.	L
Cheong et al. (2016) Singapore	Twenty-five PWD (diagnosed)	Nordoff Robbins Creative Music Therapy (CMT) including group or individual	Quasi-experimental study	Engagement: Menorah Park Engagement Scale (MPES) Mood: Lawton Observed Emotion Rating Scale (OERS)	Analysis found higher positive engagement and lower negative engagement after CMT compared to before. Positive emotion was reported as higher and negative emotion was	L

					reported as lower at the end of CMT.	
Daykin, Parry, Ball, Walters, Henry, and Platten (2017) UK	Eighty-five PWD and 12 members of staff	Weekly music group session, for ten weeks	Mixed methods study recording clinical data and observational notes alongside qualitative data collection	Patient bed notes: falls, length of stay, anti-psychotic drug prescriptions, and need for clinical attention Mood: Arts Observational Scale Qualitative data included interviews, observation, and a staff focus group.	This study found a 6.2% reduction in average length of stay, a 9.84% increase in discharges, a reduction in falls, and a 27.72% decrease in anti-psychotic drugs prescribed on the day of the music activity	L
Gold (2014) UK	Nine PWD (severe, late-stage dementia)	Weekly group music activity. Percussion instruments, singing, and whistling were all used.	Retrospective cohort study. Mood and behaviour scores on music activity days were compared with NHS staff care notes taken over the previous 4 months.	Researcher-designed categorisations of mood and behaviours, NHS staff care notes	Eight out of 9 participants showed better mood and less disruptive behaviour on music group days.	L
Kumar et al. (1999) USA	Twenty male inpatients with dementia (MMSE: 12-25)	Daily live music therapy sessions of 30 to 40 minutes, five days per week for 4 weeks. Groups included 4 to 6 patients.	Repeated-measures quasi-experimental with one group	Neurological: Melatonin, prolactin, serotonin, norepinephrine and epinephrine	Analysis reported significantly higher levels of plasma concentration of melatonin, both from baseline to end of programme and to 6-week follow-up. Epinephrine and norepinephrine increased during the programme but returned to baseline levels for the 6-week follow-up.	H
Okada et al. (2008) Japan	Eighty-seven PWD (advanced dementia with pre-existing cerebrovascular disease)	Weekly music therapy sessions, for at least 10 weeks	Quasi-experimental study	Physiological: Heart rate variability (HRV), blood plasma cytokines, and catecholamines	Analysis indicated significantly lower levels of congestive heart failure, IL-6, adrenaline, and noradrenaline in the intervention group.	L

Thornley, Hirjee, and Vasudev (2015) Canada	Sixteen PWD (diagnosed with dementia, MMSE>13)	Two intervention groups were compared: individual music therapy and individual active engagement intervention (AEI). AEI involved supportive conversation and simple activities such as "folding towels and browsing magazines"	Pilot randomised controlled study	Behaviour and psychology: Neuropsychiatric Inventory-Clinician version (NPI-C) and Cohen-Mansfield Agitation Inventory (CMAI)	Analysis reported no significant difference between music therapy and active engagement intervention groups.	H
Wong et al. (2008) New Zealand	Ninety-eight PWD (over 4 phases)	Four 12-week phases. Phase 1 provided no change to patient nutrition regimen. Phase 2 provided easily accessible snacks to encourage "grazing". Phase 3 directed volunteer and staff resources towards helping patients with eating during mealtimes. Phase 4 played ambient music during mealtimes.	Quasi-experimental study, using pre- and post- physiological measures to compare baseline control measurements with different nutritional augmentation strategies.	Physiological: body weight, body mass index (BMI), Nutrition: Mini Nutritional Index (MNI), Eating Behavioural Scale (EBS)	This study found that all intervention phases yielded an increase in BMI, while BMI decreased during the control phase. The ambient music caused the largest increase in BMI.	L

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*Note.* PWD = Person with dementia; H/L = High/Low

Table 2.

## Visual Arts-based Programmes

Author/Date/Country	Sample Details	Intervention	Method	Measures	Reported Findings	Quality Rating H/L
Hattori et al. (2011) Japan	Thirty-nine PWD (Age: 65-85, MMSE<20)	Art activity focused on using pastels and watercolours to fill in abstract line drawings.	Controlled study comparing measures of cognitive function, mood, vitality, quality of life, apathy, behavioural symptoms, and caregiver burden.	Mini-Mental State Exam (MMSE), logical memory subscale of the Wechsler Memory Scale revised (WMS-R), Geriatric Depression Scale (GDS), Apathy Scale (Japanese version), Short Form (SF- 8), Dementia Behavior Disturbance Scale (DBD), Zarit Caregiver Burden Interview.	Colouring activities were found to significantly reduce apathy measured by the Apathy Scale. No other statistical differences were found.	H
Hazzan et al. (2016) Canada	Eight PWD (middle to late stage)	"Artful Moments" was held 27 times over 11 months. It combines art appreciation with artmaking.	Qualitative descriptive design using researcher observation during intervention as well as a carer questionnaire describing the experience.	Engagement: Affect and Engagement Rating Scale and researcher-developed questionnaire that was filled out by observing carers.	Engagement was classified into five themes: carer involvement, being a part of a group activity, opportunities to share thoughts and opinions, validation of personhood, and more engagement over time. Care partners reported enhanced communication and relationship building opportunities.	H

Note. PWD = Person with dementia; H/L = High/Low

Table 3.  
Reminiscence and Conversation-based Programmes

Author/Date/Country	Sample Details	Intervention	Method	Measures	Reported Findings	Quality Rating H/L
Amieva et al. (2015) France	Six hundred fifty-five PWD (mild to moderate)	Multiple 90-minute programmes held weekly for 3 months. "Maintenance sessions" were then held every 6 weeks for the following 21 months. Programmes included group cognitive therapy, group reminiscence therapy, and individual cognitive rehabilitation therapy.	Multi-centre randomised controlled trial	Mortality: Rate of survival without moderately severe or severe dementia. Behaviour: Neuropsychiatric Inventory (NPI) Functional Ability: Disablement Assessment for Dementia (DAD) Apathy: Apathy Inventory (AI) Psychology: Montgomery-Asberg Depression Rating Scale (MADRS) Quality of Life: Quality of Life - Alzheimer's Disease (QoL-AD) Caregiver burden: Zarit Burden Interview	Analysis reported no significant impact of any intervention on the primary measures of survival rate or progression to severe dementia. Individual cognitive therapy was found to have less functional decline over 2 years and a lower rate of institutionalisation.	H
O'Rourke, Tobin, O'Callaghan, Sowman, and Collins (2011) Ireland	Six PWD (MMSE: 13-22)	Talk and reminiscence activity facilitated by playing YouTube clips. Video clips were chosen by drawing on themes from the Social Interest Questionnaire. The bi-weekly session ran for 6 weeks.	Mixed methods study using scales administered to either the participant or carer. Semi-structured interviews were also examined using thematic analysis	Cognition: Mini-Mental State Exam (MMSE) Communication: Functional Linguistic Communication Inventory (FLCI) Psychology: Geriatric Depression Score (GDS) Researcher developed Social Interest Questionnaire.	Qualitative findings included themes of improved wellbeing, communication, quality of life, and effectiveness of YouTube streamed video as an engaging medium. Analysis of the quantitative measures reported no significant effects.	H
Wu and Koo (2015) Taiwan	One hundred three PWD	Spiritual reminiscence group lasting 6 weeks. Each weekly session lasted one hour. Spiritual reminiscence emphasises spiritual meaning and connectedness.	Pre-post randomised controlled trial using cognitive and wellbeing scales to measure change within and between intervention and control groups	Cognition: Mini-Mental State Exam (MMSE) Hope: Herth Hope Index, Life satisfaction: Life Satisfaction Scale Wellbeing: Spirituality Index of WellBeing	Analysis reported that cognition, hope, satisfaction, and wellbeing were all improved through spiritual reminiscence therapy, and significant differences were found between control and intervention groups.	L

Note. PWD = Person with dementia; H/L = High/Low

Table 4

## Multiple Activity-based Programmes

Author/Date/Country	Sample Details	Intervention	Method	Measures	Reported Findings	Quality Rating H/L
Van de Winckel, Feys, De Weerd, and Dom (2002) Belgium	Twenty-five PWD (all female, MMSE<24)	Daily exercise to music activity for 3 months. Each activity lasted 30 minutes	Randomised controlled trial, with control group engaging in conversation during intervention activity	Cognition: Mini-Mental State Examination (MMSE) and Amsterdam Dementia Screening Test 6 (ADS 6). Behaviour: BOP scale (Dutch variation of Stockton Geriatric Rating Scale )	Music-based exercise yielded moderate improvement in cognition. No significant behavioural effects were measured.	H
Staal et al. (2007) USA	Twenty-four PWD	Multi-sensory behavior therapy (MSBT)	Mixed design randomised controlled trial measuring between groups (MSBT and structured activity groups) and within groups	Disease progression: Global Deterioration Scale (GDS). Agitation: Pittsburgh Agitation Scale (PAS). Negative symptoms: Scale for the Assessment of Negative Symptoms in Alzheimer's Disease (SANS-AD) Activities of Daily Living: Katz Index of Activities of Daily Living (KI-ADL) and Refined Activities of Daily Living Assessment Scale (RADL).	Results report significantly lower agitation and apathy in intervention group compared to control group. Certain measures of activities of daily living were also significantly more improved in the intervention group.	L
Rylatt (2012) UK	Thirty-seven PWD	Creative therapy sessions over 8 weeks. Activities included dance, drama, music, and movement	Bespoke service evaluation	Researcher-designed tool measuring attendance, creative self-expression, communication, pleasure and enjoyment, and engagement	Descriptive results indicated high rates of engagement, pleasure and enjoyment, and self-expression across two activity groups.	L
Vahia et al. (2016) USA	Thirty-six PWD	Tablets preloaded with a range of apps were given to restless or agitated hospital inpatients	Open-label trial	Cognition: Montreal Cognitive Assessment and researcher-designed scales of tablet app complexity and reduction in agitation	Analysis reported more staff-perceived reduction in agitation from mildly-impaired and younger participants. Descriptive results report that all participants engaged with the tablets.	H

Moss and O'Neill (2017) Ireland	Twenty-four PWD	Once or twice weekly visits by artists-in-residence for 12 weeks each. Artists interviewed, observed, and shadowed patients and their families while engaging them in artmaking. Field notes taken informed the production of a unique work of art.	Arts-based qualitative research including involvement from clinical staff and patient family members	Experience of dementia: narrative enquiry used to collect and integrate experiences of dementia.	This study reports the creation of 3 high-quality works of art that hold the potential to illuminate the experience of dementia for students and the wider public.	L
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*Note.* PWD = Person with dementia; H/L = High/Low

**1.6.2.1 Music-based programmes.** Berger et al. (2004) conducted a randomised controlled trial examining the effects of a combined caregiver support group and music therapy group for hospital inpatients with dementia. Sessions were relatively rigorous, being facilitated by two psychologists and one music therapist. Although analysis did not find statistically significant differences between control and intervention groups, poorer outcomes in cognition, global disease severity, activities of daily living, and behavioural and psychological symptoms were found in the intervention group. In a randomised controlled trial using a crossover design, Bruer et al. (2007) measured effects of music therapy in a Canadian psychiatric hospital. In an analysis of 17 participants with dementia, this study reported significantly improved cognition by 3.69 MMSE points the day after treatment. These cognitive effects did not persist, as 7-day follow up tests found that MMSE scores had returned to baseline levels. Bruer et al. pointed out that this may support the theory that music therapy's main utility is through short term reduction in anxiety. A Japanese study (Okada et al. 2009) recruited 87 persons with advanced dementia but focused on cardiovascular outcomes. Participants were allocated to a control group or a music therapy group consisting of 45 minutes once per week. Heart rate variability, blood plasma cytokines, and catecholamines were measured. Analysis of heart rate variability suggested that music therapy triggered sympathetic tone, indicating "relaxation and distraction responses in the limbic and hypothalamic systems of the brain". IL-6, an interleukin central to myocardial inflammation, was found to be significantly lower in the music therapy group. Finally, music therapy results reported significantly lower congestive heart failures over 10 months, a finding that may be linked to reduced catecholamine levels.

Another study using blood sample analysis recruited 20 male inpatients with mild-to-moderate dementia (Kumar et al. 1999). Using a repeated-measures design, this study reported increases in melatonin, epinephrine, and norepinephrine concentrations. The melatonin concentration sustained its elevated level when measured in a 6-week follow up. Thornley et al. (2015) recruited 16 participants to a pilot study that focused on behavioural and psychological symptoms of patients with dementia in a psychiatric unit. When comparing music therapy to active engagement, results showed no significant differences between groups as measured by the Cohen-Mansfield Agitation Inventory or the neuropsychiatric inventory.

Another pilot study (Cheong et al. 2016) focused on a specific music therapy approach: the Nordoff-Robbins creative music therapy. Using the Lawton Observed Emotion Rating Scale,

this study reported higher positive engagement and emotion during the creative music therapy than before and after. This result coincided with engagement measured by the Menorah Park Engagement Scale which showed higher positive engagement during the music session. Passive music listening during mealtime has also been studied. Wong et al. (2008) conducted a 4-phase study trialling different methods of increasing food and drink intake for 12 weeks at a time. After an observatory “control” phase, the study encouraged consumption by first offering more available snacks, then by recruiting assistants to help with meal time, then by playing “soothing music” in the dining area. While all 3 interventions resulted in weight gain, the passive music phase resulted in the most with 0.39 kg/m<sup>2</sup> BMI increase.

A pilot study based in a UK hospital trust used a mix of clinical data access with observation and interviews. Daykin et al. (2017) accessed anonymised clinical data on number of falls, prescribed anti-psychotic medication, and length of stay over two 10-week periods: one with a weekly music intervention and one without. This pilot study reported decreased amount of anti-psychotic medication and number of falls reported in the intervention group. The ArtsObs scale results reported consistent improvement in observed happiness among intervention patients. The qualitative results were organised into themes including “mood, enjoyment, engagement, socialising, musical preferences, nuanced responses and flexible music leadership.” The ArtsObs scale relies on observations made during the intervention itself by a researcher who is not directly participating. The authors pointed out that outcome measures not observed in the moment during the intervention cannot be directly attributed to the music programme. Additionally, the presence of a researcher allows observation to be more in the moment than if the art programme leader were observing during the programme but reflecting on the experience later.

Gold (2014), in a self-reflective paper focusing on her individual music therapy practice, performed an audit on 9 patients with severe dementia and behavioural issues such as agitation and verbal and physical aggression in an NHS inpatient unit. Study participants had very limited language abilities, and Gold noted that they “were not able to make their views known”. To circumvent this barrier to data collection, Gold studied clinical staff case notes to find patterns between days when patients received music therapy and days when they did not. Case notes were graded using researcher-developed scales for mood and behaviour. Behavioural and psychological outcomes were measured using Behavioral Abnormalities in Alzheimer's Disease

Rating Scale, Beck Depression Inventory (BDI) (Berger et al., 2004), Geriatric Depression Scale (Hattori et al. 2011, O'Rourke, et al., 2011, Berger et al., 2004), Neuropsychiatric Inventory, Cohen-Mansfield Agitation Inventory (Thornley, Hirjee, & Vasudev, 2016), and researcher-developed measures of mood and behaviour (Gold, 2014). Except for the researcher-developed scale used for a "small-scale audit" (Gold, 2014), no significant changes in the intervention group were reported. Emotion and mood were measured using the Lawton Observed Emotion Rating Scale (OERS) (Cheong et al., 2016) and Arts Observational Scale (Daykin, Byrne, Soteriou, & O'Connor, 2008),

**1.6.2.2 Visual arts-based programmes.** Hattori et al. (2011) used an amalgam of art therapy techniques centred on colouring in abstract designs. Their intervention simplified the painting technique so that as the colour was applied, natural figures such as bird or flowers emerged. This art therapy group was compared with a calculation group performing simple additions. Thirty-nine patients were randomised to these two groups, participating once weekly for 12 weeks. Two-way analysis of variance revealed improvement in vitality, as measured by the Apathy Scale, and quality of life in the art therapy group but no cognitive, mood, or behavioural change.

Qualitative methods have also been used to explore the impact of visual art-based programmes. A Canadian study (Hazzan et al. 2016) recruited eight persons with dementia to participate in a pilot investigation. Through its Behavioural Health Program, St. Peter's Hospital in Hamilton, Ontario obtained artworks from the Art Gallery of Hamilton. These artworks were then the basis for discussion in a programme called "Artful Moments". Using both art appreciation sessions and active art-making, this study held 27 sessions over 10 months. Themes identified included care partners' availability and involvement, being part of a group activity, opportunities to share thoughts and opinions, validation of personhood, and increased engagement over time.

**1.6.2.3 Reminiscence and conversation-based programmes.** In a study based in France (Amieva et al. 2015), 655 persons with mild-to-moderate dementia were recruited across 40 centres. It was the largest and most methodologically rigorous study included in the review. Patients randomised to activity groups received weekly 90-minute sessions with a psychologist trained for this programme specifically. Sessions included group reminiscence therapy focused

on personal themes, group cognitive training therapy involving tasks for “memory, attention, language, or executive function”, and individualised cognitive rehabilitation therapy tailored to each patient during the initial two meetings. This study’s primary outcomes were rates of mortality and progression to severe dementia after two years. Secondary assessments included institutionalisation rates, cognitive deterioration, behavioural symptoms, functional abilities, apathy, depressive symptoms, quality of life, and resource utilisation, measured at 3 and 24 months. Logistic regressions, the Kruskal-Wallis test, Cox models, and other logistic regression models were used to compare outcomes across groups. Results indicated no difference in secondary outcomes between group cognitive or reminiscence therapies and the control group. The individualised cognitive therapy group, however, showed lower functional decline after 2 years, as well as lower behavioural symptoms as measured by the Neuropsychiatric Inventory. Participants in the individualised therapy group were also less likely to be institutionalised after 2 years than control group participants.

A Taiwanese study (Wu and Koo, 2016) examined reminiscence-based talk programmes with an end-of-life spiritual lens. One hundred-six patients were randomised into intervention and control groups. The spiritual reminiscence intervention lasted for 6 weeks with weekly 1-hour sessions for groups of 3 to 6 patients. Based on MacKinlay and Trevitt’s spiritual model of dementia (2012), the programmes focused on meaning in life, relationships, hopes, fears, worries, transcendence, spiritual and religious beliefs, and spiritual and religious practice. Outcome measures included the Herth Hope Index, the Life Satisfaction Scale, and the Spirituality Index of Well-being, each administered at baseline and immediately after the 6-week intervention. Analysis found increases in hope, life satisfaction, wellbeing, and MMSE score in the intervention group. The control group showed decreases in all outcome measures over 6 weeks. A pilot study using YouTube as a source for reminiscence media recruited 6 participants with mild-to-moderate dementia. For 12 sessions over 6 weeks, hospital speech therapists or occupational therapists facilitated 45-60 minute sessions. Social interest questionnaires at the beginning of the study were administered in order to compile bespoke YouTube playlists for each patient. Video clips were shown on a television and used to facilitate conversation. Qualitative measures of patient participation and semi-structured interviews were then

thematically analysed. This study reported the potential for this programme to improve wellbeing, communication, quality of life, and connection.

**1.6.2.4 Multiple-activity programmes.** A number of papers reviewed studied the combined effects of different arts interventions. A randomised controlled trial (Van de Winckel, Feys, De Weerd, & Dom, 2004) comparing music-assisted exercise with conversation-based programming recruited 25 women with dementia. Analysis revealed significantly more improvement in MMSE score in the intervention group. This study also measured behaviour, finding no significant differences between intervention and control groups.

A randomised controlled trial of 24 inpatients with dementia studied an intervention called multi-sensory behaviour therapy (MSBT). MSBT was based on Snoezelen, a Dutch intervention developed for people with mental disabilities by Hulsegge and Verheul in the 1970s. Snoezelen was developed with the goal of stimulating all senses through lighting, object and surface handling, music, and smells (Chung & Lai, 2002). The UK's first Snoezelen room opened at Whittington Hall in 1987, where the first studies of the effectiveness of Snoezelen were carried out (Hutchinson, 1991). A researcher-developed intervention, MSBT aimed to create an activity environment that targeted "visual, auditory, olfactory, and tactile" preferences of the patient. Compared with cognitive activity sessions, the MSBT group experienced larger decreases in agitation and apathy. Analyses of covariance revealed improved independence as measured by the KI-ADL than the control group. In an open-label study assessing feasibility of tablet use, 36 hospital inpatients with mild-to-severe dementia were offered tablets when agitated (Vahia et al., 2017). The tablets were preloaded with a range of apps for communication, gaming, music, video playing, web browsing, and photo-viewing. All participants were found to tolerate the use of the tablets; however, app complexity and engagement time were negatively correlated with severity of dementia. Analysis reported larger reductions in agitation in those with more mild dementia than those with severe progression.

Rylatt (2012) conducted a service improvement project evaluation of a range of arts in health programmes in a hospital. Over 32 sessions, each lasting 30 minutes, researcher-developed measures indicated largely positive results for creative self-expression, communication, enjoyment, and engagement. Notably, however, only 16% of patients in one of the treatment units showed improvement in creative self-expression. This may have been due to

a lack of inter-rater reliability among the four members of staff marking the un-piloted assessment tools.

A qualitative study detailed accounts of 3 artists-in-residence at an Irish hospital (Moss and O'Neill, 2017). Using an arts-based research methodology, this study points to the completed artworks as a reflection of the artists' time spent interviewing and engaging with inpatients with dementia. The final composed piece of music, visual collage, and 15-minute original dance aimed to communicate the experience of dementia to wider audiences.

### **1.6.3 Systematic Review Discussion**

This systematic review has aimed to identify and describe findings of studies performed to examine the impact of non-pharmacological therapies for dementia in institutional settings. The studies have included a wide variety of primary outcome measures, and patterns are able to be identified across them. While cognitive screening tests, such as the MMSE, were used by eight studies, only three reported improvement in cognition (Bruer et al., 2007; Van de Winckel et al., 2004; Wu & Koo, 2016). As Van de Winckel et al. (2004) pointed out, the mechanism for cognitive improvement is not understood despite a hypothesis that music listening “enhances arousal” which augments activity and focus on the present during an exercise programme.

Many cognitive and behavioural measures did not reach statistical significance, and there is no apparent correlation with sample size or study length. Alternatively, measures for wellbeing, mood, and engagement have shown much more consistent improvement during and after arts-in-health interventions. Again, mechanisms for these improvements are not well understood. While most studies did not compare arts-based interventions with other psychosocial interventions, Thornley, Hirjee, and Vasudev (2015) found no significant differences in outcomes between a music group and an “active engagement intervention group” that participated in household activities.

The quality of studies varied, reflecting the early stages of this research field. This does not greatly affect confidence in conclusions reached by the systematic review. This is because no studies reported negative effects of engagement with the arts, and conclusions from more robust studies were modest to begin with. Most of the studies reviewed have focused on quantitative data. While many studies made use of validated scales, resource limitations often required researchers to use bespoke outcome measures developed to make use of data that was easily

available. The challenge associated with this is that the validity and generalisability of these measures is unknown, so it is not clear if they in fact measure the construct they claim to measure.

One included study measured caregiver burden, and three included caregiver proxy measures. While validity of the caregiver perspective in describing the experience of dementia is normally given in home and community settings, it may be particularly useful in a hospital setting. In addition to an intimate knowledge of the patient with dementia's history and personality, the caregiver may be able to shed light on behavioural changes since admittance to the hospital. There is, however, evidence that caregiver perspective might be more affected by caregiver burden, and therefore less accurate, when the dementia is at mild-to-moderate progression (Nygård, 2006). Additionally, the unpredictable nature of caregiver attendance in hospital makes it difficult to recruit caregivers reliably for this setting. Three included studies made use of clinical perspectives including ward notes.

Daykin et al. (2017) reported decreased numbers of falls and anti-psychotic medications prescribed during the intervention period. However, this study's reporting of incidence rather than rates is affected by the differences in group sizes: 38 persons with dementia (PWD) during the control period and 47 PWD during the music intervention period. This study also acknowledged difficulty in attributing broad outcome measures such as length of stay to the implementation of a once-weekly music programme. Studies measuring immediately before and after an intervention and randomised designs (Amieva et al., 2015; Bruer et al., 2007; Thornley et al., 2015; Van de Winckel et al., 2004) can more credibly link the activities with the outcome measures.

This review has aimed to capture the broadest scope of arts-based non-pharmacological interventions, but most studies included were music-based or had a strong musical component. The field of non-pharmacological interventions for dementia could benefit from more and stronger studies examining other therapies including visual art, artistic movement, interaction with museum objects, and tactile therapies. Emerging technology in art therapies for dementia care is also a potentially powerful area for further research. O'Rourke et al. (2011) discovered a novel use for YouTube playlist capabilities, and other internet- and touch screen-based technologies may provide effective discovery and delivery methods for non-pharmacological therapies. Most of the studies included in this review focused on mild to moderate dementias

without clear explanations as to why. Potential reasons could include issues in providing informed consent (Hegde & Ellajosyula, 2016) or difficulty engaging people with dementia in activities (Perrin, 1997). Future studies should consider a wider range of dementias or focus on the effects on severe dementia. This would help broaden understanding of the range of experience of different dementias throughout their stages as well as the potential impact of engagement the arts across longer timescales in dementia.

This review has only examined therapies in acute care settings, leaving out the many community-centred programmes that have been evaluated in the literature. Young et al. (2015) provided further review of non-pharmacological therapies for dementia in a community setting. They found that the impact on cognitive and behavioural outcome measures trended in the same direction as the studies examined here. While this review included pilot and preliminary studies, it found more studies with sample sizes larger than 20 than the community-based intervention review. Young et al. (2016) identified a lack of consideration for later stages of dementia, a conclusion also made by Sampson et al. (2004) after studying palliative care approaches for patients with dementia. The present systematic review found a similar trend. While not all studies explicitly stated the level of progression, only Gold et al. (2014) studied an intervention aimed at severe, late stage dementia.

#### **1.6.4 Systematic Review Conclusion**

This systematic review offers a comprehensive view of the state of research examining the impact of non-pharmacological therapies for dementia in acute care settings. While the literature describes sporadic improvements in cognitive and behavioural outcomes, it is strongly suggestive of the beneficial psychological impacts of arts in health programming for mild-to-moderate dementia in acute care settings. While there is little evidence for this effect among patients with severe dementia, there is no evidence of a negative effect from engaging with the arts. This finding carries clear implications for practice by showing that artistic engagement can be an effective tool in improving quality of life for patients while reducing incidence and severity of agitation and outbursts, a reduction that can be beneficial for both patients and caregiver.

## **1.7 Technology in Dementia Care**

Considering the range of cognitive, behavioural, and psychological symptoms of dementia and the growing use of arts engagement to address them, there is broad scope for the use of technology in dementia care. In a 2004 paper, Hagen et al. outlined dependent variables in the assessment of assistive aids for persons with dementia. These include factors related to: 1) the person with dementia, 2) the carer, 3) the care environment, 4) the assistive device, and 5) the researcher (Hagen et al., 2004). In 2008, Topo performed a systematic literature review focused on technology interventions to support persons with dementia and their carers. Of the 66 studies included, 36 were technologies used primarily by the carer while only 15 were technologies used by the person with dementia. Topo pointed out that the majority of these studies were performed in residential and long-term care homes, but the technologies tested could easily be transferred to other care settings.

### **1.7.1 Challenges in New Technology for Dementia Care**

Many technological interventions have been proposed and tested in dementia care. These developments, however, have also prompted concerns about their effects on personhood (Astell, 2006). Electronic tagging, for example, has been tested as a means of tracking movement and falls in persons with dementia (Hughes & Louw, 2002). While this may give more freedom for the persons with dementia to be on their own, it may also be restricting in that perceiving oneself to be under surveillance has negative connotations. New technologies can have good and ill effects, and new developments should be evaluated with care.

In designing new technological interventions for dementia care, Astell (2006) identified the goal to “assist the person with dementia without taking away control.” With assistive technologies, it has been suggested that a balance should be struck between using technology to empower and protect or restrain the person with dementia. Astell identified three dangers new technologies can pose to dementia care: confusion, infantilisation, and dehumanisation. This tension between aiding and infantilising might be solved by using new technologies as novel interventions. The relationship between novelty and engagement in activities in dementia has been examined, finding that novel interventions can slow the progression of cognitive symptoms of dementia (Fissler et al., 2013). The potential for novel interventions is greatly increased with the introduction of new technologies such as tablet-based applications.

Efforts to design technological tools for art therapy have been approached from the ground up. Hoey et al. (2010) used therapist feedback in a study designing a customisable tool for use in art therapy with people with dementia. Leuty et al. (2013) developed an onscreen prompting system that is sensitive to disengagement in individual activities. While this field of research and development shows potential for increased engagement within art therapy practice, the new technologies are not yet fully evaluated or widely distributed. Consumer tablets and artmaking apps are therefore the focus of this thesis.

### **1.7.2 Tablet Use for Dementia Care**

The use of touchscreen tablets for dementia care has become widespread enough for feasibility studies and literature reviews to have taken place. Hitch et al. (2017) performed a scoping review of people with dementia living at home, finding a landscape of studies focused on specific app development for dementia. In a broader review including 45 articles, Jodrell and Astell (2016) found upward trends in touchscreen use for assessments or providing assistance for other tasks. Fewer studies investigated the use of touchscreens as activities in themselves.

As a strategy for delivering more flexible bespoke person-centred care, tablet technology has been adopted in a range of clinical and care settings. Along with this widespread adoption, several studies have examined various aspects of tablet use in dementia care settings. A report commissioned by the Department of Health West Midlands asked broad questions about how persons with dementia interact with tablets. Using a series of interviews, case studies, focus groups, and field observations, Upton et al. (2011) collected a wide range of qualitative data. Many participants appreciated the increased social connection facilitated through the tablet. This was either through increased ability to contact others through videoconferencing applications such as Skype or through increasing interaction among residents using tablets together. Tablet-focused activities were also reported to increase intergenerational communication and were praised for their versatility in being able to facilitate a variety of reminiscence and cognitive exercises that couple conversational learning with a tablet-based action such as “dragging pictures across and then naming places” (Upton et al., 2011).

A 2015 report explored ways in which tablets can enhance care for care home residents with dementia (Evans, Bray, and Evans, 2015). By integrating feasibility of tablet use in a range of care home activities, the research demonstrates the flexibility of tablet technology for

information sharing, entertainment, reminiscence, and group activities. An exploratory study of six participants in a dementia day centre found improved mood and engagement in activities using iPads compared with the traditional versions of those activities (Leng et al., 2014). Tablet use in group music sessions has also been explored through observational studies, finding little instruction is necessary for a range of tablet-based music from abstract electronic music to baroque piano music (Favilla and Pedell, 2013).

In a 2012 study focusing on tablet usability among persons with dementia, Lim et al. (2012) recommended that tablets be introduced and taught on a person-by-person basis. Their study of 21 persons with mild dementia found that about half were able to engage independently with the tablet (Lim et al., 2012). This recommendation was echoed in a 2014 study of 177 persons with dementia in a day care centre. While playing both default and bespoke games on a tablet increased engagement, its effect on mood was found to be variable. Some participants also disliked the games or found tablet functionality or game rules too difficult to understand (Groenewoud et al., 2014).

**1.7.2.1 Novelty and tablet-based dementia activities.** Through investigation of causal effects between mentally demanding activities such as games or arts engagement and risk for dementia, Fissler et al. (2013) found that “novelty interventions” showed promise in delaying progression of cognitive symptoms of dementia. They detailed four aspects of novelty interventions: *challenge*, *overlapping variability*, *multimodality*, and *meaningfulness*. These dimensions focus on the aiding side of the technology debate, clearly focusing on challenging the person with dementia without discouraging him or her. Astell et al. (2016) asked a similar question before investigating whether persons with dementia would prefer familiar or novel tablet games. Among the 30 participating persons with dementia, enjoyment of the familiar and novel games was comparable, but there was significantly more progression through a checkpoint on the novel game. Notably, 27 of the 30 participants engaged independently with the tablet, indicating high levels of autonomy in engagement with tablets (Astell et al., 2016).

**1.7.2.2 Challenges in tablet use for dementia care.** While feedback regarding reminiscence in the West Midlands report was mostly positive, there was some frustration with being able to see food on the tablet without being able to eat it. Some users wished they had been better able to use the tablet to its full capacity. There was, however, acknowledgement that they are more intuitive than computers (Upton et al. 2011). This may be due to the increased

interactivity of the touch screen and simpler user interface. In a conference paper, Yamagata et al. (2013) outlined challenges facing mobile application development for persons with dementia. These include issues such as touch screen sensitivity, problems with magnification, need for adjustable tablet stands, and screen glare. While usability issues such as these exist with any new technology, they are solvable and leave intact the potential for tablet use among people with dementia.

### **1.7.3 Tablet Use in Hospitals**

The proliferation of new non-medical technologies in healthcare settings seems to outpace research evaluating clinical outcomes and cost-effectiveness. Indeed, no data exists summarising the global rise of tablet use in healthcare. Its widespread adoption can be seen through a variety of newspaper articles, hospital and care home statements, and some new research examining tablet technologies in these settings (Anderson, 2010; Marceglia et al. 2012). Global systematic adoption of tablets into care settings include The Ottawa Hospital, Oxford University Hospitals ('iPad Monitoring System to Improve Patient Care | NIHR Oxford Biomedical Research Centre, 2016), and Anchor care homes, the UK's largest not-for-profit system of housing and care for older people.

Tablet use in care homes and clinical settings may be as varied as software applications allow. Common uses include electronic health record monitoring, point of care communication, diagnostic imaging review and tele-healthcare. Direct use of tablet technology as an aide to physicians during hospital ward rounds has been examined. Baysari et al. (2014) examined information sharing and found that physicians only used tablets in 15.6% of patient bedside interactions. Qualitative portions of the same study showed hesitant attitudes among hospital physicians towards tablet use for communication, as they preferred verbal communication without a need for supplementary information.

In addition to the general challenges relating to tablet usage outlined above, Marceglia et al. (2012) also pointed out dangers of tablet use specifically in healthcare settings. Tablets may offer another opportunity for the mishandling of personal information, whether it be intentional or due to human error. A misplaced sense of trust might also be put into tablet applications labelled with medical or health terms. These dangers, while serious, may be addressed and avoided. Considering that hospital inpatients with dementia have a need for person-centred

occupation (Clissett et al., 2013), the use of tablets for engaging activities holds exciting potential. Their use in activities for hospital inpatients with dementia would harness the trend in technological innovation to address issues implicated in an ageing society.

### **1.8 Conclusion and Statement of Research Questions, Aims, and Objectives**

Dementia is a multifaceted condition with many orders of symptoms that have been addressed both individually and in concert. These challenges in dementia care are being addressed with non-pharmacological treatments, and arts in health programmes have emerged as particularly effective, person-centred solutions. Systematic reviews of arts in health programmes have focused on general arts in health as well as arts in health for dementia in community settings. However, no systematic review for arts in health programmes for dementia had been undertaken with a focus on acute care settings before this thesis. Furthermore, no study has linked lifetime or current home experience of the arts with wellbeing in acute care for hospital inpatients with dementia. Chapter 3 of this thesis will explore those links through a questionnaire-based cross-sectional study.

Alongside arts in health research, new tablet-based technologies have proliferated in hospitals for general non-medical use and in research regarding use in dementia care. The intersection of these areas points to the potential use of tablet-based technologies in arts in health applications. Significant gaps in research exist regarding how the use of tablet-based technology in arts in health programmes impacts the lived experience of hospital inpatients with dementia. Chapters 4 and 5 of this thesis will explore this area through the triangulation of ethnographic and quasi-experimental methods. Guided by the following research questions, aims, and objectives, the following chapters will focus on this nexus of the experience of dementia in hospital settings, arts engagement, and technology.

#### **1.8.1 Primary Question**

- How does arts engagement affect the experience of hospital inpatients with dementia?

#### **1.8.2 Secondary Questions**

- How are previous and current experiences of the arts linked to loneliness, depression, and quality of life for hospital inpatients with dementia?

- How would traditional and digital versions of arts in health programmes compare in affecting anxiety in hospital inpatients with dementia?
- How would traditional and digital versions of arts in health programmes compare in affecting wellbeing in hospital inpatients with dementia?
- How would traditional and digital versions of arts in health programmes compare in engaging hospital inpatients with dementia?

### **1.8.3 Aims**

- To explore whether there are associations between previous and current arts engagement, loneliness, depression, and quality of life in hospital inpatients with dementia
- To explore how traditional and digital versions of arts in health programmes compare in affecting anxiety in hospital inpatients with dementia.
- To explore how traditional and digital versions of arts in health programmes compare in affecting wellbeing in hospital inpatients with dementia.
- To explore how traditional and digital versions of arts in health programmes compare in engaging hospital inpatients with dementia.

### **1.8.4 Objectives**

- To complete a systematic review of the literature for non-pharmacological therapies for hospital inpatients with dementia.
- To complete a cross-sectional study examining relationships between cognitive impairment, past and current experience of the arts, loneliness, psychological health, and quality of life
- To complete an ethnographic study comparing and contrasting digital and traditional versions of music, movement, and museum programmes
- To complete a 3-arm controlled study examining engagement and anxiety before and after traditional and digital versions of an art programme

### **1.8.5 Hypotheses**

P1: Hospital inpatients with dementia who currently engage in music or art activities experience less loneliness and depression and a higher quality of life than those who do not engage in music or art activities.

P2: Hospital inpatients with dementia who do not currently, but spent at least 10 years of their life engaged in music or art activities experience less loneliness and depression and a higher quality of life than those who did not engage in music or art activities.

P3: Hospital inpatients whose sole current activities are passive, such as listening to the radio or watching television, experience more loneliness and depression and a lower quality of life than those who engage in the arts and cultural activities.

P4: Hospital inpatients with dementia participating in digital versions of arts in health programmes will show higher levels of engagement and a greater decrease in stress than hospital inpatients with dementia participating in traditional versions of arts in health programmes.

P5: Both traditional and digital arts in health groups will show higher levels of engagement, improved wellbeing, and greater decrease in anxiety than the control group.

## CHAPTER 2 METHODOLOGY

### 2.1 Introduction

This thesis aimed to fully explore how engagement with the arts affects the experience of hospital inpatients with dementia. The breadth of research questions addressing this experience led to the choice of an equally broad research perspective. I therefore chose a pragmatic approach for its embrace of a broad spectrum of methodological possibilities. This chapter will describe pragmatism and its epistemological context before discussing its strengths and weaknesses in addressing the stated research questions. It will then describe the choice of mixed methods employed for the study. While previous studies have used a variety of methods researching arts in health programmes for hospital inpatients with dementia, most have taken a constructivist or positivist approach. This thesis aimed to integrate the strengths of each approach by letting qualitative and quantitative results inform each other and guide future practice and data collection.

### 2.2 Epistemology

#### 2.2.1 Background epistemologies

Acknowledging that the experience of research and its findings are influenced by the epistemological framework, this section will begin by describing epistemologies and research paradigms that have historically informed qualitative and quantitative research. It will describe the strengths and weaknesses of these approaches before investigating the pragmatic perspective used by this thesis.

Positivism is defined by its demand for empiricism and verifiable measurement, made possible by the acceptance of a single objective reality. This verifiable measurement in health research is epitomised by the randomised controlled trial (RCT), which is the standard for pharmacological research in clinical trials. However, positivism has been criticised for its lack of attention to underlying phenomena, especially when applied to social interventions (Bonell, Moore, Warren, & Moore, 2018). Its lack of consideration for the subjective experience of study participants has led to its rejection by many research fields, especially fields that make extensive use of qualitative methodologies. Positivism has been countered by constructivist perspectives which believe that meaning is made by individuals and groups (Gomm, Hammersley, & Foster, 2000). Positivist challengers argued that the scientific method applied to physics and chemistry

were inadequate when applied to fields of human study such as sociology and anthropology (Giddings & Grant, 2007). Faced with heavy criticism, positivism gave way to post-positivist perspectives. Social constructionism and critical realism are cited as the strongest competing post-positivist perspectives (Alvesson & Sköldbberg, 2017). This evolution came about by recognising that underlying the measurable, observable world that serves as the focus of positivism is an underlying network of processes and relationships that deserve study. However, post-positivism has been critiqued for its insistence on a “one-to-one correspondence between our observations and some external reality” (Morgan, 2014).

The ontological divide between positivist and constructivist perspectives is reflected in oft-cited “paradigm wars,” which also spills over into epistemological and methodological tensions. This seemingly irreconcilable difference between closed and open-ended epistemologies has provided a challenge to researchers who have aimed to balance their strengths and weaknesses. These paradigm wars are reflected in the studies reviewed in Chapter 1’s systematic review of non-pharmacological treatments for hospital inpatients with dementia. While positivistic experimental studies (Amieva et al., 2016; Berger et al., 2004; Wu & Koo, 2016) reported inconsistent improvements in quantitative measures, constructivist qualitative studies (Hazzan et al., 2016; Moss & O’Neill, 2017) reported consistently positive results with no discernible downsides to non-pharmacological therapies. The discrepancy in results and conclusions between positivistic and constructivist studies might be reconciled by a pragmatic epistemology.

### **2.2.2 Pragmatism**

Pragmatism forms an epistemological basis for flexible and mixed methodologies that has been lauded as the “phoenix from the ashes of the paradigm wars” (Cameron, 2011). Noting the complementary nature of “hard, generalizable data” and “deep, rich observational data” (Sieber, 1973), the pragmatic approach aims to use their strengths to counterbalance each other’s weaknesses. This integration and acknowledgement of both post-positivist and constructivist perspectives signals the mark of a new paradigm with pragmatism. By giving emphasis to both experience of the world and the tools used to measure it, pragmatism aims to “break down the dualism between realism and idealism” (Morgan, 2014).

Pragmatism has been criticised for potentially producing more incremental change than foundational change (Johnson and Onwuegbuzie, 2004), and for favouring analytical approaches akin to positivism. Indeed, it has been accused as a “Trojan Horse for positivism” unless its mixed methods lie within the same paradigm (Giddings & Grant, 2007). Biesta (2010) and Morgan (2007) notably described pragmatism as an approach that falls short of articulating an entire worldview. However, as a research approach rather than ontology, pragmatism is ideally suited for naturalistic settings such as an acute hospital where research is often expected to have direct, actionable outputs (Bergin, 2017).

Pragmatism has been defined by its opposition to metaphysical paradigms in which all knowledge and action flow from fundamental beliefs about the nature of the universe (Johnson, 2011). Morgan (2007) criticised the metaphysical paradigm for its emphasis on the quest for objective truth in reality. Pragmatism, on the other hand, describes relative effects of one course of action over another. Morgan (2014) described the pragmatic epistemological paradigm as knowledge that “consists of warranted assertions that result from taking action and experiencing the outcomes.” The “top-down” orientation of the metaphysical paradigm is therefore inverted with pragmatism. Shannon-Baker (2016) pointed out transferability as a key tool of pragmatism. Considering a finding’s transferability to other settings is a key part of this process in the pragmatic paradigm. This approach is well-suited to address the policy context outlined in the Introduction and Chapter 1 of this thesis.

### **2.2.3 Pragmatism in the study of dementia**

The holistic nature of dementia and its symptoms assumes complex methodological challenges, especially in an acute care setting. Bond and Corner (2001) have separated consideration of dementia from its symptoms, asserting that research of dementia does not present new methodological challenges. Rather, it is the complexity of the experience of dementia in health services that presents unique methodological challenges. Interpretive phenomenological analysis has been used extensively in the study of the lived experience of dementia (Aldridge, Fisher, & Laidlaw, 2017; Clare, Rowlands, Bruce, Surr, & Downs, 2008; Johnson, 2016; Quinn, Clare, Pearce, & Dijkhuizen, 2008; Sharp, 2017; de Witt, Ploeg, & Black, 2010). Social constructionism has also been applied to qualitative dementia research, considering the self-identity of people with dementia as a function of their relationships with others,

especially carers. (Sabat & Harré, 1992). Research in these fields has tended to emphasise the perspectives of people living with dementia in line with Kitwood's ideas of person-centredness. While this increasing body of qualitative research is necessary for the development of themes of experience in dementia, they lack the quantitative element necessary for determining extent of experiences of health and wellbeing, as well as comparisons of change between interventions.

Studies of different types of arts in health activities for dementia have emphasised the need for epistemological flexibility. Newman et al. (2016) asserted that in order to achieve diverse objectives of multidisciplinary projects, researchers need "to embrace a wide variety of epistemological positions." While this may be seen as lack of epistemological rigour, Newman et al. seemed to describe pragmatism with its application of a variety of methods to fit the setting and research question at hand. A series of studies performed by researchers at University College London has mixed quantitative measures of wellbeing with qualitative grounded theory and thematic analysis (Paddon, Thomson, Menon, Lanceley, & Chatterjee, 2014; Thomson & Chatterjee, 2015). This has been applied to wellbeing in other groups. Post-positivist epistemologies have been used in the mixed-methods study of stroke (Clarke, 2009), childhood wellbeing (Jones & Sumner, 2009), and stress in surgical residents (Lases et al., 2016).

## **2.3 Mixed Methods**

### **2.3.1 Background**

To investigate current and previous individual artistic experience and how hospital inpatients with dementia interact with tablet-based activities versus traditional arts in health programmes, this thesis employed mixed quantitative and qualitative methods. The use of mixed methods is supported by pragmatic epistemology. Tashakkori and Teddlie (2003) described the emergence of mixed methodology as the "third methodological movement" after positivist-dominated 20<sup>th</sup> century and subsequent constructivist reaction in the social sciences. Feilzer (2009) argued that the "socially useful knowledge" prioritised by pragmatism might be best obtained by mixing available research methods. By combining quantitative and qualitative research approaches, the research presented in this thesis can combine the breadth and depth offered by each. Mixed methods designs are relatively new approaches to research, evidenced by the varying terminology used to describe its features. Morgan (2007) described "abduction," defined by an iterative dialogue between "induction" and "deduction," a process that can be

operationalised through iterative mixed-methods research. Shannon-Baker (2016) referred to this aspect of mixed-methods as “complementarity.”

The nature of the arts in health intervention necessitates this approach. Because the mechanisms and phenomena underlying arts in health activities are not well understood, mixed methods allowed this thesis to both investigate emergent phenomena and measure the quantitative impacts of these phenomena on psychosocial health and wellbeing. This follows a new tradition of research into clinical care. O’Cathain et al. (2007) have pointed to the trend of studies using mixed methods to bring a more patient-centred approach to the methodology.

An important characteristic of mixed-methods studies lies in the interplay between quantitative and qualitative components. Rather than running two parallel studies, a mixed-methods study relies on the quantitative and qualitative designs interacting in order to create a full, balanced picture of a single research question (Creswell, Fetters, & Ivankova 2004). Most often, this integration occurs at the data analysis stage where qualitative findings are used to give context and explanation to quantitative findings. This integration may occur with either qualitative or quantitative method preceding the other. If qualitative data collection precedes quantitative, quantitative data collection may be informed by themes identified in the qualitative portion. Qualitative data may then, in turn, explain and inform the quantitative data collected (Creswell, Fetters, & Ivankova, 2004). The different types of data these methods yield will let this research employ data triangulation to gain a multifaceted view of the interventions and associated phenomena.

### **2.3.2 Reviewed studies of arts in health interventions for hospital inpatients with dementia.**

Of the 19 studies included in the systematic review, 2 used mixed methods including qualitative and quantitative methods. Daykin et al. (2017) recorded clinical data such as number of falls, days stayed in hospital, anti-psychotic drug prescriptions and compared them with qualitative outcomes from researcher observation, staff interviews, and patient interviews. While the qualitative data added richness to the context of the study, Daykin et al. acknowledged that data such as length of stay and anti-psychotic prescription rates might not be connected to participation in arts in health programmes. In a pilot study, O’Rourke et al. (2011) mixed quantitative scales measuring functional linguistic communication (ability to hold a conversation) and depression with semi-structured interviews examined with thematic analysis.

This design is better suited to the study of an intervention because the validated scales used were administered in conjunction with the intervention.

**2.3.2.1 Outcome measures used.** The strategy used for selection of outcome measures for this PhD began with a review of outcome measures identified in the systematic review conducted for this thesis. The methodological review revealed a wide range of outcome measures, with little consensus. While this suggests many areas of focus in the research field, it presents an opportunity for this thesis and future research to identify and contribute to emergent trends.

The most-used outcome measure was the Mini-Mental State Exam (MMSE), a standard cognitive screening questionnaire. Six of the nineteen included studies used this scale. Other measures used by more than one study include three uses of the Geriatric Depression Scale and Zarit Caregiver Burden Interview, and two uses of the Global Deterioration Scale, activity attendance count, and Neuropsychiatric Inventory. Forty-nine other measures were used only once each across the nineteen studies.

Behavioural and psychological measures were most commonly used across studies, with fifteen measures included across twelve distinct scales. Cognitive measures were included thirteen times as an outcome measure across seven distinct scales. Eight measures of activities of daily living were included.

Gold (2014) and Rylatt (2012) included researcher-developed quantitative scales as a way to tailor the outcome measure to the art programme's particularities. While this is a potentially useful way to gather activity-based data, it risks sacrificing generalisability and ability to include results in meta-analyses. Further information for outcome measures used can be found in Table 5.

Table 5

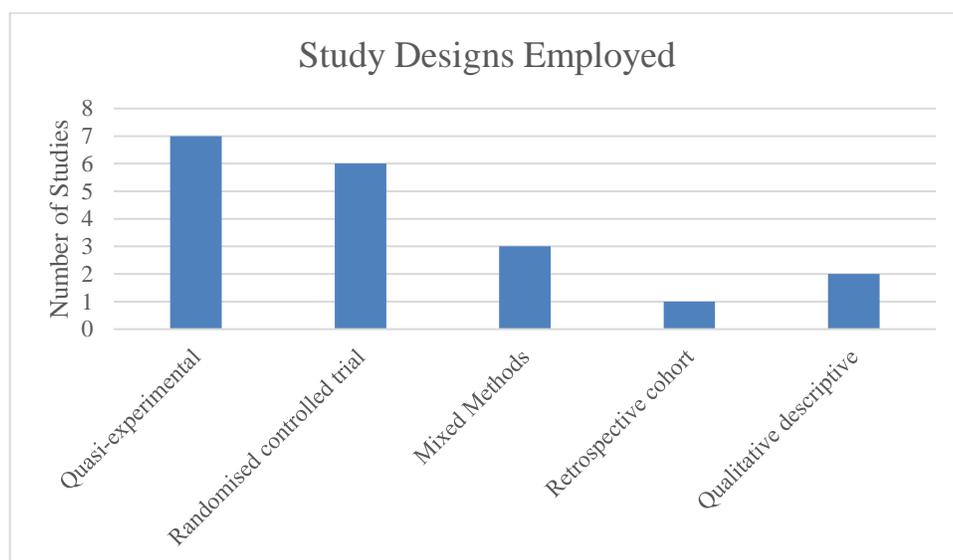
*Outcome Measures Used in Studies of Non-Pharmacological Interventions for Hospital Inpatients with Dementia*

	<b>Number of studies</b>
<b>Cognitive measures</b>	
Mini-Mental State Exam	6
Global Deterioration Scale	2
Montreal Cognitive Assessment	1
Wechsler Memory Scale	1
Amsterdam Dementia Screening Test	1
Syndrom-Kurz Test	1
Brief Cognitive Rating Scale	1
<b>Behavioural and psychological measures</b>	
Geriatric Depression Scale	3
Neuropsychiatric Inventory	2
BEHAVE-AD	1
Beck's Depression-Inventory	1
Montgomery-Asberg Depression Rating Scale	1
Dementia Behavior Disturbance	1
Pittsburgh Agitation Scale	1
Cohen-Mansfield Agitation Inventory	1
Researcher-developed measure of agitation	1
Apathy Inventory	1
Apathy Scale	1
Researcher-developed measure of behaviour	1
<b>Activities of Daily Living measures</b>	
Activity Attendance	2
Instrumental Activities of Daily Living	1
Katz Index of Activities of Daily Living	1
Refined Activities of Daily Living Assessment Scale	1
Physical Self-Maintenance Scale	1
Functional Linguistic Communication Inventory	1
Disability Assessment for Dementia	1
<b>Global measures</b>	
Nurses' Observation Scale for Geriatric Patients	1
BOP (Dutch Stockton Geriatric Rating Scale)	1
<b>Mood and emotion measures</b>	
Observed Emotion Rating Scale	1
Bed notes for falls, length of stay, anti-psychotic drug prescriptions, need for clinical attention	1

	Researcher-developed social interest questionnaire	1
	Researcher-developed measure of enjoyment	1
	Researcher-developed measure of mood	1
<b>Nutrition measures</b>	Mini Nutritional Index	1
	Eating Behavioural Scale	1
<b>Engagement measures</b>	Menorah Park Engagement Scale	1
	Researcher-developed measure of engagement	1
	Researcher-developed measure of creative self-expression	1
<b>Wellbeing measures</b>	Spirituality Index of Wellbeing	1
	Herth Hope Index	1
	Life Satisfaction Scale	1
<b>Quality of Life measures</b>	Quality of Life – Alzheimer’s Disease Scale for the Assessment of Negative Symptoms in Alzheimer’s Disease	1
<b>Neurological biomarkers</b>	Melatonin	1
	Prolactin	1
	Serotonin	1
	Norepinephrine	1
	Epinephrine	1
<b>Physiological measures</b>	Heart rate variability	1
	Blood plasma cytokines	1
	Catecholamines	1
	Body weight	1
	Body mass index	1
	Mortality	1
<b>Caregiver wellbeing</b>	Zarit Caregiver Burden Interview	3

The choice of study designs was informed by methodologies explored in the systematic review performed for this thesis. Of the nineteen studies reviewed, thirteen were quasi-experimental and randomised controlled trials. While this majority finding gives precedence for the 3-arm controlled study in this thesis, there have been no cross-sectional studies, and only two qualitative observational studies performed for the experience of arts in health programmes for hospital inpatients with dementia. Further results of study designs employed by reviewed studies can be found in Figure 4.

*Figure 4. Study designs employed for non-pharmacological interventions for hospital inpatients with dementia.*



### 2.3.3 The Present Study

This thesis is composed of three studies, ordered to make full use of the iterative strengths of mixed methods.

- 1) Cross-sectional study,
- 2) Focused ethnography, and
- 3) Controlled non-randomised study.

The cross-sectional study took the form of a questionnaire battery with constituent questionnaires addressing demographics, individual engagement with the arts, and psychosocial health and wellbeing of hospital inpatients with dementia. This descriptive study informed the

design and implementation of group arts activities in the hospital day rooms. These group activities were then studied through observation and semi-structured interviews with patient participants and clinical and therapy staff in the focused ethnography, which continued throughout the data collection period of the controlled quasi-experimental study. By preceding and co-existing with the controlled quasi-experimental study, the focused ethnography was able to provide a rich description of phenomena and experiences underlying positivistic changes in anxiety and wellbeing. Detailed methodologies for each individual study will be presented in their respective chapters.

## **2.4 Research Setting**

### **2.4.1 Funder**

These studies were funded by the charity whose activities were studied as patient interventions in Chapters 4 and 5. This charity engages in a range of charity activities designed to support the Trust and its clinics, including patient activities, environment, research and innovation, and fundraising. The remit of the thesis was to focus on the charity's Care of Older People (COOP) programme, a wide-ranging programme that brings artistic experiences to hospital inpatients. The COOP programme is organised and managed by charity staff who lead art and music programmes. It also regularly commissions local artists to bring participatory movement, gardening, and ceramic activities to patients.

The funding charity has an interest in positive promotion of its programmes. While I developed close working relationships with the arts team implementing the programmes, my relationship with the broader charity apparatus has been limited. The studentship period included consultation on award and conference applications for the charity, however the inception, progress and approach of this PhD research has been overseen by academic supervisors at the Centre for Performance Science, Royal College of Music. No part of this thesis has been reviewed by any member of charity staff before its submission. This was done in order to limit potential conflict of interest in study design, data collection, analysis and write up stages of the studies.

### **2.4.2 Participants**

The participants included in this thesis are hospital inpatients with mild-to-moderate dementia, as screened by the MMSE (Folstein, Folstein, & McHugh, 1975). All participants were

recruited from CWFT on the series of older people wards on which the COOP programme takes place. In the year 2017-2018, CWFT admitted 13,525 patients over the age of 75. Of them, 1,902 (14%) were diagnosed with dementia. Considering that the Care Quality Commission (2014) found that up to 30% of older hospital inpatients have dementia, this low number may reflect inconsistent screening practices. For inclusion in the present study, potential participants were identified with the help of clinical staff who had access to both patient records and knew patients personally. For the cross-sectional study, clinical staff recommended any patient they felt would be able and willing to be approached for a 20 minute verbally administered questionnaire. For the focused ethnographic and quasi-experimental studies, clinical staff recommended patients who had expressed interest or might be interested in participating in the art group. This sampling method, while not randomised, reflects the natural recruitment process for arts in health activities in hospital settings where participants are offered the option to participate and are given freedom to accept or refuse. After informed consent was obtained, the MMSE was administered for inclusion and data analysis purposes. Participants were not notified of their final score on the MMSE as it was not used for diagnostic purposes.

Patient recruitment for each individual study was calculated in order to maximise likelihood of statistical significance for the planned statistical procedures. The specific choice of sample size for each study is described in the relevant chapters. However, it is of note that of the studies reviewed for the systematic review, most recruited fewer than 25 participants. These were mostly made up of pilot studies whose aims were to demonstrate feasibility of the arts intervention in a hospital setting. The 5 studies recruiting more than 50 participants were quasi-experimental or randomised controlled studies. Figure 5 presents further information regarding study sample sizes.

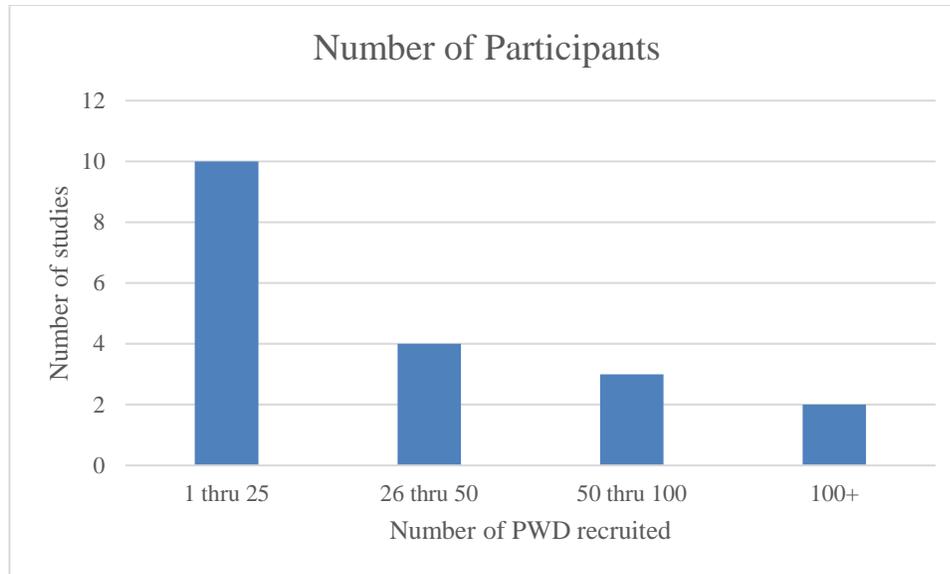


Figure 5. Recruitment of studies of arts in health interventions for hospital inpatients with dementia.

### 2.4.3 Physical Setting.

All studies took place on older people wards at an acute care NHS Trust in London. Figure 6 presents a diagram of a typical example of one of these wards. Bed bays of the wards typically consist of six beds, rows of three facing each other, with a window along one side. This ward has four bed bays and five private rooms. The day room, where group art activities took place, is situated about ten metres down the hall past the nurses' station.

The day room is used in a variety of ways, including patient consultation, ward staff meetings, as a makeshift discharge lounge, and for activities such as arts in health. It has even been used for storage. The day room is designed to fulfil functions of a living room. It has a television with access to video and radio channels, a bookcase filled with novels, non-fiction, and magazines, an electronic piano for music activities, and art hung on the walls. A square table fills the centre of the room, and it is surrounded by chairs. There is plenty of space for wheelchairs to be accommodated at the activity table.

Just past the day room is the ward entrance, a double doorway with the innermost doors being locked. Hospital staff are able to unlock the doors with a swipe of their ID card, and visitors are allowed to be buzzed in from the nurses' station via intercom.

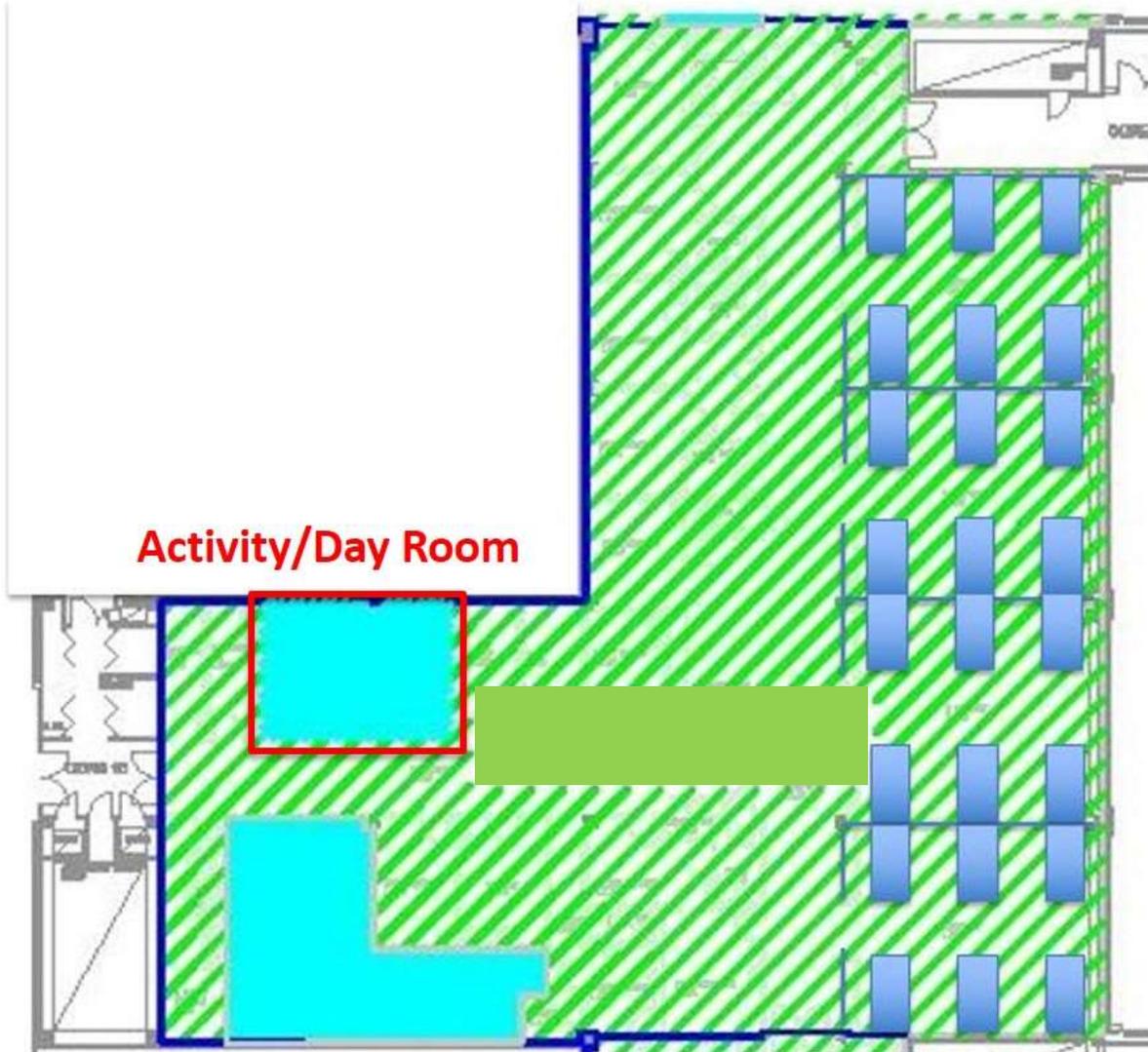


Figure 6. Floorplan of a typical ward.

## 2.5 Conclusion

This chapter has reviewed the background epistemologies and decision to use a pragmatic epistemology. Mixed methods were chosen in order to triangulate the impact of engagement with the arts for hospital inpatients with dementia. Cross-sectional, ethnographic, and quasi-experimental designs were chosen after a review of the methods used in previous studies identified by a systematic review.

Contextual elements of this thesis were then described. This included my relationship with the charity funding this thesis, the patient participants involved with the studies, and the

physical context of the research setting. Because the research setting influences particular experiences observed and reported, these details will be referred to in the studies presented in Chapters 3, 4, and 5.

## CHAPTER 3 CROSS-SECTIONAL PROFILE OF ARTS ENGAGEMENT AND LIVED EXPERIENCE OF HOSPITAL INPATIENTS WITH DEMENTIA

### 3.1 Introduction

The Introduction and Chapters 1 and 2 of this thesis outlined the policy and research landscape concerning the lived experience of hospital inpatients with dementia and the ways in which it can be impacted by engagement with the arts. As the global and UK populations age, the prevalence of dementia is rising, as is the burden of dementia among hospital inpatients. However, arts programmes including participatory art have been shown to decrease anxiety and agitation in older patients, especially those with dementia. A growing field of research has examined effects on psychosocial health and wellbeing of organised arts in health programmes for hospital inpatients with dementia. However, as of yet, no studies have examined the impact of voluntary, individual engagement with the arts.

The aim of this chapter is to explore whether there is evidence of a relationship between individual engagement with the arts and loneliness, depression, and quality of life in hospital for inpatients with dementia. Specifically, the present study aimed to explore whether current engagement with the arts is associated with better psychosocial state independent of previous lifetime engagement. By measuring individual engagement with the arts, this study removed consideration of the impact of social engagement in group arts activities. This then provided a basis for studies of group engagement, as well as an indication as to what type of activities are effective for outcomes in psychosocial health and wellbeing.

#### 3.1.1 Research question, aim, and objective

The study was guided by the following research question: *How are previous and current experiences of the arts linked to loneliness, depression, and quality of life for hospital inpatients with dementia?*

The aim was to explore whether there are associations between previous and current arts engagement, loneliness, depression, and quality of life in hospital inpatients with dementia, independent of previous and lifetime engagement. The objective was to complete a cross-sectional study examining relationships between previous and current experience of the arts, loneliness, depression, and quality of life.

## **3.2 Methodology**

To answer the research question, the present study aimed to recruit a representative sample of hospital inpatients with dementia. A cross-sectional survey was deemed the ideal method for gathering this data for its ability to gather a wide sweep of information. Previous mixed methods theses have begun with survey batteries. In a mixed methods investigation of behavioural and psychological symptoms of dementia in care homes, Backhouse (2014) emphasised the need to reach a wide range of settings and participants before narrowing the scope of the study for qualitative interviews. West (2012) measured resilience, pain, medical outcomes, and social support before an interview phase studying coping strategies for chronic pain. While these theses served as precedents for cross-sectional studies as the basis of a mixed methods investigation, their scope was exploratory. The present thesis aimed to use the cross-sectional study as a basis for understanding the experience of hospital inpatients with dementia before designing and implementing arts in health interventions. Therefore, the cross-sectional survey was designed to elicit information about preferences in art engagement.

Arts engagement and interest among hospital inpatients has been studied by Moss and O'Neill (2014) in an Irish teaching hospital. They used a phenomenological qualitative design, including 20 participants over the age of 65, however they excluded people with cognitive impairment. Considering the cognitive impairment of patients with dementia, this study chose a cross-sectional design that would not rely on qualitative interviews as its main data source. Instead, the data collection instrument would use brief validated measures which have been shown to be appropriate for use with people with dementia.

### **3.2.1 Questionnaire Design**

The questionnaire battery prioritised ease of verbal administration with hospital inpatients with dementia. Individual validated scales were chosen based on their ease of use and validity with participants with dementia as well as their brevity. Questionnaires were ordered based on priority of measures. Considering that some participants would not complete the entire battery, dependent outcome measures of loneliness, depression, and quality of life were placed last. This way, participants would first answer questions regarding arts engagement, data that has not been collected for this population by any other study. This section outlines the choice of measures used in the questionnaire battery. The full questionnaire battery can be found in Appendix A.

### 3.2.1.1 Independent variables

**Mini-Mental State Exam.** Participants with dementia were identified using the Mini-Mental State Exam (MMSE), a widely used screening tool. Developed in 1975 by Folstein, Folstein, and McHugh, the MMSE has been used in a variety of settings for research and diagnosis (Kurlowicz & Wallace, 2002). Results from the systematic review conducted for this thesis showed that an overwhelming proportion of studies on arts in health programmes for hospital inpatients with dementia used the MMSE as an inclusion screening tool. It has been thoroughly validated for primary care practice (Velayudhan et al. 2014), and its measurement of cognition is not significantly affected by functional disability. Furthermore, it is commonly used at the bedside (Aldridge & Aldridge 1992).

The MMSE scores lie between 0 and 30. A score less than 10 indicates severe dementia, a score from 10 to 18 indicates moderate dementia, a score between 19 and 23 indicates mild dementia, and a score greater than 23 indicates mild or no cognitive impairment. The present thesis focuses on mild-to-moderate dementia, excluding severe progression of dementia in all studies. It is common for dementia research to exclude severe progression for both practical and substantive reasons. Although activities for people with severe dementia are available such as Wigmore Hall's Music for Life project, severe progression of dementia might inhibit fully active participation due to reduced ability to perform activities of daily living (Andersen, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sørensen, 2004) and reduced capacity for co-operation (Hansebo & Kihlgren, 2002). The systematic literature review presented in Chapter 1 of this thesis included 19 studies, only 3 of which explicitly included patients with severe dementia. Of these, only Gold (2014) studied severe dementia exclusively. In that study, Gold noted that people with advanced progression of dementia "may have very limited engagement, movement, or concentration. And they may be hard to include in groups, because their deteriorated presence and/or challenging behaviour communicate such agitation or despair to everyone around them."

The MMSE has been criticised for its lack of sensitivity in detecting early stages of dementia, including differentiating between MCI and early dementia (Mitchell, 2009). Additionally, it has been suggested that MMSE scores should be interpreted on a sliding scale determined by the participant's level of education (Gagnon et al., 1990). However, a meta-analysis of MMSE use in clinical settings found a sensitivity of 79.8% and a specificity of 81.3%

(Mitchell, 2009). A direct comparison of the Montreal Cognitive Assessment (MoCA) and MMSE in China found that the MMSE was more efficient for dementia screening, while MoCA was more useful for detecting mild cognitive impairment (Tsai et al., 2016).

**Demographic variables.** Considering the diverse socioeconomic, educational, and demographic makeup of potential participants, the present study included a short demographic questionnaire. Taking into account demographic characteristics of the study participants such as sex, age, level of education, and household makeup, confounding variables may be controlled for. Subgroup analysis was also made possible by analysing differences between these demographic characteristics.

**Measuring engagement with the arts.** In order to measure different types of engagement with the arts, a bespoke questionnaire was developed for inclusion in the battery. The questionnaire aimed to capture current, recent, and life course experience of the arts. It included both active arts engagement such as singing, dancing, acting, and instrument playing and passive arts engagement such as museum visiting, attending the theatre, and listening to music. Engagement was measured by ordered categorical variables in order to separate intensity of engagement.

All independent variables were identified from the literature, expert clinical and academic advice, and researcher experience having spent time shadowing arts in health programmes in the research setting. This section will describe the independent variables and the statistical procedures used to test assumptions in preparation for correlation and regression model analysis.

This study measured a range of independent variables for engagement and value of the arts including

*1) recent engagement with singing, instrument playing, visual art production, music listening, dancing, reading, listening to the radio, and watching television,*

*2) past-year attendance of a concert, museum or gallery, theatre or dance performance, and cinema,*

*3) life course engagement with singing, instrument playing, visual art production, music listening, acting, and dancing,*

4) *Level of importance in their life of concert-going, attending a museum or gallery, attending a theatre or dance performance, attending a sporting event, going to the cinema, singing, instrument playing, visual art production, listening to music, dancing, reading, listening to the radio, and watching television.*

**Recent Engagement.** Recent engagement was coded on a 0-4 scale with *Never* = 0, *From time to time* = 1, *Several times a week* = 2, *Every day <30 min* = 3, and *Every day > 30 min* = 4. The language used for these categories was intentionally conversational, with *from time to time* meant to indicate “seldom” and *several times per week* to indicate “regularly.” These codes were then summated for analysis into a category called *Cumulative Current Engagement* or *Total Current Engagement*. For sensitivity analysis, codes were also grouped into *Active Engagement* (*singing, playing a musical instrument, visual art production, dancing, and reading*) and *Passive Engagement* (*listening to music, listening to the radio, and watching television*). The questionnaire asked about how often the participant engages with individual arts activities “currently,” but this was communicated to participants as referring to the past three months in order to gain a picture of the general pattern of arts engagement at their current stage of life.

**Past-year Cultural Engagement.** Past-year cultural engagement was originally measured by counts of individual events. Counts were summated for analysis of total past-year cultural engagement. Participants were asked how many times in the past year they attended a 1) *concert*, 2) *art gallery or museum*, 3) *theatre or dance performance*, 4) *cinema*.

**Life Course Engagement.** Life course engagement was originally measured by years of individual activities and can be found in Table 10. Year counts were summated for analysis of total life-course engagement. Participants were asked for how many years of their life did they regularly 1) *sing*, 2) *play a musical instrument*, 3) *dance*, 4) *act*, 5) *draw, craft, or paint*. Although this measure is subject to imprecision and recall difficulty in patients with dementia, questionnaire delivery style moderated this danger. By asking the question in a conversational way, study participants were allowed to reflect on the stages of their life and the periods of artistic engagement during them.

### 3.2.1.2 Dependent variables

**Measuring loneliness.** Loneliness was identified in Chapter 1 as a key challenge in the lived experience of dementia. It has been linked to increased risk for the development of dementia (Wilson et al., 2007), which may in turn exacerbate loneliness. Age-associated challenges such as physical health problems, death of spouse, and retirement from work may further contribute to subjective feelings of loneliness in older adults. Linked with depression, loneliness is a key concern for psychosocial health in dementia. For people with dementia, it has been cited as a reason for increased visits to hospital emergency departments (Geller et al. 1999).

To measure loneliness, the present study used the De Jong-Gierveld Loneliness Scale 6-Item Short Form (Gierveld & Tilburg, 2006). Although the De Jong-Gierveld Loneliness Scale has not been validated for use with dementia, it has been correlated with depression in dementia (Leung, Gierveld, & Lam, 2008) and was chosen in the absence of any loneliness scale validated for use with dementia. However, other scales for loneliness were considered for use in this study. The Three-Item Loneliness Scale was developed for use with large populations and was validated for use in telephone surveys (Hughes et al. 2004). Adapted from the R-UCLA Loneliness Scale, the Three-Item Loneliness Scale isolated the three highest-load questions for the loneliness construct. A report from the Campaign to End Loneliness highlighted three tools for measuring loneliness including the Campaign to End Loneliness Measurement Tool, the UCLA Loneliness Scale, and the De Jong-Gierveld Loneliness Scale (Campaign to End Loneliness, 2015). From this toolkit, the De Jong-Gierveld Loneliness Scale was chosen for use in the present study. At 6 questions, its length is double the other scales. However, it was developed for use by researchers rather than service providers, and it mixes positive and negative language in its evaluation of loneliness (Campaign to End Loneliness, 2015). It has been validated as a short-form version of the original De Jong-Gierveld Loneliness Scale (Gierveld & Tilburg, 2006).

**Measuring depression.** Chapter 1 identified depression as a key challenge to the lived experience of dementia. It occurs with high prevalence in people with dementia (Korczyn & Halperin, 2009), and it has been studied as a risk factor for, comorbidity, and result of dementia (Tekin & Cummings, 2001). Higher rates of depression are associated with hospital admission, with Migliorelli et al. (1995) reporting 51% prevalence in patients with Alzheimer's disease.

To measure depression, the present study used the Geriatric Depression Scale 10-item short form (Sheikh & Yesavage, 1986). Psychological health in dementia is a widespread concern and the focus of research in this area. The systematic review presented in Chapter 1 of this thesis reported three studies that used the Geriatric Depression Scale to measure depression in hospital inpatients with dementia.

Other scales for depression were considered for use. Berger et al. (2004) used Beck's Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and Amieva et al. (2015) used the Montgomery-Asberg Depression Rating Scale (Montgomery & Asberg, 1979). However, these scales were deemed unsuitable for inclusion in the questionnaire battery because they take longer to administer than the Geriatric Depression Scale. The short form used in this study has been validated and shown to closely track with results obtained from the long form version (Leshner and Berryhill 1994).

**Measuring quality of life.** Chapter 1 of this thesis identified quality of life as a key challenge in the lived experience of dementia. Quality of life is a holistic concept that captures objective elements of the lived experience and is generally regarded as a key outcome measure for dementia (Whitehouse & Rabins, 1992). In hospital settings, activities of daily living may be further compromised, providing a basis for concern about the quality of life of hospital inpatients with dementia.

While its measurement was originally restricted to clinical and carer observation, the Dementia Quality of Life tool showed that persons with mild to moderate dementia are able to give reliable feedback with regard to their subjective state and quality of life (Brod et al., 1999). The Dementia Quality of Life tool correlates well with Quality of Life - Alzheimer's Disease, another widely used measure of quality of life in dementia (Thorgrimsen et al. 2016).

The present study used the Quality of Life – Alzheimer's Disease (QoL-AD) tool (Logsdon, Gibbons, McCurry, & Teri, 1999). Measuring patient perceptions of global quality of life has implications for both prospective social care and current treatment in hospital where it has been used for consideration of holistic patient experience over a disease-focused care model (Higginson & Carr, 2001). QoL-AD was used by one study included in the systematic review presented in Chapter 1. Amieva et al. (2015) used QoL-AD with 655 patient participants, indicating the ability of the measure to be used in large-scale studies. With many international

versions created, QoL-AD has been validated for use with people with dementia in Mexico (Rosas-Carrasco, Torres-Arreola, Guerra-Silla, Torres-Castro, & Gutierrez-Robledo, 2010), Portugal (Bárrios et al., 2013), Brazil (Novelli, Nitrini, & Caramelli, 2010), and Thailand (Buasi & Permsuwan, 2014). Other measures of quality of life for people with dementia were considered, including Dementia Care Mapping (Fossey, Lee, & Ballard, 2002), Dementia Quality of Life Instrument (Brod, Stewart, Sands, & Walton, 1999), and Cornell-Brown Scale for Quality of Life in Dementia (Ready, Ott, Grace, & Fernandez, 2002). These scales, while validated for use with the study population, require extended periods of time observing participants and specialised training to do so. The QoL-AD was chosen for its brevity and ability to be administered verbally.

### **3.2.2 Participants**

Inpatients with dementia, aged 65 and over, were recruited from wards in an NHS hospital in London. Ward specialities included frailty, dementia, stroke, and an acute assessment unit. Recruitment did not include surgical wards, private wards, or in accident and emergency. Potential participants were identified with the help of clinical staff who proposed patients who might be willing to participate. Those who were interested in participating were provided with full information to consent. After participating in this questionnaire, the inpatients completed their involvement.

#### **Inclusion criteria**

- Participant is willing and able to give informed consent for participation in the study,
- Participant scores between 10 and 23, inclusive, on the MMSE. This score indicates mild to moderate progression of dementia,
- Participant is at least 65 years old,
- Participant is staying in a hospital dementia ward as an inpatient.

#### **Exclusion criteria**

- Participant scores below 10 on the MMSE, indicating severe dementia,
- Participant scored 24 or above on the MMSE, indicating no significant cognitive impairment,

- Participant has severely impaired sight or hearing (to the level that would affect their ability to answer questionnaire queries),
- A language barrier prevents participant from understanding the questionnaire or providing informed consent.

After the cognitive screening test (MMSE), participants answered a face-to-face questionnaire with the researcher (see measures above, Section 3.2.1). The study protocol was approved by the NHS Research Ethics Service and Health Research Authority, IRAS reference 207483. The Letter of Access for Research can be found in Appendix E. Participants were informed of the purpose of the study and what it would involve for them before providing consent.

**The Number of Participants.** There were no previous data on which to base specific power calculations for this study. However, general power calculations from Green's (1991) formula  $n = 50 + 8k$ , where  $k$  is the number of confounding variables measured, were of relevance to the statistical analyses. With 6 main confounding variables and 1 main dependent variable per model, this study aimed for a minimum of 104 participants. However, acknowledging that this study has 4 major dependent variables, the aim was to recruit a higher number of patients if possible. The upper limit was suggested as 200 participants as this had been discussed with the hospital as being feasible yet not becoming a burden on patients within the wards. No data was collected by anyone else, thereby making sure that no hospital staff used their working time as a drain to hospital resources. Final number of participants recruited was 123. Recruitment will be further described in Section 3.3.

### 3.2.3 Procedure

**3.2.3.1 Questionnaire administration.** In administering the questionnaire, it was acknowledged that hospital inpatients with dementia would construct their social reality. While this is not unique to people with dementia, dementia-focused research has noted the challenges in conducting constructivist social research (Bond & Corner, 2001). Patients with dementia would perceive themselves and their environments subjectively, but cognitive deterioration presents challenges to understanding the nature of the subjectivity. Questionnaires were administered in a friendly, casual way. While focus was kept on completing the questionnaire battery, conversational diversions were allowed in order to keep participants engaged. If study

participants wanted to tell a story, for instance, it was encouraged in order to further communication through until the next questionnaire item. For initial sections of the questionnaire battery, the casual administration style was useful for confirming recall of items such as number of years spent playing a musical instrument. The validated scales at the end of the questionnaire battery were administered in a more straightforward fashion so as to standardise responses among study participants.

**3.2.3.2 Informed Consent.** Participants personally signed and dated Version 1.2 of the Information Consent form. Written and verbal versions of the Information Consent form were presented to the participants detailing the exact nature of the study. It was clearly stated that the participants were free to withdraw from the study at any time for any reason without prejudice to future care, and with no obligation to give the reason for withdrawal. The original signed form was retained at the study site. The participant was allowed time to consider whether they would like to be involved and the opportunity to question me to decide whether they would participate in the study.

**3.2.3.3 Discontinuation/Withdrawal of Participants from Study.** Each participant had the right to withdraw from the study at any time. In addition, participants may have been discontinued from the study at any time if it was considered necessary for any reason including:

- Ineligibility (either arising during the study or retrospectively having been overlooked at screening)
- Significant protocol deviation
- Withdrawal of consent
- Participant exhibits signs of emotional distress

A plan of action was created in the case that emotional distress was observed in study participants. In order to preserve study participant anonymity, clinical staff would not be alerted unless the patient distress was severe enough to cause alarm for their safety or the safety of others on the ward. Rather than alert immediate clinical staff, printed information was made available for emotional distress and counselling services in the hospital. Data already collected was kept for analysis, but no further data was collected. The end of the study occurred when participants withdrew or completed the verbal questionnaire.

**3.2.3.4 Statistical Methods.** Data was analysed using IBM SPSS Statistics 23.0 software. Distributions were checked using skewness and kurtosis data as well as visual inspection of variable histograms. Non-normal distributions were transformed, and specific transformations are described below. Pearson correlations were used to analyse associations between different variables, and further descriptive statistics were used where necessary. All regression models controlled for the identified confounding variables. Five confounding variables were used in regression models, including education, length of stay, number of cohabitants, age, and gender. Model 1 included only current arts engagement and covariates. Model 2 additionally adjusted for past-year cultural engagement in order to ascertain whether current participatory arts engagement is merely a function of other types of broader recent cultural engagement. Model 3 additionally adjusted for lifetime arts engagement again in order to confirm that current engagement was not just a marker of engagement across the lifespan. P-values of  $\leq .05$  were considered significant. Linearity between independent and dependent variables was checked using scatterplots. Variance inflation factor and tolerance scores were used to confirm lack of multicollinearity. To suggest homoscedasticity, plots of standardised residuals vs standardised predicted values showed no clear funnelling. Cook's Distance values were calculated for regression models, and cases under 1 suggested no undue influence on the model. The Durbin Watson Test was used to check for autocorrelation among predictor variables, and values between 1.5 and 2.5 were accepted.

### 3.3 Results

One hundred and twenty-three hospital inpatients with dementia were recruited to the study from five wards. Of these, 106 participants completed the questionnaire. Participant dropout occurred at different points during the questionnaire, which lasted between 15 and 45 minutes for participants who completed the full questionnaire battery. Participant dropout was most often due to patient fatigue, although some patients did become distressed during the survey. When this occurred, I thanked the participants for their time and left, providing information for support services in the hospital if they were in distress. The numbers of participants who responded to each questionnaire item is reported alongside descriptive statistics.

#### 3.3.1 Demographics

**Age.** Mean age was 81.38 years ( $SD = 7.0$ ) with a skewness of  $-.092$  and a kurtosis of  $-.607$ .

Table 6

*Continuous Demographic Variables*

Item	<i>M</i>	<i>SD</i>	<i>min</i>	<i>max</i>
Age	81.38	7.0	65	98
MMSE	17.48	3.52	10	23
Length of stay (days)	43.03	180.2	1	1800

*Note.* MMSE = Mini-Mental State Exam

**Mini-Mental State Exam.** Mean MMSE score was 17.48 ( $SD = 3.52$ ) with a skewness of  $-.25$  and kurtosis  $-.64$ . For analysis, MMSE scores were subjected to cut-off scores for mild and moderate dementia. There is little agreement among researchers regarding specific cut-off scores. Perneckzy et al. (2006) mapped Clinical Dementia Rating cut-offs onto MMSE scores, finding a range of 21-25 for mild and 11-20 for moderate progression. National Institute for Health and Care Excellence guidelines (2009), on the other hand, distinguish between moderately severe scores (10-14), and moderate (10-20) in overlapping categories that point to this lack of organised consensus. As utilised by de la Rubia Ortí et al., (2018), this study categorised 18-23 as mild progression and 10-17 as moderate progression. Independent samples t-tests were run comparing engagement between mild and moderate progression. Levene's Test

for equality of variance was run, and equal variance was assumed if significance values were over .05.

**Sex.** Study participants were 54.5% female ( $n = 67$ ) and 45.5% male ( $n = 56$ ).

**Reason for admission to hospital.** One hundred and ten participants gave a reason for hospitalisation. However, level of detail given was variable. Responses were initially coded using the International Statistical Classification of Diseases and Related Health Problems 10<sup>th</sup> Revision (WHO, 2014). However, due to the imprecision in data collection and unavailability of patient notes or clinical consultation, reason for admission was not used for further analysis.

**Level of Education.** Level of education was coded by leaving school before age 16 (30.9%), age 16 – 18 (34.4%), undergraduate education (18.7%), and postgraduate education (2.4%).

**Number of Cohabitants.** The mean was .61 ( $SD = 1.13$ ) with a skewness of 3.15 and a kurtosis of 12.49. For regression analysis, number of cohabitants was binarised between no cohabitants and any number of cohabitants. After binarisation, skewness was .49 and kurtosis was -1.79.

**Main Career.** Reported careers were classified using the International Standard Classification of Occupations (International Labour Office, 2012). Categories include stay-at-home (7.3%), minimal technical skill involving “simple and routine physical or manual tasks” (9.8%), integrated technical skill such as “operating machinery and electronic equipment” and “driving vehicles” (43.9%), problem-solving using technical skill including compliance assurance and project management (21.1%), and high-level integration jobs such as a lawyer or physician (6.5%). During analysis, level of education was deemed a sufficient proxy for socioeconomic status, and main career was not used for further analysis.

**Length of Stay.** Mean length of stay was 43.03 days ( $SD = 180.2$ ) with a skewness of 8.65 and a kurtosis of 81.35. Length of stay was winsorised to address an extreme outlier (1800 days), then separated into quintiles for analysis.

Table 7

*Summary of Categorical Predictor Variables*

<b>Variables</b>		<b>Mean %</b>	<b>n</b>
MMSE (N=123)	Mild progression	51.2%	63
	Moderate progression	48.8%	60
Sex (N=123)	Female	54.5%	67
	Male	45.5%	56
Education (N=120)	<16 years old	30.9%	38
	16-18 years old	34.4%	56
	Undergraduate degree	18.7%	23
	Postgraduate degree	2.4%	3
Number of cohabitants (N=123)	0	61.8%	76
	1	29.3%	36
	2	2.4%	3
	3+	6.5%	8
Career category (N=114)	Stay-at-home	7.3%	9
	Minimal technical skills	9.8%	12
	Integrated technical skills	43.9%	54
	Problem solving using technical skills	21.1%	26
	High-level integration	6.5%	8
	Mixed labour	4.1%	5
Length of stay (N=123)	≤4 days	22.1%	27
	5-7 days	19.7%	24
	8-14 days	22.1%	27
	15-30 days	16.4%	20
	31-50 days	19.7%	24
	50+ days	0.8%	1

*Note.* MMSE = Mini-Mental State Exam

### 3.3.2 Arts Engagement

*Current Engagement.* The coding method for current engagement can be found in Section 3.2.1.1. Mean cumulative current engagement was 10.11 with a skewness of -.42 and a kurtosis of .315. Mean active engagement was .59 with a skewness of 1.67 and a kurtosis of 2.58. For analysis, the measure for current active engagement was binarised between no activity and any activity. After binarisation, current active engagement had a skewness of .53 and a kurtosis of -1.75. Mean passive engagement was 9.60 with a skewness of -.23 and a kurtosis of -.2.

Table 8

*Current Engagement with the Arts*

	<b>Activity</b>	<b>None of the time % (n)</b>	<b>From time to time % (n)</b>	<b>Several times per week % (n)</b>	<b>Every day &lt;30 minutes % (n)</b>	<b>Every day &gt;30 minutes % (n)</b>	<b>Score</b>
<b>Active Engagement</b>	Singing (N=123)	84.6% (104)	8.9% (11)	5.7% (7)	0% (0)	0.8% (1)	29
	Playing an instrument (N=123)	97.6% (120)	2.4% (3)	0% (0)	0% (0)	0% (0)	3
	Drawing, crafting, and painting (N=123)	78.9% (97)	17.9% (22)	1.6% (2)	0.8% (1)	0.8% (1)	33
	Dancing (N=122)	93.5% (115)	5.7% (7)	0% (0)	0% (0)	0% (0)	7
<b>Total Active</b>							<b>72</b>
<b>Passive Engagement</b>	Reading (N=122)	23.6% (29)	21.1% (26)	27.6% (34)	11.4% (14)	15.4% (19)	212
	Listening to music (N=122)	11.4% (14)	28.5% (35)	21.1% (26)	16.3% (20)	22.0% (27)	255
	Listening to the radio (N=122)	8.9% (11)	12.2% (15)	17.9% (22)	27.6% (34)	32.5% (40)	321
	Watching television (N=122)	2.4% (3)	8.9% (11)	12.2% (15)	23.6% (29)	52.0% (64)	384
<b>Total Passive</b>							<b>1,172</b>
<b>Cumulative Current Engagement</b>							<b>1,244</b>

*Past-year Cultural Engagement.* The coding method for past-year cultural engagement can be found in Section 3.2.1.1. The mean total past-year cultural engagement was 2.30 (SD = 5.34) with a skewness of 5.12 and a kurtosis of 32.21. This measure was binarised between no activity and any activity, and the new skewness was .28 with a kurtosis of -1.95.

Table 9

*Counts of Cultural Engagement Over the Past Year*

	None	Once	Twice	Three or more times
Concert	108 (90.8%)	5 (4.2%)	0 (0%)	6 (5%)
Museum or Art Gallery	94 (79%)	5 (4.2%)	8 (6.7%)	12 (9.9%)
Theatre or Dance Performance	109 (91.6%)	2 (1.7%)	3 (2.5%)	5 (4.1%)
Cinema	89 (74.8%)	4 (3.4%)	13 (10.9%)	13 (10.9%)

*Life Course Arts Engagement.* The coding method for life course arts engagement can be found in Section 3.2.1.1. Mean life course engagement was 36.39 years (SD = 31.04) with a skewness of .84 and a kurtosis of .244. The positive skew of life course activity measures was normalised using a square root transformation, with a resulting skewness of -.09 and kurtosis of -.84.

Table 10

*Number of Lifetime Years Engaged with the Arts*

Activity	Mean number of years	SD
Singing	15.65	22.3
Playing an instrument	2.59	7.6
Dancing	8.14	15.3
Acting	0.64	4.9
Drawing, crafting, or painting	9.89	19.6

### 3.3.2.1 Arts and demographics.

*Arts Engagement in Mild and Moderate Dementia.* Mean engagement was calculated for mild and moderate progressions of dementia. An independent t-test was carried out in order to determine the difference between the two groups. Full results are displayed in Table 11.

Participants with mild progression of dementia had significantly higher total engagement ( $M = 10.92$ ,  $SD = 3.08$ ) than those with moderate progression ( $M = 9.27$ ,  $SD = 2.92$ );  $t = 3.05$ ,  $p = .003$ . Significant difference in passive engagement was also measured. Those with mild progression of dementia had significantly higher passive engagement ( $M = 10.32$ ,  $SD = 2.86$ ) compared with those with moderate progression ( $M = 8.85$ ,  $SD = 2.65$ );  $t = 9.94$ ,  $p = .004$ . No significant difference in past-year and life course engagement was calculated between mild and moderate progression. Additionally, no significant difference in current active engagement was calculated.

Table 11

*Average Engagement with the Arts by Progression of Dementia*

	Mild progression (n=63)	Moderate progression (n=60)	Difference [95% CI]
Current engagement			
Total	10.92	9.27	1.65** [.58, 2.72]
Active engagement	.60	.57	.03 [-.29, .36]
Passive engagement	10.32	8.85	1.47** [.48, 2.46]
Past-year cultural engagement	2.80	1.78	1.02 [-.88, 2.93]
Life course engagement	37.23	35.51	1.72 [-9.41, 12.85]

Note. \* $p < .05$ . \*\* $p < .01$ .

**3.3.2.2 Importance of the arts.** Subjective importance of different activities and forms of art were measured on a 1-10 scale. Passive activities such as listening to music and watching television were rated as most important. Active engagement including dancing, singing, and drawing, crafting, and painting were rated as less important. Playing an instrument was rated as least important. Full results are reported in Table 12.

Table 12

*Perceived Importance of Activities*

<b>Activity</b>	<b>Mean (scale 1-10)</b>	<b>SD</b>
Playing an instrument	2.24	2.5
Drawing, crafting, or painting	4.02	3.6
Dancing	4.55	3.5
Singing	4.58	3.6
Attending a theatre or dance performance	4.70	2.5
Attending a sporting event	4.71	2.5
Attending a concert	5.36	2.3
Attending a museum or art gallery	5.83	2.6
Going to the cinema	6.45	2.0
Reading	7.77	2.0
Listening to the radio	7.78	2.0
Watching television	7.92	1.6
Listening to music	7.94	1.5

**3.3.3 Outcome Measures**

The present study measured three dependent variables including *loneliness (De Jong Gierveld Loneliness Scale 6-Item Short Form)*, *quality of life (Quality of Life – Alzheimer’s Disease)*, and *depression (Geriatric Depression Scale Short Form)*. Table 13 displays summary statistics for each scale. This section will describe the dependent variables and the statistical procedures used to test assumptions in preparation for correlation and regression model analysis.

Table 13

*Outcome Measures: Validated Scales*

Scale	n=	Mean	SD	Scale
De Jong Gierveld Loneliness Scale	111	3.08	1.3	0-6
Geriatric Depression Scale	108	5.69	2.7	0-15
Quality of Life – Alzheimer’s Disease	106	29.38	5.1	0-39

**Summary of Pearson Product-Moment Correlations among Outcome Variables.**

Correlations were run comparing results for loneliness, depression, and quality of life. Full results are displayed in Table 14. All relationships among outcome variables were found to be significant. High positive correlation was found between loneliness and depression,  $r(123) = .63$ ,  $p < .001$ . Strong negative correlations were measured between loneliness and quality of life,  $r(123) = -.50$ ,  $p < .001$ , and loneliness and quality of life and depression,  $r(123) = -.54$ ,  $p < .001$ .

Table 14

*Pearson Product-Moment Correlations of Mini-Mental State Exam Score and Outcome Measures*

Medium	De Jong-Gierveld Loneliness Scale	Quality of Life – Alzheimer’s Disease	Geriatric Depression Scale
De Jong-Gierveld Loneliness Scale	1	-.50**	.63**
Quality of Life – Alzheimer’s Disease		1	-.54**
Geriatric Depression Scale			1

Note. \*\* $p < .01$ .

**Summary of Hierarchical Regression Analysis for Variables Predicting Outcome Measures.** A series of 3-stage hierarchical regression analyses were conducted with the 3 outcome measures including De Jong-Gierveld Loneliness Scale (Tables 15-17), Quality of Life – Alzheimer’s Disease (Tables 18-20), and Geriatric Depression Scale (Tables 21-23) as

dependent variables. All models controlled for age, gender, level of education, number of cohabitants, and length of stay. For each dependent variable, past-year cultural activity was entered in the second model, life course arts activity was entered in the third model.

**3.3.3.1 De Jong-Gierveld Loneliness Scale.** Loneliness scores were measured for 111 participants. Mean loneliness score was 3.08 (SD = 1.28) with a skewness of .34 and kurtosis of .18. Individual scores greater than or equal to 2 were counted as indicative of loneliness (Vangelisti & Perlman, 2006). According to this cut-off point, 91% of participants were measured to be lonely. For analysis, missing variables for outcome measures were filled in using the mean value.

*Regression* Cumulative current activity is significantly associated with lower levels of loneliness ( $\beta = -.30$ ,  $t = -3.45$ ,  $p = .001$ ). The predictive value of cumulative current activity did not change significantly with the addition of covariates. Full regression results for variables predicting loneliness can be found in Table 15. Sensitivity analyses were performed separating current engagement into passive and active engagement categories and can be found in Tables 16 and 17. Active engagement was not found to be significantly associated with loneliness. Passive current engagement ( $\beta = -.25$ ,  $t = -2.73$ ,  $p < .01$ ) on its own is associated with lower loneliness scores, although a slight weaker effect was found with passive engagement only. The addition of past-year cultural engagement and life course activities did not significantly change the model. This indicates that current activity is beneficial for loneliness regardless of past-year cultural engagement or life course experience of the arts.

Table 15

*Multiple regression analysis of current engagement and loneliness (N = 121)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Activity	-.30**	.09	.001	[-.47, -.13]	.21	3.21**
Model 2	Current Activity	-.30**	.09	.001	[-.47, -.12]	.23	2.67
	Past-Year Activity	-.15	.10	.11	[-.32, .03]		
Model 3	Current Activity	-.29**	.09	.001	[-.46, -.11]	.23	.72
	Past-Year Activity	-.13	.09	.16	[-.31, .05]		
	Life Course Activity	-.08	.09	.40	[-.26, .10]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

\*\* $p < .01$

*Sensitivity Analysis*

Table 16

*Multiple Regression Analysis of Current Active Engagement and Loneliness (N = 121)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Active Engagement	-.11	.09	.25	[-.34, .12]	.13	1.88
Model 2	Current Active Engagement	-.09	.09	.34	[-.27, .09]	.15	2.45
	Past-Year Activity	-.15	.09	.12	[-.33, .03]		
Model 3	Current Active Engagement	-.05	.10	.59	[-.25, .15]	.16	.74
	Past-Year Activity	-.13	.10	.17	[-.33, .07]		
	Life Course Activity	-.09	.10	.39	[-.29, .11]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

Table 17

*Multiple Regression Analysis of Current Passive Engagement and Loneliness (N = 120)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Passive Engagement	-.25**	.09	.007	[-.43, -.07]	.18	2.68**
Model 2	Current Passive Engagement	-.24**	.09	.008	[-.42, -.06]	.20	3.36
	Past-Year Activity	-.17	.09	.07	[-.35, .01]		
Model 3	Current Passive Engagement	-.24**	.09	.007	[-.42, -.06]	.22	1.66
	Past-Year Activity	-.14	.09	.13	[-.32, .04]		
	Life Course Activity	-.12	.09	.20	[-.30, .06]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender

\*\*p < .01

**3.3.3.2 Quality of Life – Alzheimer’s Disease.** Quality of life scores were measured for 106 participants. The mean Quality of Life – Alzheimer’s Disease score was 29.38 (SD = 5.14) with a skewness of .21 and kurtosis of -.10. For analysis, missing variables for outcome measures were filled in using the mean value.

*Regression* No engagement with the arts were found to be predictive of quality of life, including current activity, past-year cultural engagement, or life course engagement. Despite

current activity having a statistically significant  $\beta$  value, none of the models fit significantly. This indicates a high variability in the data from which no significant association can be concluded. Full regression results for variables predicting quality of life can be found in Table 18.

Table 18

*Multiple Regression Analysis of Current Activity and Quality of Life (N = 121)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Activity	.20*	.09	.04	[.01, .38]	.13	1.82
Model 2	Current Activity	.20*	.09	.04	[.01, .37]	.15	2.76
	Past-Year Activity	.15	.09	.10	[-.03, .34]		
Model 3	Current Activity	.19*	.09	.04	[.01, .37]	.15	.07
	Past-Year Activity	.16	.10	.10	[-.03, .35]		
	Life Course Activity	-.03	.10	.79	[-.22, .17]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

\* $p < .05$

*Sensitivity Analysis* Sensitivity analysis separating active and passive current engagement found no significant separate effects.

Table 19

*Multiple Regression Analysis of Current Active Engagement and Quality of Life (N = 121)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Active Engagement	.10	.09	.29	[-.08, .28]	.10	1.40
Model 2	Current Active Engagement	.08	.09	.41	[-.10, .26]	.12	2.56
	Past-Year Activity	.15	.10	.11	[-.05, .35]		
Model 3	Current Active Engagement	.09	.10	.36	[-.11, .29]	.12	.15
	Past-Year Activity	.16	.10	.10	[-.04, .36]		
	Life Course Activity	-.04	.11	.70	[-.26, .18]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

Table 20

*Multiple Regression Analysis of Current Passive Engagement and Quality of Life (N = 120)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Passive Engagement	.17	.09	.08	[-.01, .35]	.12	1.6
Model 2	Current Passive Engagement	.16	.09	.08	[-.02, .34]	.15	3.56
	Past-Year Activity	.18	.09	.06	[.00, .36]		
Model 3	Current Passive Engagement	.16	.09	.08	[-.02, .34]	.15	.00
	Past-Year Activity	.18	.10	.07	[-.02, .38]		
	Life Course Activity	.01	.10	.95	[-.19, .21]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

**3.3.3.3 Geriatric Depression Scale.** Depression scores were measured for 108 participants. The mean Geriatric Depression Scale score was 5.69 (SD = 2.70) with a skewness of .61 and kurtosis of .18. Participants who scored from 0 to 5 were considered not depressed, and participants who scored 6 and above were considered depressed. According to this cut-off point, 47.2% of participants are considered depressed. For analysis, missing variables for outcome measures were filled in using the mean value.

*Regression* Neither current activity nor any additional predictors were significantly associated with variation in Geriatric Depression Scale score. Full regression results can be found in Table 21.

Table 21

*Multiple Regression Analysis of Current Activity and Depression (N = 121)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Activity	-.15	.09	.11	[-.03, .04]	.08	1.12
Model 2	Current Activity	-.15	.09	.13	[-.33, .04]	.10	1.16
	Past-Year Activity	-.122	.10	.21	[-.31, .07]		
Model 3	Current Activity	-.14	.10	.14	[-.33, .05]	.10	.29
	Past-Year Activity	-.11	.10	.26	[-.31, .08]		
	Life Course Activity	-.05	.10	.59	[-.25, .14]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

*Sensitivity Analysis* Sensitivity analysis separating active and passive current engagement found no significant separate effects.

Table 22

*Multiple Regression Analysis of Current Active Engagement and Depression (N = 121)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Active Engagement	-.18*	.09	.05	[-.36, -.001]	.09	1.27
Model 2	Current Active Engagement	-.17	.09	.08	[-.35, .01]	.10	1.19
	Past-Year Activity	-.11	.10	.28	[-.31, .09]		
Model 3	Current Active Engagement	-.17	.10	.10	[-.37, .03]	.10	.00
	Past-Year Activity	-.11	.10	.29	[-.31, .09]		
	Life Course Activity	-.001	.11	.99	[-.22, .22]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

Table 23

*Multiple Regression Analysis of Current Passive Engagement and Depression (N = 120)*

	Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1	Current Passive Engagement	-.04	.10	.71	[-.24, .16]	.06	.83
Model 2	Current Passive Engagement	-.03	.10	.73	[-.23, .17]	.09	2.5
	Past-Year Activity	-.15	.10	.11	[-.35, .05]		
Model 3	Current Passive Engagement	-.03	.10	.73	[-.23, .17]	.09	.73
	Past-Year Activity	-.14	.10	1.7	[-.34, .06]		
	Life Course Activity	-.09	.10	.40	[-.29, .11]		

*Note.* All models control for Education, Length of Stay, Number of Cohabitants, Age, and Gender.

### **3.4 Discussion**

This is the first cross-sectional survey presenting data on how hospital inpatients with dementia engage with the arts and how this engagement relates to psychosocial health and wellbeing outcomes. Results were presented for demographic variables, individual engagement with the arts, and measures of loneliness, depression, and quality of life. Regressions were run investigating the relationship between engagement with the arts and wellbeing outcomes of interest.

#### **3.4.1 Cognition**

The mean MMSE score measured was 17.48 (SD = 3.52). This comes very near the cut-off point where scores 10 to 17 are considered moderate progression and scores 18 to 23 are considered mild progression. This largely matches other studies of hospital inpatients with dementia, as reviewed in Chapter 1 of this thesis. Most studies included in the systematic literature review measured mild-to-moderate progression. Mean baseline MMSE scores were measured at 20.5 by Berger et al (2004), 18.3 by Bruer, Spitznagel, and Cloninger (2007), 24.6 by Hattori et al (2011), 17.5 by O'Rourke et al (2011), 23 by Wu and Koo (2015), and 12.9 by Van de Winckel et al (2002). Of the studies included, only Cheong et al (2016) studied patients with severe dementia, with a mean MMSE score of 6.

#### **3.4.2 Engagement with the arts.**

This is the first cross-sectional study measuring the amount that hospital inpatients with dementia engage with the arts. Current arts engagement, past-year cultural engagement, and life course arts engagement were measured, and engagement levels were found to be lower than older populations in other studies. Rajan and Rajan (2017) reported past-year cultural engagement among older adults age 55 years and older in the United States. Among them, 68.7% attended cultural activities including a museum or gallery, arts or crafts fair, live performance, or cinema. This result is very different from past-year cultural engagement among the participants in the present study, where the cinema, the most commonly attended cultural activity, was only attended by 25.2% of participants. This difference might be attributable to several factors. First, older adults in the Health and Retirement Study were age 55 and older while participants in the present study were age 65 and older. Second, cultural engagement is protective against dementia (Fancourt, Steptoe, & Cadar, 2018), so participants in the present study are likely to have engaged with the arts less than members of the general population. Third, the adults in the present study were hospital inpatients with

dementia who might be more likely to have been infirmed in the past year. Rajan and Rajan (2017) reported that older adults who participated in cultural activities were less likely to have physical limitations interfering with activities of daily living. No causality was attributed, but older people living with full mobility could be more able to engage with the arts than hospital patients with dementia who might place similar importance on the arts. This might explain the low levels of active artistic engagement among participants in the present study. Moss and O'Neill (2014), in a qualitative study, found that hospital admittance has the potential to reduce engagement with the arts, including when the arts are rated as important in their lives. Finally, the Health and Retirement Study was based in the United States where cultural practices are different to those of central London.

Ascribing meaning to engagement with the arts was correlated most often with life course experience with the arts compared with current activity and past-year cultural engagement. This speaks to the enduring nature of life course activities, indicating that no longer participating in an activity does not necessarily decrease meaningfulness of the activity in older age or in dementia.

While study participants reported low levels of past-year activity, they reported high levels of current engagement with passive activities including reading, watching television, and listening to music and the radio. This may be due to the relative financial and practical difficulty of actively engaging with those activities, considerations which have distinguished between "highbrow" and "lowbrow" pursuits (Levine, 1990). Toepoel (2011) has considered participation and satisfaction between different levels of cultural events, finding that older adults are more likely to engage in rarefied cultural activities, while people who engage in more common activities are more likely to be socially integrated. Among the more common activities identified by Toepoel was attending the cinema, which more participants in the present study reported doing in the past year than any other activity. Other studies have investigated outcomes from engaging in more frequent, easily attainable activities, reporting that small constant pleasures are better for wellbeing than rare, expensive trips (Dunn et al., 2011). This finding may be summarised by Benjamin Franklin, who believed that "happiness consists more in the small conveniences." This finding could have implications for the planning of arts in health activities for people with dementia. While study participants reported moderate levels of passive arts engagement, current active engagement was low. This leaves scope for structured arts activities to provide active arts engagement for hospital inpatients with dementia.

### 3.4.3 Mean values of outcome measures.

**Loneliness.** Among study participants, 91% were measured to be lonely. This is a very high rate, especially considering surveys of people living with dementia in other settings. An Alzheimer's Society survey reported that 39% of people with dementia in England, Wales, and Northern Ireland felt lonely, compared with 24% of the general public over age 55. Of those who lived alone, 62% reported feeling lonely. However, elements of the hospital setting may be associated with higher rates of loneliness than in home or community settings.

The scale cut-off score may also have influenced the high rate of loneliness reported. For analysis in the present study, a cut-off score of 2 was used to indicate loneliness, as recommended by the scale developers (Jong-Gierveld & Tilburg, 1999). However, this cut-off score has been criticised for being too liberal in its classification. Hansen and Slagsvold (2015) argued that its low threshold ignores nuanced categories of moderate and severe loneliness.

While number of cohabitants outside of hospital was associated with lower levels of loneliness, hospital environments have previously been linked to increased loneliness. A convenience sample survey in the United States found a correlation between loneliness and number of emergency department visits (Geller, Janson, McGovern, & Valdini, 1999). Loneliness has implications for recovery in hospital. It has been linked to the perpetuation of poor quality sleep, which may then exacerbate loneliness. In hospital environments, noise and light hamper sleep, potentially contributing to effects of loneliness (Hawkey & Cacioppo, 2010).

**Quality of Life.** The present study reports an average Quality of Life – Alzheimer's Disease score of 29.38, a finding closely in line with a finding of 29.32 among community-dwelling people with dementia in a Brazilian study (Inouye, Pedrazzani, Pavarini, & Toyoda, 2010). This average is lower than a clinical trial for patients with dementia, where the baseline Quality of Life – Alzheimer's Disease score was measured at 37. However, this population had a higher average MMSE score of 22.5 (Kahle-Wroblewski et al., 2016). The similarity in quality of life scores between community and hospitalised populations may be due to the stability of measured elements. The Quality of Life – Alzheimer's Disease scale includes items for relationships with family and type of living arrangements – factors that are

less likely to change during a period of hospitalisation than mood as measured by the De Jong-Gierveld Loneliness Scale and Geriatric Depression Scale.

The present study reported low quality of life among hospital inpatients with dementia, indicating the importance of addressing quality of life and leaving scope for its improvement. Albrecht and Devlieger (1999) have proposed a model that describes quality of life as a balance of physical, mental, and spiritual factors. Applied to the present study, the physical factor is compromised by hospitalisation, and the mental factor is compromised by dementia. The spiritual factor for hospital inpatients with dementia might still balance out the physical and mental factors. Albrecht and Devlieger described this balance as the “disability paradox” in which participants with a range of functional disabilities often reported a high quality of life. Future interventions might investigate this disability paradox in efforts to improve quality of life for hospital inpatients with dementia.

**Depression.** The present study reported 47.2% of participants above the threshold for mild depression, according to the Geriatric Depression Scale cut-off point of 5. This rate compares with the upper limit of prevalence reported for hospital inpatients with other morbidities. A survey of 460 patients age 60 and over without dementia found a range of 24% to 46% of depression prevalence, including minor and major depression (Koenig, George, Peterson, & Pieper, 1997). This range was attributed to differing diagnostic strategies, including “inclusive, etiologic, exclusive-inclusive, exclusive-etiologic, substitutive-inclusive, and substitutive-etiologic.” A survey of hospital inpatients two months post-stroke diagnosed 32% with minor or major depression (Morris, Robinson, & Raphael, 1990). A survey of patients hospitalised with congestive heart failure found 51% scoring above the cut-off for depression on the Beck Depression Inventory (Jiang et al., 2001).

Rates of depression among people with dementia are generally found to be lower in community settings. Although an Alzheimer’s Society report on people with dementia in England, Wales, and Northern Ireland found that 63% felt anxious or depressed, this survey defined a much broader category of anxiety or feelings of depression. Some existing research has measured rates of depression and dementia, but not comorbid rates. A cross-sectional study of elderly London residents found a 15.9% rate of depression and a 4.7% rate of dementia. In this survey, those screened for depression were more likely to have recently visited acute care or the general practitioner (Livingston, Hawkins, Graham, Blizard, & Mann, 1990). A case control study of older people in Houston, Texas found higher rates of both depression and dementia in those who were considered victims of self-neglect (Dyer,

Pavlik, Murphy, & Hyman, 2000). While self-neglect was not measured in the present study, it may have been a confounding factor as hospitalisation and readmission have been reported to be higher in elders who self-neglect (Dong & Simon, 2015; Dong, Simon, & Evans, 2012). A survey of 1080 elderly residents of Zaragoza, Spain found that 5.5% lived with dementia, 25.4% of whom reached “case level” of depression according to the Geriatric Mental State Schedule (Lobo, Saz, Marcos, D  a, & De-la-C  mara, 1995).

By asking how respondents have felt over the past two weeks, the Geriatric Depression Scale assumed there have been no major life changes during the period. However, seventy-eight respondents (63.4%) were admitted to hospital within two weeks prior to participation in this study. The Geriatric Depression Scale has been validated for use with people with MMSE scores over 10 (Conradsson et al., 2013), so recall over the past two weeks should not be in question. Therefore, most respondents would have ostensibly portrayed their depression status for their home life. However, the magnitude of environmental and activity change occurring upon admission to hospital may have distorted this, so depression results might be more accurately interpreted as if participants have been in hospital for two weeks.

#### **3.4.4 Associations between cognition and independent and dependent variables.**

**Arts engagement and cognition.** Current engagement with passive activities was found to be significantly higher in participants with mild progression than those with moderate progression of dementia. This finding echoes previous studies that have examined cultural engagement among older people and people with dementia in community settings. Fancourt and Steptoe (2018), in a 10-year follow-up study of 3,445 participants, found that cultural engagement in older age were linked to lesser decline in cognition. Additionally, cultural engagement was found to be associated with decreased risk for the development of dementia (Fancourt, Steptoe, & Cadar, 2018). In research on the impact of broader activities, individual social engagement and participation in leisure activities have been linked with reduced risk for developing dementia (Fabrigoule et al., 1995; Wang, Karp, Winblad, & Fratiglioni, 2002; Zhou, Wang, & Fang, 2018). Therefore, people who have developed dementia are less likely to be socially and culturally engaged than those who have not. The present study found that participants with mild dementia were significantly more engaged in passive activities than those with moderate progression of dementia, presenting evidence that cognitive decline may be associated with decreased engagement with the arts through the

progression of dementia. Further research into arts engagement in severe dementia would extend this finding.

**Quality of life and cognition.** While quality of life was not found to be associated with measures of engagement with the arts, it was the only outcome measure significantly correlated with cognitive decline with a moderate correlation of .19 ( $p = .04$ ). This association echoes findings from a longitudinal study of care home residents in the UK, which found links between change in quality of life and mood and cognition changes (Hoe et al., 2009). In another study measuring the effects of cognitive stimulation therapy, improvement in quality of life improved in line with cognition (Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006). However, other studies have not found a similar result linking cognition and quality of life. Selwood et al. (2005) found no correlation between quality of life and cognition. They did, however, report negative correlations between quality of life and anxiety. The impact of engagement with the arts on anxiety will be examined in Chapter 5 of this thesis.

**Depression and cognition.** The present study reported no association between depression and progression of dementia. However, existing literature has described a more complex relationship between depression and dementia. Depression has been researched as a risk factor for (Jorm, 2001) and symptom of (Mulyala & Varghese, 2010) dementia. A small-scale longitudinal study ( $n=105$ ) found that 21.9% of people enrolled progressed from MCI to dementia over 3 years. The paper posited that depressive symptoms may be a risk factor for this progression (Gabryelewicz et al., 2007), a finding that has implications for hospital care for dementia considering the high rates of depression reported. Longer term care may be more effective for addressing depression in dementia. A longitudinal study of 201 care home residents for memory impairment found a gradual decline in depression rates from the time of admission (Payne et al., 2002). This may indicate effective screening and treatment for depression in long-term care, an implication that can inform hospital services for patients with longer lengths of stay. Cohort studies of Swedish adults have considered a physiological mechanism for the effect of cultural engagement on depression. By seeking out an enriching environment and experience, neural receptors in the hippocampus might be augmented, thereby lowering depression (Johansson, Konlaan, & Bygren, 2001; Konlaan, Bygren, & Johansson, 2000).

The present study did not distinguish between different forms of dementia, a practice common in research in settings not dementia-centred such as a general hospital. A study

considering the diagnostic criteria of dementia and depression in older age suggests that detailed comparison of population rates require more nuanced measurements and diagnoses (Kay et al., 1985). However, previous research has compared rates of depression between dementias. Depression was found in 19% of people with vascular dementia versus 8% of those with Alzheimer's disease. Rates were higher for those with severe dementia (Ballard et al., 2000).

**Loneliness and cognition.** The present study did not find loneliness to be associated with severity of progression of dementia. However, past research has found that loneliness increased risk for cognitive decline and the development of Alzheimer's disease (Wilson et al., 2007). A further link between loneliness and dementia has been explored in physiological functioning. Cardiovascular disease throughout the life course is linked to loneliness (Hawkley & Cacioppo, 2010) and is a significant risk factor for dementia. Of the literature reviewed, no literature linked loneliness to further progression after onset of dementia.

#### **3.4.5 Associations among outcome measures**

Significant correlations were reported among all three outcome measures. Loneliness was negatively correlated with quality of life and positively associated with depression. Across the life course, previous research has reported links between loneliness and depressive symptoms. For example, a cross-sectional and longitudinal analysis of American middle-age and older adults reported associations between loneliness and depressive symptoms (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006). Among demographic variables measured by the present study, number of cohabitants was found to correlate negatively with loneliness. This potentially shows that the hospital environment may not be a primary driver of loneliness - those likely to be socially lonely at home will remain socially lonely in hospital, but those living with a spouse or children will feel less lonely even if admitted to hospital.

Quality of life was strongly correlated with depression among study participants. Fuh and Wang (2006) report similar findings in a cross-sectional study of hospital inpatients and their caregivers. They found that depression most strongly predicted quality of life for the person living with dementia. Fuh and Wang (2006) also found that caregiver distress predicted gaps between patient and caregiver quality of life. Banerjee et al. (2006) identified other correlates with quality of life while investigating potential proxy measures. They found that decreased quality of life tracked with behavioural and psychological disturbance as

measured by the neuro-psychiatric inventory. While carer mental health and age of dementia onset correlated with quality of life, these effects were dampened when assessed by multivariate models.

### **3.4.6 Regression analysis**

Regression analysis found that current engagement with the arts is associated with lower levels of loneliness, suggesting the importance of current artistic engagement to the psychosocial wellbeing of hospital inpatients with dementia. Additionally, this finding is independent of past-year and life course engagement with the arts, which shows that previous experience does not serve as a barrier to the benefits derived from current engagement with the arts.

This finding provides a basis for the appropriateness of structured arts activities for all hospital inpatients with dementia. Furthermore, the social aspect of structured arts activities has the potential to enhance the effect of artistic engagement on loneliness. The social isolation accompanying dementia is well documented around the world, and some research has suggested that healthcare providers make up the most important social networks of people with dementia (Borge, Martinsen, Ruud, Watne, & Friis, 1999). Considering the clinical demands placed on hospital staff across the NHS, funding staff for social and pastoral support could ease the burden of clinical staff burnout and loneliness in hospital inpatients with dementia.

Regression analysis in the present study found no association between quality of life and engagement with the arts. However, Särkämö et al. (2014) found that listening to music had the potential to improve quality of life for people with dementia. This randomised controlled trial included patient-carer dyads and bespoke music listening sessions over 6 months, factors potentially impacting quality of life in that individual engagement with the arts may not (Särkämö et al., 2014). Correlational analysis in the present study echoes this finding, showing that past-year cultural engagement was correlated with quality of life. This finding should be met with caution as no significant association was found in a hierarchical regression analysis. Andersen et al. (2004), in an interview-based survey, found that quality of life was most predicted by ability to perform activities of daily living, a finding that indicates quality of life might be higher in a home environment rather than a hospital where activities of daily living are disrupted as a matter of course.

Regression analysis performed for this study found no association between life course or past-year cultural engagement with the arts and outcome variables of loneliness, depression, and quality of life. This diverges from findings reporting better health outcomes for older adults who have engaged with the arts in the past. Rajan and Rajan (2017) found that older adults who engaged in cultural activities reported better health outcomes. The relationship was somewhat linear, with people who were more frequently engaged with arts and culture reporting better health. The divergent results could be attributable to one of several factors. For one, participants in the present study might report worse health outcomes due to their admittance to hospital. The substantially different population of the present study may have been ill for a long time, thereby decreasing their potential to be engaged with the arts. Another potentially important difference is the presence of dementia in this study's population, which could have affected their memory about past engagement with the arts or cultural activities. Further study into patterns of engagement and health outcomes in community settings might explicate these differences.

#### **3.4.7 Additional relationships between arts engagement and outcome measures.**

By separating current engagement into active and passive categories, more can be learned about specific effects on outcome measures. Sensitivity analysis revealed that passive engagement including watching television and listening to the radio was associated with lower levels of loneliness. Among passive activities, the link between television viewing and loneliness has been studied at length, with no strong consensus yet reached. Studies of people without cognitive impairment have reported links between television viewing and increased loneliness but have not explored causal relationships (Finn & Gorr, 1988; Perse & Rubin, 1990). Other research has argued that social belonging can be fostered through simulated relationships with characters on preferred television programmes. This "social surrogacy hypothesis" was investigated through a series of studies showing that even thoughts about a favourite television show can buffer moods and self-esteem (Derrick, Gabriel, & Hugenberg, 2009). This effect has been explained by citing the human tendency to see relationships where they might not objectively exist. Hawkley and Cacioppo (2010) compared relationships between viewers and television characters to the relationship between author and reader or people and God. The present study does not support this hypothesis fully as it aggregates passive activities such as reading and listening to the radio with watching television.

### 3.4.8 Strengths and Limitations

Recruitment for this study was more difficult than originally anticipated. Assuming 20 minutes per interview, the original study protocol planned to recruit 10 participants per recruitment day. However, many questionnaire batteries took much longer to administer. This was due to the conversational approach taken to keep participants engaged and answering questions freely. For participants who answered questions in a matter-of-fact manner, the questionnaire battery lasted about 15 minutes. However, for many participants, the questionnaire battery lasted between 30 and 45 minutes. Additionally, finding willing and able participants was unexpectedly difficult. Reasons for slow recruitment included clinician and visitor priority and narrow visiting hours made narrower by unpredictable tiredness and unwillingness to participate. Finally, the study protocol did not anticipate the turnover rate of inpatients with dementia at the study site. With an average length of stay of 28.6 days, many beds in the dementia wards remained occupied by inpatients who had already participated in the study. Because of the unpredictable nature of these delaying factors, further recruitment help from clinical staff was deemed to be unhelpful. However, the addition of another recruiting site would have been helpful for days when all potential participants had already been approached.

A major limitation of the present study is in the conception of frequency of arts engagement. Because no existing scale was found to quantify current levels of engagement with the arts among patients with dementia, a bespoke scale was created. However, its coding has not been validated. Another limitation of the questionnaire is its reliance on the memory of participants. Because they were screened for mild- to moderate progression of dementia, their recall of past-year cultural engagement and life course experience with the arts may have been compromised. Additionally, dementia could affect executive function, thereby presenting a potential bias on outcome measures scoring. This is possible despite previous use of these outcome measures with people with dementia.

Despite the potential biases listed above, it is still possible that recruitment skewed towards more mentally and psychologically healthy patients. Potential participants were approached based on their demeanour as assessed by ward staff and myself. Inpatients who seemed likely to engage in conversation were approached first. Potential participants who were too tired or not in the mood to be interviewed may have had worse outcomes on measures of loneliness, depression, and quality of life.

Recruitment and interviewing took place at the hospital bedside. For most interviews, the setting was in a bay composed of 6 beds. This was done to reduce time, resources, and participant energy needed to move the interview to a more private space. When possible, a dividing curtain was drawn to increase privacy. It is possible a more private interviewing location could have solicited different responses.

#### **3.4.9 Recommendations for future research.**

Considering the social withdrawal common in those who develop dementia, future studies should consider rates of cultural participation among people with dementia across settings. There is evidence that loneliness attenuates the ability to direct attention towards effortful tasks (Hawkley & Cacioppo, 2010). Considering this study's findings linking passive engagement with decreased loneliness, future research could investigate the potential of passive engagement with the arts as a precursor to active, more effortful engagement with the arts.

Further research would benefit from considering more diverse arrays of cultural engagement across the world. This could outline the broader context of ways in which people engage with the arts and associated personal and cultural benefits. In a broad survey of engagement with the arts and its effect on health across various populations, Rebecca Gordon-Nesbitt (2015) outlined the state of research. This review noted the concentration of studies in the Nordic region, citing data collection and availability standards in Scandinavia as the primary reason for the level of research conducted. This research, however, mostly used mortality as the main outcome measure. A large-scale survey of adults in Western Australia measured engagement with the arts and its effect of wellbeing. Participants with high-levels of arts engagement over the past year had significantly better mental wellbeing, as measured by the Warwick-Edinburgh Mental Wellbeing Scale (Davies, Knuiiman, & Rosenberg, 2016).

A survey of 4,278 Swedish caregivers over age 75 found that loneliness significantly predicts low quality of life (Ekwall, Sivberg, & Hallberg, 2005). This finding aligns with this study's reported negative correlation between loneliness and quality of life. Considering the links found between loneliness and engagement with the arts, future studies might explore how interventions aimed at decreasing loneliness can impact longer-term quality of life.

Cross-sectional studies such as the present study assess correlations and bi-directional links between outcomes, but causal relationships cannot be determined. Hyypä (2010)

recommended undertaking prospective cohort studies that measure demographic variables and population-level outcomes in order to more rigorously assess the causal relationship between engagement with culture and the arts and public health outcomes. In order to illuminate subjective perspectives on reasons for and effects of arts engagement, Gordon-Nesbitt (2015) recommends further qualitative research.

The present study also highlights the need for methodological diversity in future research. The major limitation described above regards the reliance on recall for participants with dementia. Intervention studies measuring qualitative and quantitative data in the moment of arts engagement would be able to better link the process of arts in health activities with their impacts on the lived experience of dementia in hospital settings.

The present study found that current engagement with passive activities was associated with lower levels of loneliness. This may be contrasted with a finding by Queen et al. (2014), who found that older adults who were lonely engaged in similar activities to those who were not lonely. Lonely people, however, were found to be more likely to engage in these activities alone, suggesting that doing activities with others is associated with less subjective social isolation. This individual engagement with the arts sits at one pole of models of arts in health that include continua between individual and social elements of engagement with the arts (Aldridge, Franco, Ruud, & Wigram, 2001; MacNaughton, White, & Stacy, 2005). Participation in group art activities introduces the element of social engagement alongside artistic engagement. The investigation of this interaction would build upon and be compared with the research on solitary engagement with the arts.

### **3.4 Conclusion**

The present study found that current individual engagement with the arts is associated with lower levels of loneliness, suggesting the importance of current engagement with the arts for the psychosocial wellbeing of hospital inpatients with dementia. This association is not affected by past experience, indicating that engagement with the arts is beneficial for everyone regardless of background. However, low levels of current engagement with the arts were also reported, calling for the implementation of structured arts activities to reduce levels of loneliness and potentially improve psychological health and wellbeing.

The present study also found that loneliness had a significant positive correlation with depression and a significant negative correlation with quality of life. By addressing the high levels of loneliness found in hospital inpatients with dementia, low average quality of life and

high prevalence of depression might also be impacted. These findings pave the way for the evaluation of structured group art activities for hospital inpatients with dementia.

Considering the growing body of evidence for the effectiveness of arts in health interventions for the lived experience of dementia, group art activities were implemented at Chelsea & Westminster Foundation Trust. Two further studies were undertaken for this thesis: a focused ethnographic study and a 3-arm controlled study. This use of mixed methods will investigate the experience of these programmes and their impact on health-related outcome measures. Rather than focusing on outcomes of interest for individuals, such as loneliness, these studies were concerned with outcome measures that had significance within group environments. Therefore, the research questions for these mixed methods studies were

- How would traditional and digital versions of arts in health programmes compare in affecting anxiety in hospital inpatients with dementia?
- How would traditional and digital versions of arts in health programmes compare in affecting wellbeing in hospital inpatients with dementia?
- How would traditional and digital versions of arts in health programmes compare in engaging hospital inpatients with dementia?

## CHAPTER 4 FOCUSED ETHNOGRAPHIC INVESTIGATION

### 4.1 Part One: Study background and methodology

#### 4.1.1 Introduction

The Introduction and Chapter 1 of this thesis described the state of dementia in hospital environments and the potential for arts in health activities to address health and wellbeing of hospital inpatients with dementia. Chapter 2 then described the methodological strategy undertaken for this thesis, focusing on the strengths of mixed-methods when applied to arts in health research. Chapter 3 detailed a cross-sectional survey of 123 hospital inpatients with dementia, exploring the relationships between individual, unprompted engagement with the arts and outcome measures for loneliness, depression, and quality of life. The most important finding of that study related to loneliness, reporting links between lower levels of loneliness and individual engagement with passive activities such as reading, watching television, and listening to music and the radio. This finding has implications for broader outcomes considering that loneliness has been linked with accelerated progression of frailty, cognitive decline, and depression in dementia (Gale, Westbury, & Cooper, 2017).

While individual engagement with the arts in the hospital bed may have promising implications for loneliness, engagement with the arts in a group setting presents further opportunities for socialisation, group learning, and decreased self-consciousness. Holden and Woods (1995) described group activities for people with dementia as being beneficial for “stimulation and self-care,” opportunities that may be missing from the hospital experience for patients with dementia. The addition of socialisation, creative collaboration, and change of environment are unique features to hospital art programmes that cannot be replicated through individual arts engagement in the hospital bed. The complex interplay among these factors would be difficult to assess with a standalone quantitative study, therefore a qualitative focused ethnographic account was undertaken to later triangulate results with a 3-arm controlled study.

#### 4.1.2 Ethnographic methodology

Closely tied to phenomenology, ethnography aims to understand the human perspective of complex systems and how individuals might make meaning through participating in those systems (Al-Busaidi, 2008). Built on a constructionist epistemology, ethnography emphasises the importance of the lived experience. Coupled with quantitative studies performed for this thesis, ethnography can contribute to a pragmatic mixed-methods

approach that benefits from both quantitative specificity and qualitative context. As described by Hammersley (1990), ethnography focuses on the meaning and motivation behind human actions rather than quantification through scales designed to measure those actions. Seen through this lens, this thesis considers quantitative and qualitative methods as necessary complements to each other. An ethnographic study can be useful for investigating the ways in which cultural practices of a subject are influenced and intertwined with therapies and technologies in an acute care setting (Prout, 1996).

The method used in the present study was defined by participating with, observing, and conversing with participants in a naturalistic environment. As a method of qualitative research, the ethnographic approach has an advantage defined by its broad scope. By focusing on depth of description and detail, the ethnographic approach will provide a rich portrait of the environment in which these arts programmes exist. This “thick description” can be produced after being embedded in the patient activity environment for many hours (Reeves, Kuper, and Hodges 2008). While the present study included many hours of embedded observation, it did not reach the level of time committed to full ethnographic studies. Furthermore, the present study was conceived as the qualitative component of a pragmatic study using mixed methods. Therefore, the present study is considered as an focused ethnographic study.

The ethnographic approach is also useful for making sense of the multiple activities and actors involved in complex organisational systems. When used within healthcare settings, it can describe the organisation of healthcare services and interactions between multiple services occupying the same space (Savage, 2000). Applied to this research, this could mean describing the interactions between occupational therapists, nurses, and physicians on the ward throughout the day, identifying the personnel most likely to direct patients to available arts in health programmes, and identifying times and spaces most amenable to hosting programmes on the ward.

The ethnographic approach allows for a variety of data collection methods including focus groups, observation, directed conversation, and structured interviews (Al-Busaidi, 2008). Considering the unpredictable, frenetic acute care setting of this research, this focused ethnography used participant observation as its primary data source. Semi- and un-structured interviews were also conducted with patients, clinical staff, and art programme leaders. These interviews were conducted throughout the data collection period. As themes and phenomena

were identified, later interviews aimed to further explicate and develop themes. This iterative process reflects the pragmatic stance of the research.

#### **4.1.3 Ethnography in hospitals**

Entire PhD theses have been conducted solely on ethnographies of hospital settings. While some have focused on clinical practice, including physician habitus, object use and record permanence (Hightower, 2010; Zhou, 2010), others have focused on the lived experience of inpatients (Ashencaen Crabtree, 2002). The depth of ethnographic observation, interviewing, and reporting in these theses spanned several years and institutions. While the present study's ethnographic observation period spanned 8 months, it only included 2 months of dedicated ethnographic observation before sharing focus with the 3-arm controlled study. The comparison with full ethnographic theses provided further basis for the present study to be considered as a focused ethnographic investigation to be seen through the lens of its relationship to the 3-arm controlled study to follow.

Hospitals provide challenging and engaging settings for ethnographic research. Diverse views on the role of hospitals in society have been expressed, alternatively as “a tight little island” (Coser, 1962) or as a microcosm of the society in which it is embedded (Zaman, 2005). The open nature of ethnography allows both of these viewpoints to be considered, however the pragmatic perspective of the present study focused on the immediate environment itself. While some hospitals are concerned mainly with chronic conditions or community care, many, including the study sites serve as acute care centres. The history of modern acute care hospitals has been described by the development of the biomedical model (Wade & Halligan, 2004), coming about by necessity as healthcare technologies and bureaucratic medical systems moved healthcare away from religious systems and the home-based care. Thus, the acute hospital has been identified as an institution that separates the ill from the non-ill (van der Geest & Finkler, 2004). Furthermore, the biomedical model has been challenged as insufficient for addressing mental health issues (Deacon, 2013) and for disregarding “social, psychological, and behavioural dimensions of illness” (Engel, 1989).

The role of the arts leader may subvert this biomedical dynamic by serving as a foil to the challenges to providing person-centred care in the modern biomedical model (Mazzotta, 2016; McGreevy, 2015). Rather, the arts programme leader seeks to facilitate individual expression by encouraging a collaborative, creative dynamic that aims to empower participants. In doing so, the arts programme leader's perspective might be better positioned

to explore and empathise with the patient's perspective. Furthermore, the arts programme leader works within the hospital bureaucracy. He or she must liaise with ward staff, visiting artists, and commissioners in order to produce a successful arts session. Therefore, broader factors such as hospital budgets, staffing, and use of space impact on the successful running of arts programmes. The interactions between patients, clinical specialists, administrators, and outside stakeholders such as hospital charities are complex and ever changing. This interplay is difficult to model and is therefore ideal for study using ethnographic methods (Finkler, Hunter, & Iedema, 2008).

Although the main research questions focus on the patient experience once engaged in the arts programmes, an understanding of the organisational context is valuable. In a PhD dissertation, Hatton (2016) used case studies to explore not only the arts for dementia care but the larger organisational structure surrounding the programmes. This allowed for a pragmatic consideration of the environment in which people with dementia were engaging with the arts, depicting a richer picture of the lived experience of dementia in care homes. The present study aims to do the same for the hospital setting.

An understanding of informal relationships and variables at the hospital ward level might inform the likelihood of arts in health programmes being adopted more widely in NHS and private hospitals in the UK. This can be especially true for arts in health programmes that use new consumer technologies. In a study of organisational innovation, Kimberly and Evanisko (1981) reported that "individual, organizational, and contextual variables were found to be much better predictors of hospital adoption of technological innovations than of administrative innovations." Greenhalgh and Swinglehurst (2011) argued for the use of ethnography to investigate the use and impacts of information and communications technologies, pointing out the fallacious assumption that information and communications technologies would be able to seamlessly transfer to new settings. The present study aimed to explicate the ways in which arts in health programmes, both traditional and digital, might be introduced to and adopted by a hospital ward. By shadowing the arts programme leader, I aimed to investigate the creative perspectives of patients as well as detail how the art programme leaders approach a session and navigate hospital bureaucracies.

#### 4.1.4 Background of the interventions researched

**Activity space and environment.** All arts programmes took place with patient groups of 2-10 people in ward day rooms, about 10 metres down the hall from the bed bays. Detailed information of the day room layout can be found in Section 2.4.3 and Figure 6 of this thesis.

**Study sites.** Data collection was carried out at two hospitals comprising a single NHS Foundation Trust.

**Hospital 1.** This hospital is situated on a main two-lane thoroughfare in an affluent area of London. Wards observed were all reserved for care for older patients.

These wards are situated on the third and fourth floors of the hospital and branch off of the main, open air atrium. The atrium has a glass ceiling that allows sunlight to stream in through the hospital. This exposes each ward to daylight from windows facing both the hospital exterior and the interior atrium. All day rooms have windows facing the atrium, allowing for a view up through the skylight and down into the hospital.

**Hospital 2.** This hospital is situated about 7 miles west of Hospital 1 in a quieter residential area of London. While arts programmes occurred in several wards in Hospital 1, group art activities took place at only one ward at Hospital 2. This was in the day room of one of the wards dedicated to older patients and care for frailty. The day room of this ward is the largest of any activity space observed across the trust, and it doubles as a discharge waiting room. Therefore, there were often other groups in the day room alongside the programme. These included patient families, discharged patients, and clinical staff on break. One wall of the day room is composed of windows looking out towards a park, adjacent to the River Thames and local botanical gardens.

**Programme design.** The digital and traditional art programmes were organised by a hospital charity employee and artist in charge of delivering the Care of Older People (COOP) programme at the NHS Foundation Trust. By the beginning of data collection for this study, this employee had been the lead organiser for 2 years. The hour-long sessions were loosely structured, beginning with an explanation by the programme leader before aiding each participant to the extent to which they are comfortable. The sessions included unstructured conversation throughout, and the end of the arts in health programmes were not often clearly defined. They did not always end for everyone at once. Rather, individual patients were brought back to their beds when they 1) finished their work early, 2) became tired, 3) became distressed, 4) had visitors or 5) were served a meal.

The COOP programme involved a wide array of arts in health activities, including visual art, music, creative movement, clay sculpture, reminiscence, gardening, flower arranging, storytelling, and poetry writing. While data collected for the present study included practitioner interviews with the creative movement and clay sculpture programme leaders, the participant observation and semi-structured interviews were focused solely on the group music and visual art groups. These sessions are described in detail below.

***Visual art group.*** Led by a hospital charity employee and head of the COOP programme, this hour-long art group took place around a table in the centre of the ward day room. The visual art group was scheduled to take place in Hospital 2 each Tuesday at 11:00 and Hospital 1 each Thursday at 14:00. The sessions took place on other wards at independently scheduled times and at less-regular intervals.

Each session included a group of 2-10 patient participants and began with casual conversation. The group leader asked about patient interest in art and painting, leaving space for participants to direct their own art group. Despite this, patients were usually happy to be told what to paint. Therefore, most sessions were based around a theme chosen by the programme leader. This usually centred on a nature theme using photographs or paintings as inspiration. In order to provide the potential for patients to connect with their surroundings, the art programme leader often used a print of an artwork hung in the hospital as a starting point for each programme, as shown in Figure 8. The leader began by giving broad directions such as “ok, let’s all start with a big blue sky.” Patients proceeded at their own paces, with the art programme leader or a volunteer aiding in the process as needed. Some participants stopped immediately unless they had personal attention from a volunteer or member of clinical staff.

***Digital visual art group.*** This art programme involved drawing and colouring on a tablet app. The digital art intervention was implemented for its potential to increase interest and engagement using a more colourful, versatile, novel object. The aim was for this to lead to a more productive, anxiety-lowering programme. Digital visual art groups were provided with tablets preloaded with a Brushes, a free painting application. Brushes features the ability to choose colours, line thickness, and line type in creating a digital artwork.

***Traditional visual art group.*** Participating in a traditional visual art programme involved painting, drawing and colouring on canvases. This group was provided with a small

rectangular canvas, pencils, paintbrushes, a mixing tray, and a variety of colours of acrylic paint.

*Group music.* Led by a hospital charity employee and music group leader, this hour-long, twice-weekly music session took place seated in a circle in the ward day room. Each session included a group of 2-10 patient participants. The group music sessions were scheduled to take place in Hospital 1 on Thursdays at 10:30. Group music programmes on other wards were scheduled at less regular intervals and only one at a time.

To begin the group music session, the music programme leader generally led a simple rhythm to be played in unison before building more complex, multi-part rhythms and melodies. Throughout the sessions, the group leader took care to ask participants if they had a particular attachment to a genre, musician, or specific song. The music programme leader's encyclopaedic knowledge of music history meant that very few requests went unaccommodated.

*Digital music group.* The digital art intervention was implemented for its potential to increase interest and engagement using a more versatile, novel instrument. The aim was for this to lead to a more dynamic, anxiety-lowering programme. The digital instrument used was Oval, a tablet-based instrument that triggers notes, chords, and drum sounds at the touch of an onscreen button. Additional digital apps were developed and trialled by the music session leader during the data collection period. Due to limited resources, digital music groups mixed traditional instruments with digital instruments. Patient participants had opportunities to use both digital and traditional instruments and were encouraged to compare experiences. The simplicity of the tablet setup allowed the digital instruments to be passed around and tried by everyone.

*Traditional music group.* This session used traditional acoustic percussion instruments such as maracas, shakers, small marimbas, and glockenspiels, laid out on the day room table. These were purchased from music education shops online. At the outset of the programme, participants were encouraged to choose their own instrument. Throughout the programme, participants were provided opportunities to choose a new instrument. The

transition from rhythmic instruments such as a maraca to melodic instruments such as a xylophone proved to be especially popular among participants.

**Time horizon.** Data collection for the focused ethnographic study occurred between September 2017 and July 2018. Adhering to the definition of a partially mixed sequential equal status mixed methods design (Leech & Onwuegbuzie, 2009), there was a period of only ethnographic data collection before the 3-arm controlled study began in January 2018 (See Section 5.3). The ethnographic data collection then continued alongside 3-arm controlled study data collection in order to continue gathering qualitative insights alongside quantitative data collection. Before data collection began, the COOP programme had been a regular fixture of hospital wards across CWFT. It was established in 2015 and therefore was familiar to and supported by many clinical staff members across the trust.

**Materials and costs.** Material cost and setup and clean-up time pose important considerations for long term implementation of arts in health programmes. Setup for the traditional visual art programme involved laying out paints, pallets, brushes, canvases, and fresh water for brush rinsing. Setup for the traditional music programme involved using sanitary wipes to sterilise all instruments before use. This usually took at least 5 minutes, and it often took up to 10 minutes if previous occupants of the day room need time to pack up and leave. Clean-up from the traditional visual art programme regularly took at least 15 minutes. This included thorough washing of brushes and pallets, cleaning up dribbled paint from the table top and floor, and resetting furniture in the room. The mess associated with physical paint was received in mixed ways.

*The art programme leader pointed out a green splodge of paint on the front of his t-shirt. “How did that get there??” he gasps. He plays at being aghast. “That’s now an artist’s t-shirt”.*

*I spotted two patients playing with the paint in mischievous ways. One splodged a mound of blue paint on the art programme leader’s hand. The other pressed her whole palm into the wet surface of her canvas.*

*Field note, traditional visual art*

#### 4.1.5 Methods and data collection

**Participant observation.** The primary method of data gathering used was participant observation. This was done from the “observer as participant” stance, as described by Gold (1958). Rather than the “complete observer” stance characterised by sitting hunched over in the corner scribbling notes, I participated in the running of the arts programme while still being primarily identified by my role as a researcher. This involved collaboration with the art programme leaders to set up the space, aid with the musical or artistic process throughout, and participate in clean-up after the programme. While participants would be aware of my researcher status, most of my activities and conversation would be as a fellow participation. This participation in the implementation of the programme kept me from the perspective of “participant as observer,” a more deeply embedded stance in which the researcher is considered a member of the group studied (Gold, 1958). Participant observation presented challenges to identifying my perspective as the researcher who would sometimes take notes as I related to the study participants.

Despite entering the study with an explicit observer as participant stance, participant observation required constant maintenance and negotiation as data collection proceeded. By attempting to participate as a natural member of the setting, I often had a difficult time fitting into the physician-patient dichotomy that dominates the core medical activities of the acute care hospital. While Coser (1962), in a pioneering example of hospital-based ethnography, attempted unobtrusive observation, he openly acknowledged the probability of affecting the interactions he observed. Indeed, in a review of hospital ethnographies, van der Geest and Finkler (2004) asserted that “in a hospital, participant observation in the true sense of the term is an oxymoron.” Van der Geest and Finkler also pointed out the array of hospital-based ethnographies observed and reported from the perspective of the physician or other clinical staff. By emphasising the clinician’s perspective, they argued, the patient perspective was therefore minimised. Very few ethnographic reports have been conducted from the patient perspective, largely due to the complicated ethical issues inevitably involved with the medical care associated with being a patient.

Rather than fully embodying either, a balance between the clinician and patient perspective has been described by Wind (2008). Wind described “negotiated interactive observation” as a technique suggested specifically for hospital settings. Because hospitals are among the most highly specialised settings in contemporary society, Wind argued that

ethnographers cannot truly fill the role of “them” as clinical staff. The element of negotiation is therefore ever present during data collection because the researcher fills a new, non-institutionalised role in the hospital ward. Throughout the data collection period for the present study, I found that the dynamics of this role had to be negotiated on a constant basis.

**Semi-structured interviews.** To supplement passive ethnographic observation, study participants were given the option to participate in a semi-structured interview following the art activity. Semi-structured interviews have the potential to give explicit description to attitudes and occurrences observed during the observation period. In making aspects of the art programme experience explicit, semi-structured interviews have been used to identify and describe key themes for further analysis in mixed-methods studies (Creswell, Fetters, & Ivankova, 2004). Additionally, semi-structured interviews may be useful for engaging with people who may not agree to fill out a written questionnaire (Gorden, 1975).

Semi-structured interviewing presents a methodological challenge in reliability. Interviewer training is paramount because each interview presents unique, unforeseeable challenges. Barriball and While (1994) presented two main priorities for interviewer training:

- 1) Establishing competent use and understanding of the specific interview schedule being used in the study
- 2) Developing an awareness of the errors or bias which can arise with the personal interview technique

After each participatory art programme, I asked participants to sit for a semi-structured interview. I did this by reintroducing myself as the observer-participant who was undertaking PhD research on the arts programmes. I reiterated the terms of the participant information sheet, emphasising that participation in the interview is voluntary and the participant could decline to answer any question or end the interview at any time.

The interviews focused on how the patients felt about the participatory art programme. The interviews were structured to allow participants to express general feelings in addition to eliciting specific information regarding activities, reactions, or tendencies I observed in the preceding programme. The interview questions were loosely structured with the aim of identifying elements of the programme while letting the participant take the conversation in any direction. Some notes were taken during the interview, but full field notes

were written immediately following the interview. The full semi-structured interview schedule can be found in Appendix B of this thesis.

**Unstructured Interviews.** Unstructured interviews were conducted with a variety of clinical partners, visiting arts practitioners, and patient participants. “Unstructured interview” in the present context refers to informal conversation between myself as the researcher and others within the research context. For example, if I were to ask a question to a patient participant during the art programme, their answer would count as data collected as part of the unstructured interview.

Minichiello et al. (1990) characterised unstructured interviews by their lack of predetermined questions or answers. Rather, they rely on the personal relationship and impromptu social interaction between the researcher and participant. The unstructured interview has also been called the “informal conversational interview,” which Patton (1990) described as occurring spontaneously during the undertaking of fieldwork.

While organised semi-structured interviews were valuable for their focused direction and more in-depth data, they were sometimes impossible to schedule due to the unavailability of staff to take time from their clinical duties. For this reason, some clinical partners were only interviewed using unstructured interview methods, which revealed their own advantages in gathering field data. Rich data was derived from conversations occurring in the moments of action rather than from a formal interview atmosphere. As data collection was not to take place in the bed bays, I found myself engaged with conversations with clinical staff while the art programme leaders coordinated with healthcare assistants and therapy staff in transporting patients to the day room. Rather than carefully considered answers, these unstructured interviews tended to elicit natural responses borne out of an extemporaneous practice. Unstructured interview were recorded using short notetaking in the moment and full field note writing immediately following the programme.

#### **4.1.6 Participants**

I approached inpatients on dementia wards aged 65 and over who had chosen to participate in arts activities to take part in the ethnographic study. The choice to participate was made after potential participants were approached by clinical staff or art programme leaders. I offered them information to consent to participation in the study. If they refused to take part in the study, I excluded their activities from my field notes. After informed consent was given, I administered the Mini-Mental State Exam (MMSE). If the participant scored

between 10 and 23 points, inclusive, I included the participant in the ethnographic observation during the art activity. I observed engagement and interaction while participating as a volunteer facilitator of the programme. Field notes were taken during observation, and all patient names were anonymised. No patient or facilitator names are reported in this thesis. After the participatory art programme, I asked the participants to sit for a semi-structured interview. The interviews focused on how the patients felt about the participatory art programme. Ward staff and art programme leaders were also invited to participate in unstructured interviews, which are reported in the results section of the present thesis chapter. After the interviews were completed, participant involvement ended. If a participant did not participate in a semi-structured interview, their involvement ended with the completion of the arts session.

This study recruited 43 participants, 25 of whom participated in semi-structured interviews. Of the 43 participants, 10 participated in digital music, 10 participated in traditional music, 10 participated in digital visual art, and 13 participated in traditional visual art. Of the 25 participants in the semi-structured interview, 3 participated in digital music, 5 participated in traditional music, 10 participated in digital art, and 7 participated in traditional art.

#### **4.1.7 Study ethics**

This study and the study presented in Chapter 5 were reviewed and approved by the NHS Research Ethics Service and Health Research Authority, IRAS reference 218091. The letter of Health Research Authority Approval can be found in Appendix F. The ethics governing the unstructured nature of the ethnographic approach has proven to be a reliable source of debate. Informed consent in particular has been deemed necessary to renegotiate throughout the relationship between ethnographer and participants (van den Hoonaard, 2002). Murpy and Dingwall (2007) argued that ethical considerations and thresholds are fundamentally different for ethnographic research compared with experimental research generally undertaken in a clinical setting. Rather than a traditional researcher-participant relationship, Murphy and Dingwall advocated for a host-guest relationship in which those being studied fulfil the role of host. This power dynamic, they argued, provides an ethical balance whereby the participants under observation set the rules of interaction, and the guest defers.

I approached my interactions with participants guided by the host-guest relationship throughout the observation period, and it most explicitly came through towards the end of the art programmes. For all participants, including those who did not sit for a semi-structured interview, I made sure to have a brief conversation with them to capture specific themes or overall impression of their experience before saying goodbye. While I remained sensitive to the mood and preferences of participants throughout the programmes, I limited constantly re-evaluating consent during the art programme so as not to distract from the experience itself. By communicating with participants towards the end, I created a space for them to reaffirm or retract consent.

*Informal ethics.* During the observation period, I encountered the interface between policy and practice regarding patient interaction and recruitment. Reading patient personality and mood is an endeavour governed mainly by informal ethical guidelines. Informal ethics should fall within formal ethical frameworks. However, where formal ethics do not exist explicitly, informal ethics fill in gaps and expand along philosophical lines guided by formal ethics. LeCompte and Schensul (2015) described informal ethics as existing day-to-day between people in the field. While prioritising formal ethical guidelines for patient care, hospital care routinely involves persuasion in encouraging patient behaviours best suited for recovery. In recruiting for arts in health programmes, patients who staff thought might especially benefit from participation were more thoughtfully encouraged to participate. Informal ethics came into play several times when patients seemed to indicate contradictory desires. At times, participants' words had to be understood in the context of how they were known to act by family or other long-term carers. When therapy staff and family members attended the art groups, the art programme leader took more cues from them. In the case

presented below, I and the art programme leader deferred to the therapists and family members who knew to wait through a participant's outburst.

*I don't believe this patient ever picked up a paintbrush, despite several promptings from the art programme leader and her granddaughter. After about 25 minutes, the patient stood up and exclaimed "I'm agitated, and I'm going home!" The therapists nearby looked at each other and patient's granddaughter, swapping knowing looks. This is a typical outburst for the patient, apparently. Her granddaughter seemed unfazed and continued painting for her. The patient settled back down and began chatting about her house keys.*

*Field note, traditional visual art*

#### **4.1.8 Data analysis**

Data analysis for this focused ethnography was informed by two ethnographic techniques – cultural domain analysis and event-structure analysis. These techniques were chosen for their complementary strengths - cultural domain analysis is useful for identifying and describing categories of personnel, stimuli, and activities (Borgatti, 1994), while event-structure analysis is useful for characterising how events unfold over time (Griffin, 1993).

As a key method in modern ethnography, domain analysis is characterised by the identification of major elements of the rituals, relationships, and structures of the group under study (Borgatti, 1994). This requires the researcher to identify and elicit participant identification of existing elements of the object of study. This is often iterative, with themes identified and tested through conversations with multiple participants. While these themes should be shared among participants, each participant might experience the theme in a unique way (Borgatti, 1999). Undertaking domain analysis was a collaborative process, especially during the unstructured interviews with art programme leaders and clinical partners. Conversations with them in the field allowed me to identify domains as they revealed themselves. This then allowed me to probe further, using both semi- and un-structured interview questions alongside continued observation recorded in field notes.

The themes identified by cultural domain analysis were observed to develop over the period of an art programme. The documentation and analysis of this change was informed by

event-structure analysis, or narrative analysis, which is characterised by sequencing events as observed through field notes, developing a temporal structure to outline relational exchanges, and assigning “action principles” to these exchanges (Corsaro & Heise, 1990). It is especially useful in capturing elements of processes that are often overlooked. The structure of the results in Section 4.2 of this thesis is organised by the temporal process of arts programme implementation and is therefore a direct result of event-structure analysis. For both cultural domain analysis and event-structure analysis, field notes served a critical function in providing a snapshot of observations and conversations. Field notes were analysed on a continuing basis before, during and after the data collection period. Analysis occurring before and during data collection periods was with the intent of identifying themes to further investigate. Field note analysis occurring after data collection was in order to identify stirring case studies, anecdotes and quotes to support the communication of themes.

The present study is concerned with describing the culture surrounding and embedded in the arts programmes, and the combination of cultural domain analysis and event-structure analysis allowed me to identify and explicate what the programmes mean for patients, clinicians, and arts programme leaders (Borgatti, 1999). Additionally, by describing how emergent phenomena might explain other observed effects, the present study was able to be triangulated with the cross-sectional study presented in Chapter 3 and the 3-arm controlled study presented in Chapter 5 of this thesis. This triangulation is discussed in Chapter 6. Further data analysis occurred through post-hoc theme identification in field notes. In addition to theme development in the field, patterns were identified across longer periods of field note taking. Because the data collection period lasted for close to one year, this allowed further field investigation of themes, even if themes were identified from months’ worth of field notes.

#### **4.1.9 Reflexive account**

The pragmatic nature of the present study was especially important to keep in consideration throughout observation, note-taking, reporting, and analysis. Because I, as the researcher, served as the data collection instrument, I needed to constantly calibrate myself to this pragmatist perspective. Researcher perspective has been tested, showing that while factual observations may be more consistent across researcher perspectives, analysis and emphasis in reporting can vary widely (Hellesø, Melby, & Hauge, 2015). For this reason, this study’s perspective was from an observer as participant (Gold, 1958) point of view described in Section 4.1.5. During the period of data collection, I adapted this perspective by including

elements of negotiated interactive observation, as described by Wind (2008). By attending art classes, activities involved ethnographic observation alongside actual participation in the activity with the hospital inpatients. This was an attempt to experience the programmes as inpatients might while still having access to facilitator perspectives.

This stance was not always easy to maintain. During periods when I furiously scribbled notes at the group table, patients took notice. At the outset of a programme early in the data collection period, I had not yet grabbed a brush or interacted with patients sufficiently.

*When the programme leader referred to me in conversation with a patient, the patient turned towards me and said “oh, you mean that creepy man writing on the pad over there?” Mortified, I shoved the paper behind my back and reached for a paintbrush. “Sorry about that. Just getting some thoughts down before I focus on this with you!” I hastily replied.*

*Field note, traditional visual art*

From that day on, I prioritised initial impressions with the patients. I took an extra few minutes to chat and establish my presence before picking up my notebook. Often, the first thing listed in my field notes would be a list of orders for tea.

While ethnography normally calls for an observer fresh to the scene to comment dispassionately on the proceedings, I had spent significant time embedded prior to officially beginning data collection. This time included about 2 years of intermittent attendance to the COOP programme as I was able to attend during academic training periods of the PhD studentship. This precluded my ability to observe the holistic scope of the COOP programme with fresh eyes. However, my knowledge of the programme was deeper and more historically informed than a fresh researcher’s would have been. Having seen and participated in 2 years of previous programme development, I was able to more quickly identify patterns in patient reactions and the implementation of the programmes. Over time, I had developed a communication style when approaching and engaging with patients, and I had informally rehearsed asking patients pointed questions about their experiences, both in hospital and in their daily lives. Importantly, relationships built with clinical and art programme staff over the preceding two years gave me a level of comfort and familiarity navigating hospital spaces and relationships. This facilitated the process of data collection considerably. Feeling confident in my relationships with clinical staff was especially valuable given the challenges

hospital ethnographers face being taken seriously as researchers in a hospital setting (Wind, 2008).

At the outset of my PhD studies, I quickly developed a close working relationship with the head of the COOP programme. We regularly met for coffee to catch up on details of programme scheduling. Her social working style fuelled the flexible, improvisatory nature of the COOP programme. She kept in regular contact with ward managers, head nurses, occupational therapists, and many other members of the regular hospital staff. This approach paid off especially when staff were rotated between wards and between the two hospitals of CWFT. The COOP programme leader has a useful ability to keep track of who works where and for how long. Most of my clinical contacts at both Hospitals 1 and 2 came from stop-and-chat meetings while I walked with her through the hospital corridors. This habit of constant casual meetings proved indispensable to keeping up with the fast-paced scheduling and ad hoc changes that occur in a hospital environment.

#### **4.2 Part Two: Study results and discussion**

Results for the focused ethnography were organised temporally after examination informed by event-structure analysis. The first section describes personnel involved in the implementation of arts in health programmes, including descriptions of the relationships among clinical, therapy, and arts staff. This is followed by a description of the patient recruitment process, including the types of patients who attend arts and health programmes. Finally, the art programmes themselves will be described, focusing on the impacts experienced by participants. The organisation of these sections is illustrated in Figure 7. Where appropriate, separate sections will illustrate the divergent experiences between digital and traditional groups.

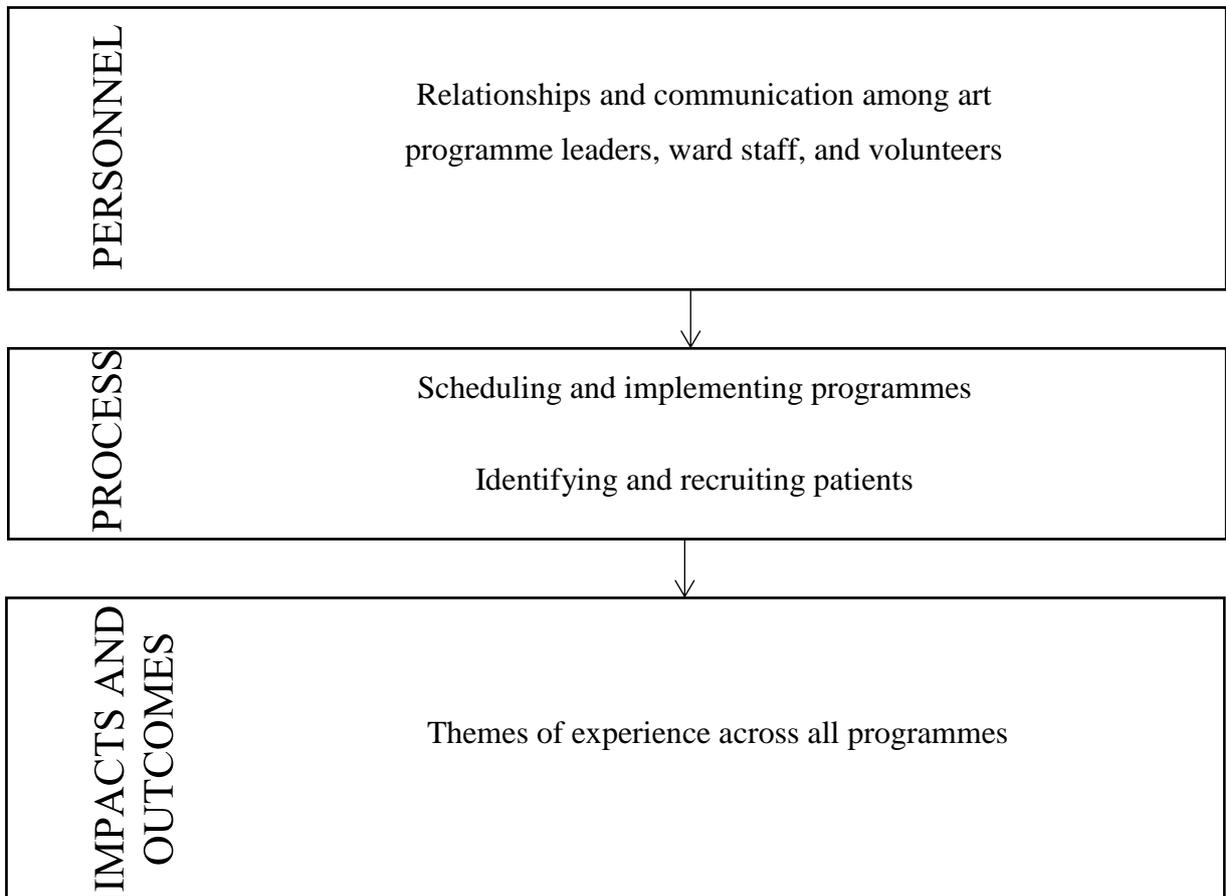


Figure 7. Order of focused-ethnographically results section: temporal process of art programme implementation.

#### 4.2.1 Personnel

The present section will describe the hospital staff and volunteers involved with the planning and implementation of an arts in health programme on a hospital ward. This will include key clinical partners including therapy staff and healthcare assistants, and volunteers including student and community volunteers. Observed interactions between these partners and the art programme leaders will be described.

Patient recruitment for the hospital arts programmes occurred through a collaboration between the art programme leader and local ward staff. Art programme implementation was most effective when the art programme leader and local ward staff had a familiar and close working relationship. These working relationships were observed to fit into the existing complex network of communication and coordination required for the delivery of healthcare.

**4.2.1.1 Key clinical partners.** The key clinical partner in organising an art programme schedule varied from ward to ward. For example, on a ward in Hospital 1, a healthcare assistant served as the main liaison between patients, the music leader, and the art leader. The lead nurse for dementia and frailty at Hospital 2 served as the main liaison and coordinator for the ward under observation. The main arts programme champion on a ward at Hospital 1 was a consultant physician. However, this was an unusual case where particularly passionate, interested physician showed a proactive interest. While support for the art programmes generally existed among physician and nursing staff, their medical priorities and more unpredictable work schedules made it difficult to support long-lasting relationships. Medical staff rarely served as main liaisons, however their support and enthusiasm made a palpable difference in ward atmosphere and staff relations with ongoing art programmes.

Regular and rotating ward staff at all levels were observed to be useful partners, including

- Ward managers,
- Head nurse/dementia leads,
- Therapy team, and
- Healthcare assistants.

Members of therapy teams and healthcare assistants often came in closest, most regular contact with patients and were therefore best positioned to inform patients about the art programme and build anticipation. Where a clinical partner championed a programme, the programme became an integral part of the ward culture. A senior ward sister at Hospital 1, was one of these champions. She began a project commissioning butterfly art for the walls throughout the ward. Each butterfly was made by a patient, so she asked the arts in health team to lead the patient creation.

*The senior ward sister came over for about 10 minutes. She was so enthusiastic about this butterfly project, snapping pictures as the patients began work. I spied a butterfly pattern on her lanyard. It's clearly a passion for her. She beamed as she congratulated the patient on a job well done.*

*Field note, clay programme*

This attitude extended from the ward manager to the consultant physicians just in for a quick visit.

*A physician came over, clearly excited. "I want to make one" she exclaimed. "I'd much rather be doing that than what I have to do" she joked.*

*Field note, clay programme*

This senior ward sister was a clear example of a clinician with a fully engaged, collaborative relationship with an arts in health programme. She believed in the beauty of the art and its display on the ward. While the above anecdote outlined the most positive clinical perspective observed, much of the interaction between clinical staff and art programme leader was based on sharing work stresses and confusion.

*All the HCAs had taken a break together. The lead nurse was nervously chatty today. She seemed stressed out with a million things to take care of. The art programme leader commiserated because she had just gotten a huge workload with her promotion. She considered getting volunteers to run the art group. I told her that her talent was appreciated.*

*Field note, traditional visual art*

**Therapy staff involvement.** Occupational therapists and physiotherapists often had a vested interest in patients attending art programmes because they viewed the art activities as complementing their work whose aim is to help the patient become functional in tasks of daily living. They represented the most common example of direct involvement with arts programmes on the ward. In the stroke ward for Hospital 1, physical therapy staff often accompanied their patients, using the art programme as an opportunity to work on motor skills outside of a traditional therapy environment.

*They [physiotherapists] spoke clearly and slowly to him, leading him along. It was not totally clear he knew what's going on, but he did show small signs of acquiescence. The physios led the programme, basically. They brought his arm up above the table, the art programme leader loaded a brush with orange paint, and they wrapped his fingers around it. They then dragged his hand across the canvas. "That's right, move it across. Use your muscles in this arm". They seemed to be turning this into a physiotherapy session. Focused on motor skills.*

*Field note, traditional visual art*

**Healthcare assistants.** Healthcare assistants (HCAs) were integral to the running of group arts programmes on the wards. Because the groups were held in the ward day rooms, staff was needed to help with patient transport. Very few patients were able to walk to the day room unassisted, and arts programme leaders needed the help of HCAs to aid patients with frames, wheelchairs, and medical equipment transport. The HCA for Hospital 1's stroke ward was a trusted, regular collaborator for the COOP programme. His care for patients was apparent through his voluntary acts of kindness bringing them treats from the corner shop or chaperoning them on outdoor trips in good weather. His perspective on the lived experience of dementia in the hospital was the most valuable to the art programme leader, who could then tailor their approach based on the HCA's recommendation.

*The HCA described one patient who had a lot of agitation. He was regularly up all night, going up to other patients in their beds as they slept. "It can be quite surprising and upsetting if that happens to you," he explained. He thought the music group would provide a good distraction for this agitated patient.*

*Field note*

In addition to serving as a practical accompaniment to clinical practice, the arts in health programmes gave clinical staff an opportunity to get to know patients better. This was most apparent when physical therapists came to help explicitly with motor function, but HCAs, nurses and occupational therapists have also expressed positive emotions after their patients have attended art group.

*"You actually get to know the patients as people. Like, I didn't know he could draw like that."*

*Nurse, Edgar Horne Ward*

**4.2.1.2 Art programme volunteers.** The CW+ COOP programme relied heavily on a core roster of dedicated volunteers. The tasks of art programme volunteers could be described by two domains: verbal encouragement and technical assistance. The technical assistance provided by volunteers included setup and clean-up as well as providing individual technical support to patients during the programme. Volunteers began visual art sessions by filling paint pallets and guiding patients through initial sketches and background filling. In the music group, this involved cleaning instruments prior to the art programme and showing participants how to use the various instruments provided. Following these initial stages,

patients often chose to focus either on the activity or had settled into a conversation with a volunteer or fellow patient. In the visual art groups, if the patient was focused on painting, the volunteer would continue social engagement by chatting and encouraging further artistic engagement. If the patient was engrossed in conversation, the volunteer often took over painting in order for the patient to have a completed artwork by the end of the session.

Many volunteers were students of music or art from local colleges. CW+ has ongoing relationships with staff at Royal College of Art and Royal College of Music, and CW+ is often recommended as a partner for practical experiences as a part of coursework. Students of art and music therapy were welcome to sit in on any given programme, as were practitioners of music and art interested in unconventional collaborations or audiences.

Music programme volunteers included conservatoire students whose presence provided inherent interest. In one session, the music programme leader invited two students from the Royal College of Music playing trumpet and violin. Before the programme began, he introduced them.

*The music programme leader asked the violinist how old her instrument was. She looked in through the bridge and said, "It was made in 1647." The room oohed and aahed. A patient exclaimed "Wow, you are amazing. And you came all the way from Japan? What an honour!"*

*Field note, traditional music*

After that introduction, the volunteers followed his lead, becoming part of the music group by playing and encouraging patients to improvise.

Community volunteers, while fewer in number than local students, were cherished members of the arts in health team. They were seldom beholden to changing academic schedules and were therefore more reliable, long-term volunteers. They may have been retired or have had free days after sending children off to school. A notable example of this type of volunteer lived in Chiswick, in the midpoint between the two hospitals included in this study. She played a key role in the delivery of the art programmes by working closely with the head of COOP programme to catalogue hospital artworks and facilitate the participatory programme. Her expertise, dedication, friendliness and open schedule made her an ideal volunteer for these arts programmes.

Volunteer help was considered critical to the normal implementation of art programmes. This reliance at times proved to be a liability.

*The student volunteer called last minute to explain that they needed to finish an assignment that was soon due. Although I normally help with set up and clean-up, I did my best to fill in the gaps during the music programme as well. I was more of a volunteer this session than a researcher.*

*Field note, digital music*

My stance as both observer and participant provided scope for me to fill in the space left by the volunteer. However, this instance shifted the balance further towards participant than I had experienced prior. This compromised my ability to observe acutely or take as many field notes as I was accustomed to. I attempted to make up for this by writing an especially detailed summary account immediately following the programme. Furthermore, there is no researcher present during the normal running of an art programme, in which case there would be no one available to cover for a missing volunteer.

**4.2.1.3 Summary of personnel involved in the implementation of art programmes.** The art programme leader served as the organising hub for all relationships described. By identifying key clinical and volunteer partners, the art programme leader was better positioned to have a programme that ran smoothly and included all patients who would want to or might benefit from participation. These relationships worked best when the art programme leader clearly communicated the expectations for any single art programme or any recurring series of interventions. This could be challenging when the personal or professional pressures conflict with the running of the art programme. The natures of these conflicts tended to be quite different between clinical staff and volunteers, as volunteer conflicts were not as easily addressed due to physical distance. This difference presented a need for the art programme volunteer to change mindsets quickly when evaluating the priorities and tendencies of key partners. In addition to clinical staff workload, unexpected events on the hospital ward proved challenging to the regular implementation of planned programmes. These will be discussed in the following section.

This section outlined the personnel involved in the scheduling and implementation of arts in health programmes for hospital inpatients with dementia. The key personnel identified were *clinical staff*, *art programme leaders*, and *volunteers*. As with all organisational efforts, the upstream leadership and organisational structure influenced the final programme and

patient experience. By understanding the process of how programmes are organised and implemented, the reader might better understand the experiential context of the participants. Furthermore, the relationships among personnel outside of the arts programmes influences the ways in which they interact during the arts programme, among themselves and with the patient participants.

#### **4.2.2 Process**

The influential clinicians identified above played important roles in the implementation of the arts programmes. However, key roles were not specific to certain positions. Rather, individual personalities and relationships were leveraged in the regular planning of arts programmes. The present section describes the organisation of arts programme scheduling among key clinical partners and patient recruitment strategies used by arts programme leaders and clinical staff. The themes identified for explication were *scheduling art programmes* and *recruiting patients* to art programmes. Two important themes were identified in recruiting patients – *patient type*, which was influenced by patient personality and patient mood, and *first contact*, which describes the manner in which patients were approached to participate in the art programmes. By investigating the scheduling and recruiting processes, the present section sets the context for the atmosphere and personalities that contributed to the patient experience once engaged with the digital and traditional group art programmes.

**4.2.2.1 Scheduling art programmes.** Art programmes were scheduled with a mix of regularity and ad-hoc improvisation. The main visual art programmes ran at 11:00 Tuesday mornings and 14:00 Thursday afternoons, and the main music programme ran at 10:30 Thursday mornings. Further information regarding the scheduling and implementation of the visual art and music programmes can be found in Section 4.1.4. The predictability of these schedules was ideal for continuity of programmes and clinical staff weekly planning. Because clinical staff knew to expect a programme, they often identified patients days ahead of time, notifying both the patients and the art programme leader.

Despite having a fixed weekly schedule, at times clinical or therapy staff requested that a programme be moved to a different time or day due to outside ward scheduling issues. Art programme staff may also have needed to reschedule if a volunteer was unable to attend or charity works were needed elsewhere in the hospital. At times, these rescheduling requests occurred in the hours before the art programmes were scheduled to take place. Under these

conditions, replacement art programmes were scheduled without anticipation or preplanning, which decreased the chance that any patients would be recruited. To begin recruiting patients, the art programme leader would first approach the ward manager or head nurse to ask permission to set up the day room and approach patients. This request was almost always happily granted. Exceptions occurred when there was no free space in the ward. Reasons included

- Family meetings in the day room – emergency or otherwise;
- Hospital staff meetings in the day room – this was not an “approved” use of ward day rooms, however hospital space restrictions mean staff meetings have nowhere else to go;
- Ward closures – These were due to ward-wide infections resulting in diarrhoea and vomiting;
- Patient occupation - Some group activities were cancelled due to lack of interest in the moment. Common reasons include patient visitors and tiredness. Often, no reason was given for declining to participate, including patients who had previously expressed interest. Even so, patient familiarity with the programme described above seemed to protect against general disinterest in participation;
- Lack of transport staff - In a rare case, all therapy and healthcare assistant staff took a break together during the scheduled art programme. This left the ward without any staff available to transport patients to the day room. The art programme leader planned to do bedside work until they came off break, but they did not return for the scheduled hour.

In most of the above cases, art programme leaders often continued their programme with individual patients at the bedside. This was done rather than rescheduling the art group for earlier the next day.

*The art programme leader thinks afternoons are better for these art groups. Morning groups are more tired and grouchy, she tells me.*

*Field note, cancelled visual art programme*

In rare cases, bedside art programmes could include an entire bed bay of 6, however bedside work is defined by individual engagement for the most part. Bedside art programmes were not included in the present study because of the one-to-one nature of the engagement. However, anecdotal evidence was collected through unstructured interviews with art programme leaders and clinical staff. While the bedside art programme was seen to elicit

positive emotions, it lacked group dynamic and environmental change discussed later in the present chapter. Lack of free space for an art activity can be unavoidable at times, however the primary way to ensure regular access to the day room was to maintain a close, active relationship with managers and staff members at the ward level.

A close relationship with the ward staff did not always guarantee patient recruitment, but it was immensely helpful both in and out of the day of the art programme. On the day of a scheduled programme, good relationships with staff meant recruitment was more likely to be prioritised, and “approach energy” was likely to be higher. On days leading up to scheduled art programmes, ward staff were more likely to include reminders when routinely visiting patients if they had a close relationship with the art programme leader.

While all efforts might be made to ensure the smooth implementation of a programme, very little could be done to prevent unexpected care needs on the ward. Although the clinical staff in the older people wards were supportive of the arts programmes, they prioritised patient needs that came to their attention without notice. Below is presented one example of many instances where unexpected activities on the ward delayed the art programme.

*I met the community volunteer on the ward at 10:30 this morning. We chose morning because the afternoons had been crowded/sleepy for the past few weeks. We thought patients might be a bit more perky after their morning tea. We briefly caught up and spoke about the programme for the day before venturing out to see who might be available on the ward to recruit. The lead frailty nurse was nowhere to be found.*

*We went to the main nurses' desk and found a staff nurse who seemed able and happy to help. I returned to the day room and sketched and chatted with the community volunteer for about 10 minutes. No one came in. At 11:00 I ventured back out there, where I found the nurse in the bay doing about 3 things at once. She asked an HCA to bring a couple of his patients over. He got one who had to go to the bathroom first. I returned to the day room to wait.*

*Five minutes later, the HCA came in with a very mobile patient.*

*Field note, digital visual art*

**4.2.2.2 Recruiting patients to art programmes.** In general, the more aware a patient was of hospital art programmes, the more likely he or she was to participate. As explained above, casual mention of the programmes by clinical staff in the days leading up “planted the

seed” for the patient. If the patient was primed in this way, he or she had less to process when time came for the art programme to begin. The primary way patients were recruited was through this early identification and interest probing. However, recruiting patients without prior notice was also often done due to the impromptu scheduling of art programmes.

When approaching patients on the day of the art programme, programme leaders and clinical staff agreed on the importance of framing the programme as something that would be interesting and fun without being intimidating. However, while clear communication among art programme organisers was essential, a close working relationship was no guarantee of patient interest. Art programme participation was often deprioritised compared to almost anything else that might occupy a patient’s time including visitors, physician visits, napping, or general disinterest. Additionally, patients who previously expressed interest in attending an art programme have changed their minds when it came time to move to the day room.

***Patient types.*** Recruitment approaches and strategies must always remain sensitive to patient personality and mood. Strategies have been identified as the result of months of intuitive trial and error on the part of the art programme leaders, and they may be used in greater or lesser amounts depending on the context of the interaction. Domain analysis of the observational and interview data was used to identify themes through an iterative process and led to categorisation of participants into three groups:

- 1) Enthusiastic joiners;
- 2) Refusers;
- 3) Hesitant joiners.

Enthusiastic joiners were defined by their keen, immediate interest in participating. Therefore, not much interaction was needed before they could be taken immediately to the day room. Refusers were defined by their immediate and forceful rejection of the offer to participate. The tone of their rejection led clinical staff and arts programme leader to judge them to be closed to persuasion. Therefore, refusers were usually left alone with a parting message that they were always welcome to change their minds. Hesitant joiners were defined by their equivocation on whether they should join the art programme or not. Often, they had been judged by clinical staff to potentially benefit from participation and were therefore approached with care. Strategies for recruiting hesitant joiners are outlined in the next section.

It was not always clear to clinical staff or art programme leaders which group a particular patient might fall into before approaching the patient. While clinical staff often knew a patient's general personality and care preferences, this did not always predict willingness to participate. These categories may have been more correlated with mood than any other personal factor. A single patient may have been defined as an enthusiastic joiner one day and a refuser the following week. Rather than a permanent characterisation of personality, the three patient categories define the attitude of the patient in the moment of consent to participate and the type of experience they are then likely to have during the art programme.

Enthusiastic and hesitant patients seemed to experience the art programme in different ways. A quintessential enthusiastic joiner was eager to turn everything into a joke:

*After painting a few hedges with a commanding, dab-spiral brushstroke, he proclaims them to be done, pointing to the sky above and saying he doesn't want them any higher. He is all jokes, especially when he insists he's serious. All smiles. He hasn't painted before this day, but he says "I like this. In the future, I'm going to do this." When the art leader points to a big splotch of green on his t-shirt, he gasps "how did that get there?? Now that is an artist's t-shirt." The other patients laugh at his antics.*

*Field note, traditional art*

This participant came to the programme in high spirits, and the programme allowed him to express and share those high spirits in a setting away from the hospital bed. Hesitant joiners who entered the room in a more tentative mood were uplifted just by watching him. This made them less self-conscious and more likely to pick up a paintbrush. Enthusiastic joiners made it easy for hesitant joiners to take risks, both socially and artistically. So, the artistic and social journeys of enthusiastic and hesitant joiners were distinct. Enthusiastic joiners often came to the art programmes to escape from the boredom of the hospital ward, and their extraversion was satisfied during the course of the programme. Hesitant joiners tended to come with a lower mood, and the socialisation and artistic engagement brought their mood up by the end of the programme. Further description of differentiated impacts will be described in Section 4.2.3: Themes of experience.

***First contact.*** I interviewed a series of visiting artists to explore a range of perspectives and strategies for meeting new patients. The artists commissioned by CW+ often worked across many types of settings, and their flexibility and ability to adapt to new settings made their perspectives valuable. Each artist has his or her own personality and interactive style. The following examples include observations of how contrasting styles can be effective.

A commissioned ceramicist came to Hospital 1 after years working with local veterans living with and without dementia. Upon observing her interactions with patients, I was soon struck by her quiet, empathetic ability to draw a smile out of patients. Her initial approach was open and friendly, introducing the artmaking obliquely. Bringing the clay and tools to patients, she would begin moulding the clay by herself, hoping to intrigue the patient with what she was doing. After chatting with the patient, she would ask for help with rolling, shaping, or carving the clay. By beginning as the primary artmaker herself, she was able to take pressure and expectation off the patient.

A visiting movement specialist took a similar approach. Using a portable speaker and tactile accessories such as fabrics and fronds, he came to the wards prepared to perform all by himself. Immediately upon entering, he invited collaboration by wordlessly reaching out to patients. Because hospital patients, especially older patients with dementia, often experience decreased mobility, he began by focusing on hand movement. At first, he mirrored patient gestures and hand positions, then he slowly added a range of movement to wrists, then elbows, then shoulders, then the rest of the body. The physiotherapeutic effects here were apparent, evidenced by the regular attendance of therapy staff to his movement programme.

However, transport to the day room presented an additional challenge. Invitation to participate to an unseen programme that had not yet begun tended to be more intimidating for patients. General patient sluggishness presented a challenge to art programme leaders and clinical staff who developed a variety of strategies for enticing a patient to the day room. This depended on the patient's reason for hesitation.

If the patient hesitated because the walk was too far, a healthcare assistant or therapy team member offered to accompany the patient with a frame or chair if necessary. If the patient did not consider him or herself to be an artist, there were a few strategies that were attempted. Firstly, the art programme leader would try to ask them to come in to have a chat, to observe, or just to keep them company. If the patient insisted they were not an artist, the art

programme leader would try to persuade them by saying that everyone says that, and they are always wrong.

These strategies were always negotiated on an individual basis, with attention paid to informal ethical norms, as described in Section 4.1.7. Recruitment was always sensitive to both verbal and nonverbal cues from the patient. Often, a potential participant would be stern and immediately closed off, indicating a mood or personality that fit into the “rejecter” patient type. It was left to the art programme leader or clinical staff to respect boundaries by persuading without coercing.

The ceramicist and movement specialist also emphasised initial eye contact:

*“It’s all in the head and the neck,” he explained as he adopted the alert, curious position. “It’s the first sign of curiosity, interest, but also fear. So be careful with that.”*

*Visiting movement specialist*

Despite strategic recruitment strategies, art groups were somewhat self-selecting. Inpatients who were observed to exhibit personality traits of wellbeing including openness to new experience, resilience, and positive affect were much more likely to be enthusiastic joiners at the suggestion of participation in an art programme.

**4.2.2.3 Summary of process of implementation of arts programmes.** This section has outlined scheduling considerations and the art programme recruitment period, a critical influence for the group art programme to come. The immediacy of the process cannot be circumvented, and the recruiting clinical staff and art programme leaders must be flexible and positive in setting the tone. This is done by the type of approach, the patient mood, and the general patient personality. This tone does not prescribe the experience of the programme to come, however it does influence its trajectory, having strong implications for the entire experience of the arts programme for patient participants. The next section will demonstrate the ways in which these elements interact when the programme begins.

### **4.2.3 Themes of experience**

This section will describe general themes of patient experience across all programmes observed. In doing so, anecdotes and quotes from different groups will be integrated and, where appropriate, the type of medium will be disclosed. However, the general term “art group” or “art programme” will serve to describe all sessions observed across visual art and

music in digital and traditional media. Where differing experiences between digital and traditional media were observed, they will be reported in a dedicated subsection.

Three themes of patient experience were outlined after analysis of observational and interview data: *physical*, *social*, and *emotional*. The physical element describes the artistic technique as well as functional physical movement aspects of the arts programmes. The social element describes the nature of interactions between participants and between participants and art programme leaders observed during the programmes, including how they differed between digital and traditional media. The emotional element describes how participants reacted, both through my observation and through their own responses when asked during the semi-structured interviews. All three elements are influenced by the environmental change after transport to the day room, which will be outlined first. These themes are outlined in Figure 8.

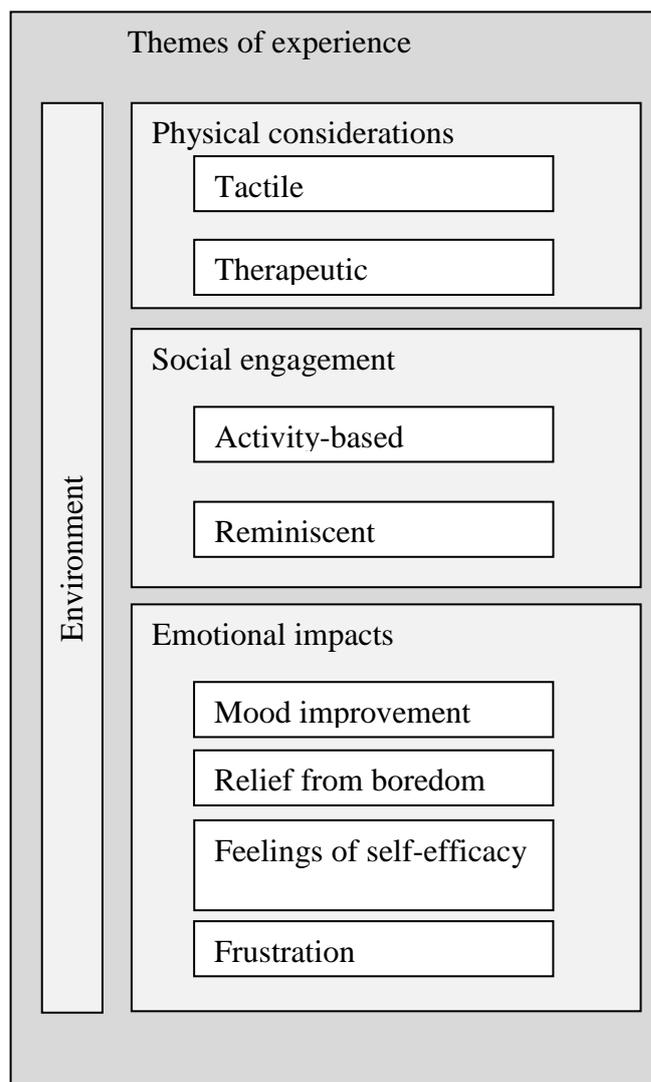


Figure 8. Themes of experience in digital and traditional arts in health programmes for hospital inpatients with dementia.

**4.2.3.1 Environment.** Environment and environmental change are critical considerations for any aspect of care for people living with dementia, especially for hospital inpatients. The hospital environments observed in the present study were confusing, loud, ever-changing and contributed to disorientation for patients with dementia. The act of movement to a more natural or domestic environment from the bed bay was observed transform the patient experience. Many patients expressed surprise in the change of feeling of simply moving to a new room.

The day rooms were usually furnished in a more familiar, domestic way with padded chairs, coffee tables, bookshelves, and televisions. “Where’s the remote control?” I was asked by an excited patient who seemed to feel immediately at home.

*She looked out the window into the main hospital atrium. “Oh, it’s so big here, isn’t it?”*

*Patient, digital music*

*“Oh, it’s so nice and warm in here! So nice. Much better than the ward.”*

*Patient, traditional music*

The environment had a pervasive effect on the experience of arts in health programmes. For some participants, the change of environmental conditions was unexpected, shifting their mentality to one where anything could happen. One participant came into the day room while remarking how cramped she felt in her bed.

*“There’s a different light in here. I can see the painting better than I could sitting in bed.”*

*Patient, traditional visual art*

Further examples of the encompassing effect of the environment will be discussed as they pertain to further themes of experience, including the physical experience of artmaking, social engagement, and emotional responses to artmaking.

**4.2.3.2 Physical considerations.** The programmes observed were of active artistic and musical engagement and therefore contained an element of physical engagement. There

existed a wide range of physical ability among study participants, but art programme leaders were accustomed to tailoring the engagement to any physical ability.

***Digital and traditional media: Physical technique.*** Physical technical requirements varied widely between the instruments used for digital and traditional art and music. Given the same group leader, physical environment, and patient group, the traditional and digital objects functioned differently and were taken to with varying levels of familiarity. Most patients were fluent in their ability to immediately use a paintbrush in the traditional art groups. Intuitive percussion instruments made up most of the traditional music groups, and they were easy to quickly teach to patients who were unfamiliar.

The main technical challenge observed in the digital art groups was in using the Brushes app. For the digital visual art group, the physical technique involved was skill-based, involving technical learning in addition to manual dexterity. When initially presented with the tablet, patients expressed general interest. Some met the painting app with scepticism, but it did not generally take long to convince them to begin experimenting. Gesturing on the painting app was intuitive for the most part. It began with a simple swipe of the finger to make a line. However, most patient participants had little to no experience with touch screens. Participants who were not used to touch screen devices tended not to understand the multitouch feature (e.g. using two fingers to zoom in or out of the image). Consequently, participants often rested the palm of their hand on the touch screen or held the tablet so that their fingers activated the edges of the touch screen. This caused stray strokes and inadvertent changes to brush styles and colours. Furthermore, many participants had difficulty gesturing with one finger without using the base of their palm or other fingers to anchor their movement. This prompted the introduction of touchscreen styluses to the digital programmes, which reduced the problem. In lieu of specialised tablet holders, art programme leaders either held the tablet for the patient or encourage them to leave the tablet flat on the table. While these strategies helped to lower the amount of unintended screen manipulations, it remained difficult to eliminate them altogether. Unintended screen manipulations were easy to undo using a “back button” on the main screen of the app. Once this was done, the patients had a sense of how to sketch, and the programme continued in a similar manner to the traditional version.

While initial line-making in the brushes app came quickly, patients rarely became fully accustomed to the menus of the painting app within the one-hour span of the art group. Art group volunteers needed to help with almost all changes to colour or type of brushstroke

by navigating through the digital application interface. This usually required a one-to-one ratio of art group volunteers to patients. While deliberate control over colour, brush styles, and line thickness was difficult, inadvertent changes were quite common.

In digital music groups, the technical challenges were of a different nature. The simpler interface was more quickly learned by participants who enjoyed experimenting with onscreen buttons triggering sounds. While the tablet used as a digital instrument was quite robust, tablet speakers tended to be too quiet for patients who were hard of hearing. Quiet tablets were drowned out especially when mixed with louder traditional instruments. To combat this, the music programme leader brought in an external speaker to plug into the tablet. However, this connection could be quite fragile and prone to malfunction.

Many patients complained about the disconnect between their gesture and the sound produced. At times, latency of the software itself created a delay from gesture to sound. More often, the disconnect had to do with timbre and dynamics. No matter how soft or hard patients tapped on the tablet screen, the sound would remain the same.

*“I’m bashing the key, but the sound is so quiet!”*

*Patient, digital music*

A novel aspect of tablet-based music making was the complexity and array of available sounds. When given an instrument capable of producing full chords or complex drumbeats with a single tap, patients were usually surprised and often delighted.

*“It’s amazing what they can do with such a small thing, isn’t it?”*

*Patient, digital music*

Compared with the digital art app, the digital music app was found to be much more accessible. The large screen with simple buttons makes for an experience free of confusion or

*I brought the tablet, and she seemed interested. I demonstrated that she could touch anywhere on the screen to make a sound. Her fingernails were long, and she pointed out that she might not be able to do it. I told her the pad of her finger would work, but she figured out that she could use her knuckle to knock on the screen. Her rhythm is good, keeping time with the crotchets of the music leader’s playing.*

*Field note, digital music*

mishap. The complexities of multi-touch commands present in the visual art programme did not enter into the experience of music-making on a tablet. One particular patient showed an ability to adapt to challenges encountered with digital music making.

The same patient, when asked about the digital and traditional instruments, had a clear preference.

*I asked whether she preferred the maraca or the tablet, and she pointed towards the screen. "It's just got so many more sounds, doesn't it?" She took up the maraca and shook it a few times, looking bored by the single noise she was able to make.*

*Field note, digital music*

However, this relatively simple interface did not stop some patients from asking for a more familiar experience that would be free of the array of options that had the potential to overwhelm.

*"This stuff is too confusing. Hand me a maraca!"*

*Patient, digital music*

***Tactility of the physical object.*** While digital interfaces were useful for their wide array of options on a simple glass screen, the tactility nature of traditional artmaking makes for more intuitive handling of instruments, both musical and artistic. This was well conveyed through a visiting artist's clay workshop, where the tactility of the activity was immediately understandable to new artists. Additionally, participants in the clay activity expressed interest in the novelty of the medium.

*2 ideas about why the clay butterflies are immediately successful*

- 1) It's a simple, clear theme. Paper butterflies already adorn the wall. It's a simple, nice feature of the ward that has a deeper story if you want to delve into it. But for most people, they see butterflies on the wall, and then they see patients making butterflies. It just makes simple, intuitive sense*
- 2) Clay is novel (you don't usually find it in hospitals, or even in art classes), but familiar and intuitive. It feels good in your hands, and it's not intimidating. Even though it's new and exciting. It strikes a perfect balance between novel and comfortable.*

*Field note, clay*

The benefit of tactility was also apparent for traditional music activities. Musical instruments, especially percussion, lend themselves to immediate understandability. This eliminated a preoccupation with technique that characterised digital artmaking, letting

participants enjoy creative expression. Participants who were not concerned with technique were also more socially engaged, indicating a general expressiveness in traditional artmaking over digital artmaking.

***Physical therapy.*** The physical benefit of art groups was made most apparent by the interest and involvement of occupational therapists and physiotherapists. Often, these were the first members of ward staff approached to recommend patients for the art group. Therapy work is more closely associated with real-world functional movements. Therefore, therapy staff had a more intimate knowledge of patient ability and receptivity to ward activities.

Many saw art group as complementing their own work. In the stroke ward, physiotherapists commonly attended alongside patients, helping along with motor coordination and referencing previous sessions in which finger or wrist movement was emphasised.

*It's very common for a member of the therapy team to approach and ask the patient "how are you getting on?" They always ask in a caring, familiar way, as if they were family.*

*Field note, traditional visual art*

Too much involvement by the clinical care team was found to lead to decreased focus on the patient experience. A balance must be struck between helpful accompaniment and overbearingness.

*For some reason, the patients today hardly interacted with each other. It may have been the number of visitors and therapists in the lively, sociable room. With 6 therapists along with the art group leader, me, another 2 volunteers, and a patient's daughter, the room felt very cramped.*

*Field note, traditional visual art*

***Summary of physical considerations .*** Physical considerations were of primary importance to the experience of artistic engagement. This was due to the use of an artistic implement in the creation of visual art or music. Because artistic engagement was not observed to be physically taxing, occupational therapy and physiotherapy staff saw the art programmes as complementary to their work in exercising small movements to improve activities of daily living. Fundamental differences were observed in the physical technique used between digital and traditional media, and novelty of digital media prompted substantial

portions of digital programmes to be dedicated to learning how to use tablet screens. Furthermore, the tactility of the physical art materials and musical instruments was missed during the digital programmes. Downstream effects were observed and will be presented in the following sections regarding social engagement and emotional impacts in the arts in health programmes.

**4.2.3.3 Social engagement.** Alongside its own environmental advantages, the day room provided opportunities for hospital patients to interact as a group. This most obviously included bringing together patients who had never met. However, the relationship between patients who were already acquainted while in bed on the ward was also changed by attending an art group. Often in a bay formed of six beds, hospital patients formed relationships with one another. These relationships were most often centred on the reason for admission and the medical care received on the ward. So, when the same bay-mates were transported to the day room, sharing an art activity, their relationship changed. Rather than seeing each other as fellow patients, viewing each other from respective hospital beds across the ward, patients sat upright and interacted with one another. This often involved general chat and concern for one another's conditions.

Beyond this general hospital-based conversation, the art groups provided a focus for interaction. I found two distinct categories of interaction among patients in the art groups: *activity-based conversation* and *reminiscent conversation*

***Activity-based conversation.*** The art group provided opportunities for easy small talk about the shared activity. The novelty of picking up a tablet or a paintbrush or a drum while staying in hospital was often enough to spark an exclamation and shared laugh. Further conversation about the activity concerned technique sharing and praise of each other's work.

*In the day room, one patient asked her bay mate about her hip injury, wishing her well with it. This is one moment where an otherwise sarcastic personality seemed sincere.*

*Field note, traditional music*

*A patient who spent a lifetime as an illustrator took over as a volunteer today. He immediately leaned over to the other patient and began encouraging him, suggesting different brushstrokes to get different effects.*

*Field note, traditional visual art*

*The art programme volunteer lifted a patient's completed painting, and the room rejoiced in admiration of a nice painting.*

*Field note, traditional visual art*

***Reminiscent conversation and story-swapping.*** The subject of the artwork often prompted storytelling. Early in the observation period, a strategy for facilitation was identified. If the topic of the artwork could be quickly tied to a memory or story from patients' lives, patient investment and engagement would be more deep and enduring. For the visual art groups, this meant choosing paintings that depicted familiar scenes such as the British coast or iconic British buildings. For music groups, this meant beginning with a discussion of favourite musical styles or artists. The music programme leader even used previous bedside work with patients to inform music group later in the week. By getting a sense of what patients like to listen to, he was better able to prepare music for them to play if they came to music group later in the week. However, many moments of reminiscent conversation came about through improvisation. By staying sensitive to small changes in body language and affect, the music programme leader was able to direct the style to memories and tastes of individual participants.

*A few minutes later, the music programme leader's piano playing shifted into a waltz, and the participant perked up. The programme leader asked if she had done the waltz before, and she said "of course! All the dresses whirling about. Lovely."*

*Field note, traditional music*

Art programme leaders quickly recognised the power of arts engagement to elicit stories and consulted with the hospital dementia leads to better encourage reminiscence as part of the arts in health practice. Reminiscence is used widely as an approach and technique in dementia care. Despite research suggesting reminiscence might increase carer stress, reminiscence (Woods et al., 2012) has been researched for its use in arts in health programmes for hospital inpatients with dementia (O'Rourke, Tobin, O'Callaghan, Sowman, & Collins, 2011; Wu & Koo, 2016). For this focused ethnographic study, the reminiscent dimension served as an extension to the social engagement dimension. By providing a focus for engagement, the art or music provided a lens through which to remember and express. This was expressed through both the artistic medium and through conversation in the art groups.

*When the music programme leader shifted to the tango, I picked up a maraca for the participant to play. She grabbed it and took immediately to the syncopated beat. The music group leader asked if she had played music in her life. She told us a story of her mother's violin playing. It was the most fluently she had spoken during the entire hour. By the end, she had told us a full, 5-minute story.*

*Field note, traditional music*

***Digital and traditional media: Social impacts.*** Traditional media seemed to facilitate the most conversation between patients. During traditional art programmes, patients seemed to spend equal or more time socially engaged compared with artistic engagement. At times, traditional groups seemed to treat the painting or music as an accompaniment to the conversation by punctuating a verbal point with a jab of their paintbrush or a tap on the drum. There was generally much less socialisation during digital visual art group compared with traditional visual art group. Because so much mental energy was directed towards the new medium, patients had little time to sit back and absorb the environment, including consideration of their fellow patients.

*I don't think the patients interacted once during the entire hour-long session. They were so focused on the tablet screen, they hardly looked up. Despite being focused and finding interest in the new activity, I don't think they experienced the social effects of the painting groups.*

*Field note, digital visual art*

The lack of social engagement was observed across the variation of participants' technical facility with the touchscreen. The participants who quickly learned how to use the painting application seemed as engrossed in the tablet as participants who were continually frustrated by unintended manipulations. The tactility of the traditional media also facilitated group social interaction. Because participants using traditional media could feel their tactile instruments, they could more easily look up at their fellow artists while staying engaged with the art activity itself. While tablet screens were more versatile, they had to be looked at in order to manipulate effectively.

***Digital visual art case study: Doodle-directed conversation.*** Traditional media were generally observed to be more conducive to social engagement than digital media during

group sessions. However, during a one-to-one session, the art programme leader and I experimented with a different use for the tablet drawing application. For this to work effectively, the practitioner eschewed use of the embedded menus in the digital application. This meant that elements such as colour and line thickness stayed the same throughout the session. With this particular participant, a textured black stroke with medium thickness was chosen, approximating the effect of a thick pencil mark. This allowed him to draw quick sketches with his finger as a method for literally illustrating his points as we conversed. By asking the participant to sketch what he was speaking about, the art programme leader prompted both social engagement and artistic engagement. After subsequent trials of this method, we began calling it “doodle-directed conversation.”

*The patient was immediately chatty. I started him off, and he put his finger to the tablet immediately. He laughed and seemed slightly annoyed at the fiddly new rules for the tablet. But he was still immediately game. He first drew "a picture of my neighbour," which actually looked a lot like a fish.*

*Field note, digital visual art*

Figure 9. Doodle-directed sketch No. 1.



*“Does your neighbour look like a fish”? Asked the art programme leader.*

*“No, he smells like a fish,” replied the participant.*

*I helped him along with zooming and scrolling through. He soon began complaining a bit about the care staff. The art programme leader asked about it, and he disclosed his self-conception as a negative person.*

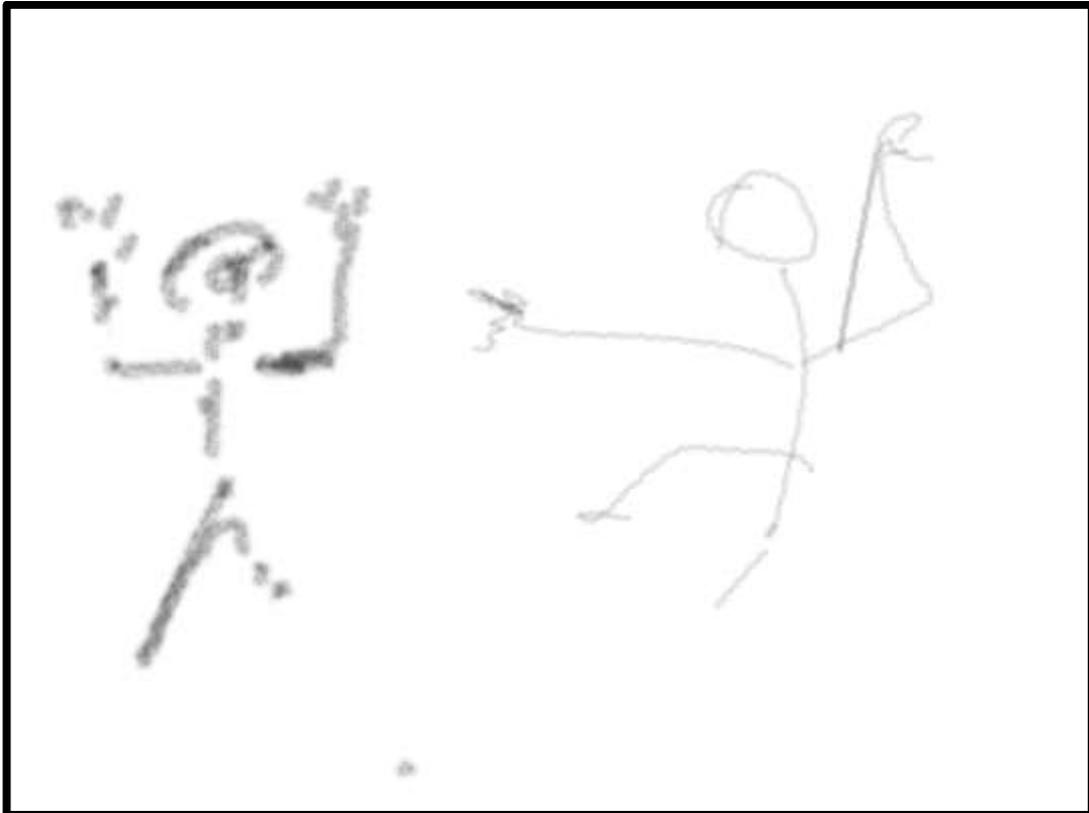
*The art programme leader disagreed “oh you don't seem like that.”*

*The participant said: “well I can have a positive outlook but negative thoughts.”*

*I asked the participant to sketch what a bad day looks like. He drew a second sketch, pointing to the nurse's finger raised and a stick brandished in the other hand. Then he sketched himself, hands raised, at the nurse's mercy.*

*Field note, digital visual art*

Figure 10. Doodle-directed sketch No. 2.



*The participant complained about the staff some more. I tried to change the subject to art and creativity. The participant had a keen eye, looking at branches outside, a hung coat, clouds... he saw colors shift and faces and shapes in his surroundings. I told him he has a keen eye and was an acute observer of his surroundings. He retorted "there's nothing else to do!"*

*I asked him to sketch a good day. He began with his fellow patient, across the bed bay, whom he had earlier spoken about with some concern. "here are his arms, and here's a nurse and her arms. And they're hugging each other. And she's smiling." He sketched as he described the scene.*

*I zoom in on her face to draw a smile. The participant told me that unless you see teeth, it's a smirk. I tried to draw teeth. He filled in the "sparkling eyes" and nose.*

*Field note, digital visual art*

*Figure 11. Doodle-directed sketch No. 3.*



*The participant went back to complaining about the nursing staff. I wrapped it up and ask how he felt about using the tablet.*

*"You don't start out with talent. You just think oh this'll be fun. And you do it."*

*Field note, digital visual art*

Doodle-directed conversation was found to be an effective method for engaging with a single patient. However, it was not observed to work well with group activities. Doodle-directed conversation worked for the tablet because it did not treat the piece of art as the end product. Rather than focus on artistic integrity, doodle-directed conversation aims to use an artistic medium as a tool for the facilitation of social engagement. By avoiding the pressure associated with creating art, it allowed the participant to explore the tablet more freely. By focusing on the conversation rather than the image itself, participants were not preoccupied with physical technique. Additionally, by taking away the focus from the work of art itself, participants were less disappointed by not having a physical piece of work to take back to their beds.

The effectiveness of doodle-directed conversation rested in its ability to direct attention. If the art leader wanted to direct conversation towards a sensitive topic, they might ease nerves by focusing on the doodling process. Alternatively, self-consciousness about the quality of the art using the novel medium could be balanced by a focus on the conversation. This type of reciprocal distraction was observed to apply to traditional art activity as well, but the technical ease of traditional media made it more conducive for group socialisation.

***Summary of social engagement.*** This section described elements of social engagement for traditional and digital art and music programmes among patients with dementia on a hospital ward. Two domains of social impacts were identified: *activity-based* and *reminiscent*. All types of social interaction were more prevalent among traditional media. This was due to both familiarity with the medium and tactility allowing patients to look at their conversation partner while still feeling their paintbrush or musical instrument. Despite this, a specific strategy was developed for one-to-one social engagement. This “doodle-

directed conversation” de-emphasises artistic engagement, using it as a catalyst for engaging the participant in expressive conversation.

**4.2.3.4 Emotional impacts.** A range of emotional impacts were observed throughout art programmes. Positive emotional impacts of the arts in health programmes were organised into three categories including *improved mood*, *relief from boredom*, and *increased self-efficacy*. Below these categories, I describe negative and neutral reactions observed during the course of the art sessions.

***Improved mood.*** Improved mood was found to be most prominently experienced by patient participants who would be classified as hesitant joiners, as described in Section 4.2.2.2. Participants classified as enthusiastic joiners tended to begin the programme in a positive mood, and in no cases were their moods dampened by participation in art group. Hesitant joiners who had to be convinced, however, experienced mixed reactions. While some reported distress during the programme and were escorted back to bed early, most patients experienced improved mood over the course of the programme.

Reflecting on her time during a traditional visual art programme, a patient said: “I suppose I wasn’t thinking of going home so much.” Another reported “It feels wonderful to make music with you.” A third alluded to the loneliness of hospital stays, saying “I was feeling forgotten in that bed before you lot came by.”

Only one patient interviewed stayed for the entirety of the programme and reported a worsened mood. He had thought the exercise was a waste of time and found no value in the painting created. He asked that the painting be thrown away. The art programme leader did this after expressing sympathy and calling the HCA to take the patient back to bed.

Given the high rates of loneliness and depression among hospital inpatients with dementia reported in Chapter 3 of this thesis, improved mood can make a noticeable difference for the experience of hospital inpatients with dementia. Many patients considered time admitted to hospital to be existentially difficult chapters in their lives:

*When I asked a patient how she felt about her time in the programme, she answered with a non-sequitur: “It’s been a difficult few weeks. A dark time in my life. But I’ve had a lovely time with you all just now.”*

*Field note, traditional music*

**Relief from boredom.** While hesitant joiners were observed to experience markedly improved moods, enthusiastic joiners were observed to appreciate the relief from the boredom on the ward provided by the arts in health programmes.

When asked about his experience after a traditional visual art group, an enthusiastic joiner told me “I was having a bloody boring day before you all came in.” Another alluded to the isolation felt in a hospital ward when she said, “No one’s talked to me in the past few days but the nurses, really.” After a traditional music group singing old sea shanties, an enthusiastic former naval recruit said, “All I was doing was staring out the window at that tree today...It feels good to be reminded of my days as a sailor.”

I define this effect as relief from boredom that is distinct from relief from loneliness or depression. Many inpatients with dementia who attend art programmes were enthusiastic joiners who generally came into the art programme in a positive mood. Rather than lifting them from a dark mood, the art programme gave them a diversion from a boring stretch of day in the morning or afternoon.

**Self-efficacy.** During the recruitment and implementation of the arts programmes, I and the art programme leaders often found a resistance among patients who did not think they could be considered artists or musicians. Often, those who showed vulnerability by trying were rewarded by feelings of self-efficacy by accomplishing something that seemed intimidating at first. This was a very common patient experience, as demonstrated by the many quotes I collected from conversations with patient participants:

*“I never thought I could make something like that. I’ve never fancied myself an artist.”*

*Patient, traditional visual art*

*“I don’t think I’d call myself a musician, but I could definitely do that again.”*

*Patient, traditional music*

*When I asked about how he felt about his finished canvas, a patient told me “That was mostly the art programme leader. All I did was choose the colour.”*

*Patient, traditional visual art*

*A patient who was reluctant to join the group grabs a brush, all the while repeating “I’m not a painter. I’m not an artist.” Throughout, she smiled and went along with whatever happens in the group. Her daughter comes in about 20 minutes later to sit with her. The patient tells her daughter “I’m not an artist,” but her daughter responds, “it looks like you are, mum.” The patient beamed at this.*

*Field note, traditional visual art*

*“All my life I wouldn’t have done something like that. But this...Honestly, I’m surprised.”*

*Patient, digital visual art*

Patients who did not, at least initially, identify as artists often did so after a lifetime of telling themselves they are not capable of art.

*Towards the end of the session, the patient turned to her friend and repeated her favourite line "I'm not an artist." The art group leader contested this point, gesturing towards the flower she painted. The patient thoughtfully replied, "When I was in school, I was told I was rubbish." The patient's friend chimed in "that happened to me as well." I reflect that their shared formative experience kept them from trying their hands at painting their whole lives until today.*

*Field note, traditional visual art*

*"I'm very pleased because none of us are artists. But we are today."*

*Patient, traditional visual art*

Not all patients were immediately persuadable on this point. An especially vivacious nurse on Crane Ward at West Middlesex University Hospital, had a playful strategy for convincing patients to pick up the paintbrush:

*She will sit with them, pick up the paintbrush, and begin to paint. Five seconds later, she'll begin with the histrionics. "Oh no, I've become so tired," she wailed. "I need you to do this. I'm tired. I can't do this anymore." And she will continue with this until the patient becomes either concerned or fed up enough to take the brush away from her. Nadine used this strategy five times today, and it worked perfectly every time. Once she passed the brush off to the patient, she was very quick to lay on the praise.*

*Field note, traditional visual art*

Similar observations were made in the music programmes, where patients expressed hesitation by shying away from the label of musician or having musical talent. Furthermore, it was unclear to many patients exactly what they would be expected to do once engaged with the music. The perception of requirement of musical technique and talent could be overcome by bringing a sample instrument to the bedside. If this did not work, participants seemed happy to sit with the group and listen to the music being made. As the sessions progressed,

the music group leader made sure to check in from time to time, offering them a chance to join in.

*The music leader often recruits by being vague: “Oh, would you like to come listen to some music?” Then he puts a drum in their hand.*

*Sometimes they have a clear idea “one bloke grabbed a drum right out my hand and said, ‘let’s play some reggae!’ and I said ‘ok’ and went right along with him”*

*Field note, traditional music*

*Self-efficacy in digital media.* The majority of participants had little to no experience using a touch screen. Consequently, the digital art groups served as teaching sessions for the use and quirks of touchscreen apps. Some patients were delighted by the new medium, taking pleasure in their control over the glowing digital surface. This delight in what is novel speaks to the freedom from pressure patients often experienced with traditional painting.

*“It’s not something you have to have talent to come into. You just handed it to me, and I thought ‘ok, I can go with this’”*

*Patient, digital visual art*

Referring to the tablet, another patient marvelled at the power of the touchscreen.

*“You can just touch it, and you’re an artiste”*

*Patient, digital visual art*

When we described a possible plan to display the digital artworks on screen in the hospital, this patient became excited.

*“At the end of our time here, we’ll have a wall full of these lovely artworks. You don’t have to think about it. You just put your finger down, and you don’t have to worry about being a fool.”*

*Patient, digital visual art*

**Summary of positive experiences.** Three domains of positive experiences were identified: *improved mood*, *relief from boredom*, and *self-efficacy*. Trends were identified, including the tendency for hesitant joiners to experience improved mood and the tendency for enthusiastic joiners to experience relief from boredom. These separate effects are distinguished by the transformation observed. Enthusiastic joiners were not observed to

experience improved mood per se, due to their positive mood observed at the beginning of the programme. *Increased feelings of self-efficacy* was the most prevalent emotional impact, as patients across demographics began the programme with a sense of hesitation regarding their artistic or musical abilities. Most participants were rewarded by making art or music they did not think they were capable of producing.

***Negative experiences.*** While the clear majority of patients experienced positive emotions over the course of the art programmes, not all reactions were positive.

*A particularly distressed patient expected her son to come by any minute this afternoon. I asked the local healthcare assistant about this, and she informed me that her son had come by the previous day and said he would be in the following week. The art programme leader and I believed participating the art group might distract this patient from waiting for her son. During the art group, she insisted on being seated facing the door. She did not look down at the canvas during the programme and repeatedly moved to stand. Although she did not respond to offers to return to bed, she repeated that painting “doesn’t do anything for me.”*

*Field note, traditional visual art*

However, even if medical issues arise during the programme, many patients seemed to express enthusiasm for the art itself.

*One patient has very small movements. She has a catheter and nasal tube. When she gets thirsty, she needs assistance from her attending therapist to drop the paintbrush and pick up the teacup. Towards the end of the session, she began coughing and sputtering mucus. The nearby therapists help her. She doesn’t want to continue painting, but she wants to stay at the table. She closes her eyes in peace for the remainder of the session, painting about halfway from completion. The art programme leader asked her if she enjoyed herself, and she nodded, asking to finish her painting next week before being wheeled back to bed.*

*Field note, traditional visual art*

*Negative experiences in digital media.* While patients in digital art groups expressed pride in the work created, they also expressed disappointment in not being able to bring their work with them. As an ad hoc response, we offered to email or print copies of the artwork. This was generally met with lukewarm responses because the print quality was not good, and email tended not to work. Patients were usually unable to provide an email address, either because they did not have one or had forgotten it. When patients were able to provide email addresses, the disappointment of not having a tangible product remained. The deferred enjoyment of the fruits of their labour seems to tamp down the improved mood coming from the art class.

*“So this is just going to stay on the iPad then?..it would have been nice to take it back with me.”*

*Patient, digital visual art*

The COOP programme began exploring ways to address this common issue. One idea was to create a public display of patients’ digital artworks. By installing a television in the ward’s main hallway, patient art could be displayed for all to see. A looping slideshow would be simple to maintain and update. Another idea was higher-quality prints. However, there were hurdles to overcome including price and speed. This would be a valuable challenge to address, given the observed benefit to participants in having a physical artwork of their own to bring home.

*“Oh, it’s lovely. I’m going to show this to my son.”*

*“I’m bringing this one home!”*

*“I get to bring this with me? Oh, good!”*

*Patients, traditional visual art*

**Neutral responses.** Sometimes engagement with the art activity did not seem to impact on mood observed before and after a programme.

A patient seemed engaged with an art programme that created a stained-glass window effect using glue and ripped tissue paper. Despite participating in the art activity and attendant conversation, the patient seemed preoccupied the entire time by the expected arrival of her daughter. While the patient may have been anxiously waiting for her daughter while in bed, she was made more anxious by being moved to the day room where her daughter might not find her.

*The patient heard a voice and said, “sounds a bit like my daughter’s voice”. She moved to get up, but the art programme leader ushers her back down. The art programme leader asked about her children, which seemed to assuage her for a bit. After about 10 seconds of focus on the activity, she abruptly stood and walked to the nurses’ station. The art group leader hurried after her. 1 minute later, the patient came back, mentioned her worry about missing her kids, then said “I’m puffed. I’d like to take a break”. I muse that the novelty of the day room environment can either be a breath of fresh air or a provoker of anxiety.*

*Field note, traditional art*

**4.2.3.5 Summary of experiences of the art programmes.** This section described patient experiences of the arts programmes, including *environmental, physical, social, and emotional* impacts. The environmental change of transferring to the day room from the bed bays were observed to affect all other domains of patient experience. Physical technique was central to the experience of artistic engagement and was of keen interest to occupational therapists and physiotherapists. However, physical technique was observed to diverge substantially between digital and traditional media, ultimately impacting social and emotional impacts of digital media engagement. Across media, almost all patient experiences were positive, and participants reported benefits from both social and artistic activities. Participants were organised by how they responded to recruitment to arts in health programmes, including *enthusiastic joiners, hesitant joiners, and refusers*. The interplay among participant types was observed to affect social and emotional outcomes. Digital activities were less conducive to loose social engagement because participants required more one-to-one assistance from art programme leaders, volunteers, and attending therapy staff. However, digital art activities were found to be effective as facilitators of one-to-one interaction through “doodle-directed conversation.” Finally, the emotional impact of self-efficacy was observed to be the most universal experience among participants. Although most participants did not identify as

artists or musicians, the process of the art programmes gave them the ability to enjoy both artistic engagement and the products of their effort. These patient experiences will be integrated and compared with extant literature in the following section.

***Conclusion of results for patient experience of digital and traditional art programmes.*** Patient experience of art groups was found to be influenced by many factors, beginning with patient personality and mood. The patient type then influenced how participants were influenced by engagement factors including the balances in novelty-familiarity and social-artistic engagement. The ways in which these engagement factors manifested then influenced the types of experiences had by participants. These factors were described in detail in Sections 4.2.2 and 4.2.3, and they were summarised below in Figure 12.

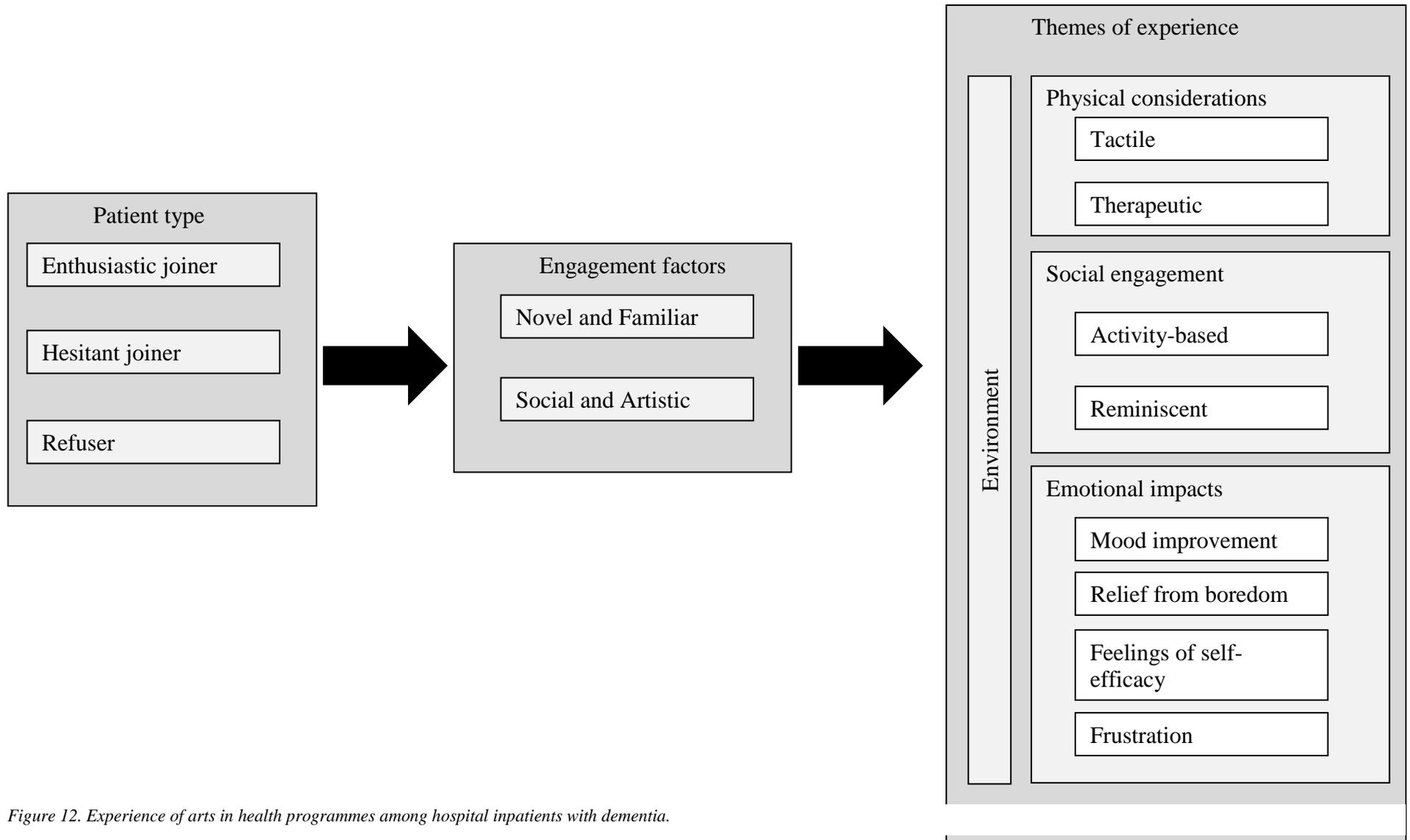


Figure 12. Experience of arts in health programmes among hospital inpatients with dementia.

#### 4.2.4: Discussion

This focused ethnographic study investigated the personnel, processes, experiences, and outcomes of arts in health programmes for hospital inpatients with dementia. It first described programme design, people involved with the production of an art programme, the method of programme organisation, and types of patients who attend the art programme. It then reported broad experiences of the art programmes in general alongside programme-specific experiences of inpatients with dementia. Comparisons were made between visual art and music across digital and traditional media. Results from participant observation and semi- and un-structured interviews revealed near-unanimous positive reception of the arts programmes among patient participants, hospital therapy staff, and clinical care teams.

Arts in health activities have been investigated by many qualitative studies across patient groups and care settings. These studies report similar results with regards to positive effects for the lived experience of the patient group under study. A report funded by the Department of Health reviewed the qualitative research on arts in mental healthcare settings, finding that they “can create opportunities for meaningful activity and can generate a sense of identity and ownership in relation to healthcare environments” (Daykin, Byrne, Soteriou, & O’Connor, 2008). This feeling of ownership might be described by the present study’s findings regarding self-efficacy. Deep internal changes in realms of “spirituality, empowerment and self-validation” were also reported in an interview-based study of community mental health patients in Australia (Lloyd, Wong, & Petchkovsky, 2007). Effects of art as part of the hospital environment have also been explored through a series of observations and semi-structured interviews (Nielsen, Fich, Roessler, & Mullins, 2017). Artmaking has been described as having the potential to form a bridge to the outside world, a powerful effect considering the potential for patients to feel demoralised in a hospital environment (Clarke, Cook, Coleman, & Smith, 2006; Sansone & Sansone, 2010). In the present study, this was facilitated by the confluence of environmental change, social engagement, and artistic engagement.

Analysis of the results presented in Sections 4.2.1, 4.2.2, and 4.2.3 were integrated and organised into three main themes: *Novelty and familiarity*, *Wellbeing*, and *Implementation*. Novelty and familiarity will be presented first, as they describe the general terms of engagement with the arts in health programmes. This engagement will then serve as the entry point to the second main theme Wellbeing, where engagement is a key element of the PERMA wellbeing model described in Chapter 1 of this thesis. Two forms of engagement

were identified through data collection and analysis, including *artistic* and *social* engagement. The remaining four elements of the PERMA model will be discussed, outlining the multivariate ways engagement with the arts can improve wellbeing. Finally, the Implementation subsection details the effects on arts practitioners and clinical staff, including implications for broader hospital culture as it relates to the lived experience of inpatients with dementia.

**4.2.4.1 Novelty and familiarity.** Both digital and traditional media were found to be mediated by the interaction between novelty and familiarity. The improved mood and relief from boredom experienced by participants were results of the novelty of artistic engagement during an otherwise dull afternoon on the hospital ward. Artistic expression and reminiscent conversation were observed to be results of the familiarity fostered by the art programme leader. Their differences were also defined by their differing balance of novelty and familiarity.

Hospital inpatients with dementia were found to be receptive to digital media in the present study. Engagement with digital media was characterised by curiosity and excitement when faced with the novelty of discovering new technologies and associated skills. However, this curiosity was also accompanied by scepticism and frustration when unexpected marks occurred in the digital visual art group or the sound connection sputtered in the digital music group. This dichotomy of reactions might be described by the dichotomy between novelty and familiarity. Novelty, while observed to potentially produce frustration, can be stimulating for people with dementia, who were measured to progress through novel tablet-based games more quickly than familiar games (Astell et al., 2016). Liao, Yeh, & Shimojo (2011) described preferences for novelty and familiarity as being related to past experience with the subject. Reactions to novelty and familiarity also change across the life course. Eson, Cometa, Allen, & Henel (1977) found that children between 22 and 49 months old had a strong preference for novel activities, but this effect was reduced with increased age. Cognitive research has also examined the different ways in which novel and familiar stimuli are processed. Förster (2009) found that participants had more holistic, global reactions when presented with novel stimuli and detailed, focused reactions when presented with familiar stimuli. This result fits with the experience of the art programmes observed. The art programme leaders, knowing that the art group would be a novel experience for many participants, began more holistically. They also aimed to balance the novelty of the experience by engaging in reminiscence-based conversation. Later in the session, when the

activity became more familiar, the art programme leaders began to challenge participants by encouraging more expressive, novel techniques. This practice outlined the general strategy of balancing the novelty of medium with the familiarity of method. Later, the familiarity of the medium was balanced by the novelty of method.

Dementia care activities research has investigated novelty and familiarity, finding that broad cognitive engagement in response to novel activities had potentially protective effects (Fissler, Küster, Schlee, & Kolassa, 2013). The present period of ethnographic observation found that the line between novelty and familiarity must be constantly negotiated on an individual basis at all stages of arts in health programmes for hospital inpatients with dementia. Patients were more likely to be visibly engaged and feel excited during and after engagement with something novel. With regard to patient recruitment, patients were less likely to agree to participate if the perception of novelty was central to the activity. To counteract this effect, art programme leaders intuitively deemphasised the newness of the activity when recruiting patients to the activity. As described above, they often began the activity by referencing a familiar, reminiscent topic or subject. The goal was then to ease patients towards a state of exploration and novelty as the art programme progresses.

Many patient participants had never used a touchscreen before. While no one explicitly rejected participation based on the unknown skill required to use the tablet, hesitation due to excessive novelty did exist. For the most part, this hesitation was successfully addressed by demonstration. If a volunteer sat with the patient for a few minutes, they quickly saw how accessible the tablet could be. This experience emphasised the importance of simple interface design. Because this population has a particularly high barrier to clear in the adoption of touch screens, simpler interfaces can lower the bar significantly.

***Creativity.*** The balance of novelty and familiarity in dementia might also be examined through the lens of creativity. As with many concepts considered over the course of this thesis, creativity has a multitude of definitions. Runco and Jaeger (2012) posited that creativity needs both “originality and effectiveness,” with a broad allowance for what it might mean to be effective. Franken (1982) defined it as “the tendency to generate or recognize ideas, alternatives, or possibilities that may be useful in solving problems, communicating with others, and entertaining ourselves and others.” The Franken definition includes ideas of originality and effectiveness, but it is more specific about creativity being potentially useful in communicating or entertaining. Creativity has been found to emerge in some people with dementia after a lifetime of limited creative engagement (Miller & Hou, 2004). Analysis of

observational field notes and semi-structured interviews indicated that arts in health programmes facilitate creative engagement in hospital inpatients with dementia, through both communication and entertainment. Furthermore, this creative expression can be accomplished through both artistic and social engagement. Creative expression was found to be a valuable end in itself, as many participants reported a feeling of self-efficacy and pride in having created new works of art or having played new styles of music.

Creativity has also been regarded as an expression of divergent thinking, which Guilford (1950) defined as keeping an open mindset when facing challenges. Dementia reduces divergent thinking, thereby making creativity more challenging. Palmiero, Di Giacomo, and Passafiume (2011) considered the effect of divergent thinking in creativity in dementia, finding that engaging in creative endeavours might exercise divergent thinking, helping people with dementia to express emotions and improve wellbeing.

The combination of art and social interaction observed in this study provided a potent facilitator of memory and reminiscence. The artistic and social mechanisms were observed to be distinct yet complementary. They shared validation through externalisation, which was accomplished separately through engagement with the arts and through social interaction. By representing feelings or stories through art, participants were able to view or hear their expression reflected back to them. For participants in the present study, this was empowering because it reinforced the memory and feeling through external media. Social interaction served a similar purpose. By seeing another person nod along to personal stories, the storyteller felt validated. It is unclear whether the mixture of art and social interaction has a magnifying effect. Future research could investigate this by comparing the social act of conversation with the social act of group artmaking.

The validation through externalisation of creativity can have impacts that reach beyond the day room used for group activities. The present study reported that clinicians and therapists who attended an art group or viewed the work of their patients regarded them anew in the light of the work they created. This could impact future interactions between patient and carer as they share points of connection and understanding beyond the traditional clinical relationship. The power of creativity for communicating the experience of dementia can have even broader impacts. Works of art by people with dementia have served as advocates to wider communities, inviting them to a new understanding of the lived experience of dementia in a way words might not be able to. William Utermohlen, a 20<sup>th</sup> century artist, painted a notable series of self-portraits in his final years after diagnosis with Alzheimer's disease. The

expressive changes visible through the nine-portrait series as his mental state deteriorated have been investigated by academia (Crutch & Rossor, 2006; Harrison, 2013) and popular media (Brownlee, 2006; Grady, 2006) alike.

Creativity has been investigated across different forms of dementia. Creative ability is thought to be distorted in Alzheimer's disease as it affects right posterior lobe of the brain responsible for visualisation (Cummings, Miller, Christensen, & Cherry, 2008). However, people with Alzheimer's disease might still be able to engage with the arts by focusing on other elements of the arts, including colour and general form. Additionally, Sellal and Musacchio (2008) suggested that despite potentially compromised visuospatial perspective, some people with dementia experience enhanced creativity through being "less bound by social conventions, enhancement of motivation and pleasure, etc" (Sellal & Musacchio, 2008). Frontotemporal dementia (FTD) has been measured to affect focal cognition, and therefore some people with FTD experience a resurgence of creativity and visual capability in dementia (Miller & Hou, 2004). However, the present study is the first qualitative research to investigate the ways in which creativity is expressed and facilitated through group art and social engagement for hospital inpatients with dementia. Future qualitative research should investigate how creative engagement might be optimised for specific forms of dementia.

***Reminiscence and present focus.*** Novelty and familiarity might also be viewed through the lens of reminiscence and focus on the present. The present study reports reminiscence used as a strategy at the outset of the arts programmes. Both artistic content and associated conversation were geared toward the familiar. The COOP programme incorporated reminiscence in many of its activities. Rather than group conversation solely focused on reminiscence, the art and music were used as focal points for reminiscent conversation. Norris (1986) defined reminiscence as involving "the process of reliving the past rather than of factual recall of historic events." In a Cochrane review, Woods et al. (2009) pointed out that reminiscence therapy should have a defined aim for it to be effective in a specific context. This review included interventions of individuals and small groups, using multimedia prompts. While the review included both controlled trials and qualitative studies, it found more substantive conclusions in the qualitative findings, suggesting that more experimental research is needed. The reliance on qualitative findings makes it difficult to generalise effects of reminiscence therapy. Holden and Woods (1995) recommended using historical and personal objects as focal points for reminiscence. While these objects may prompt interesting conversation, engagement with the arts may provide a more engaging

focal point. The arts, while serving as a reminiscent focal point, also demand in-the-moment expression unlike a static object.

**Boredom.** When novelty and familiarity are balanced well, the art programme is likely to prompt focused engagement in the participant, whether it is social engagement or artistic engagement. This balance may be difficult to achieve for hospital inpatients who are bed bound on the ward. The overabundance of familiarity on the ward might describe the boredom reported in Section 4.2.3. Analysis of qualitative field notes indicated that only one type of participant experienced boredom while in the hospital bed: the enthusiastic joiner. Distinguished in the results from hesitant joiners, enthusiastic joiners generally did not need persuasive strategies in order to be brought to the group. Additionally, enthusiastic joiners tended to begin the art programmes in high spirits, leaving little room for mood improvement during the course of the programme.

Enthusiastic joiners did, however, experience relief from boredom. These results might not seem to carry the implications for wellbeing that are described by “improved mood.” However, boredom might have served as a conversational euphemism during the data collection period. Binnema (2009) described the connections between boredom and broader mental health conditions, citing boredom as an “indicator of a lack of experience and meaning.” He further argued that hospitals generally lack a therapeutic element. By reducing boredom in hospital inpatients, therefore, broader therapeutic goals may be reached.

A population survey in Ireland found that boredom-proneness and loneliness were associated with reduced cognitive function among people over age 65 (Conroy, Golden, Jeffares, O’Neill, & McGee, 2010). Tadd et al. (2011) also reported boredom among older hospital inpatients, citing the “loss of communal spaces and activities.” While hospital settings face challenges in creating a home-like environment, the day room environment with arts activities represents a potentially powerful intervention to address this barrier. However, Conroy et al. (2010) contrasted boredom with loneliness by pointing out that boredom exists in the non-social environment while loneliness is defined by the social environment. This distinction has implications for the method by which enthusiastic joiners, hesitant joiners, and rejecters are identified and approached for participation in an art programme. Further consideration of personality type could better define those who are willing to participate and those who would benefit from participation in an art programme.

Furthermore, boredom might be influenced by a distorted perception of time in dementia. A grounded theory study investigated experiences of 11 hospital patients in southern England (Kelly, 1999). Its main findings focused on the experience of time in the hospital. Because normal routines are overhauled in favour of an unpredictable environment with unpredictable passage of time between consultations. Ultimately, time in hospital is bound by an unknown date of discharge which can act as a catalyst for boredom and anxiety. This research found that patients struggled to find effective, sustainable routines to structure their days spent in hospital (Kelly, 1999). Regularly scheduled arts in health programmes can provide this structure. Additionally, the cross-sectional study presented in Chapter 3 of this thesis showed that individual engagement with the arts can also be an effective strategy for providing this structure.

**4.2.4.2 Wellbeing.** By investigating emergent phenomena surrounding arts in health programmes for hospital inpatients with dementia, the present study considers how wellbeing might be impacted. To do so, it considers the PERMA model elements of positive emotion, engagement, relationships, meaning, and accomplishments (Seligman, 2012). Results from the present study indicate that all elements of the PERMA model are addressed by the art programmes observed, as outlined below

- Positive emotions – improved mood, pride in work created
- Engagement – social and artistic engagement, modulated by the balance between novelty and familiarity
- Relationships – social engagement during the programme and richer relationships reported with clinical staff
- Meaning – self-efficacy as an artist
- Accomplishment – pride in work created

Themes of personhood and person-centred care are key to this conception of wellbeing. Kitwood and Bredin (1992) emphasised the interaction of personal, environmental, social, and biological factors in the lived experience of dementia. The present study reported the experience of these elements except for biological factors. However, the emphasis on biomedical care in an acute setting precluded a focus on biological factors during the implementation of the art activity in the ward day room. The social factor of the lived experience of dementia is where the digital and traditional activities differed the most. Traditional activities were found to facilitate group socialisation, with the art programme

leader more of an equal part in the group. Digital activities were found to require more hands-on leadership from the art programme leader and volunteers, creating a social dynamic requiring trust on the part of the hospital inpatient with dementia. This trust was rewarded, evidenced by the feeling of self-efficacy reported by digital group participants.

The present section identified two themes for explication: *Identity as an artist* and *social engagement*. While other themes contributed to wellbeing, these were seen as particularly strong across types of art programmes and not discussed in other sections.

***Identity as an artist.*** The PERMA elements of meaning and accomplishment were explored through participants' self-conception as artists. The present study reported that most participants, including enthusiastic joiners, expressed some concern about their identity as an artist or musician. As self-identity across roles declines in dementia (Cohen-Mansfield, Golander, & Arnheim, 2000), arts interventions represent potentially powerful tools for the exploration of self-identity including one's creative and technical abilities. While research has indicated that activities reinforcing previously-held identities can be beneficial for wellbeing (Cohen-Mansfield, Parpura-Gill, & Golander, 2006), the present study suggested that participants who did not previously self-identify as an artist experienced improved mood and self-efficacy after successfully creating art.

The high number of participants who hesitated due to not considering themselves artists may have been due to social risk aversion. In a population-based study across the life course, Dohmen et al (2017) found that willingness to take risks decreases with age until age 65: the minimum age for inclusion in the present study. Art therapy research has outlined elements involved in the process of forming a stronger self-identity in patients creating portraits (Carr, 2014). Further research looking at self-identity and openness to new experience in dementia could extend understanding on the balance presented here as well as findings in new learning in the arts and technology. Little research has been conducted on the impact of or capacity for new learning in dementia. Case studies (Bier et al., 2008) and experimental research (Clare et al., 2000) have investigated strategies for adapting activities of daily living, but new learning in the arts is poorly understood.

While traditional art participants unanimously experienced pride in the work they created, more uneven reactions were observed in the digital programme. The present study reported that participants experienced frustration adjusting to the use of a new digital interface. Upton et al. (2011), in a qualitative study across 11 care homes, found similar

results. However, the findings regarding individual versus group tablet use were opposite. While Upton et al. found that group activities reported that tablets were easy to use, “in contrast, participants experiencing one-to-one interactions were less convinced that the iPad was easy to use.” This discrepancy might have been due to the method of implementation or the activity itself.

***Socialisation during the session.*** The PERMA element of relationships was most thoroughly expressed through the social engagement during the session. The present study found two main types of socialisation among patient participants: art-focused and reminiscent storytelling. The positive relationships through shared experiences were also found in a variety of other arts in health group programmes. An analysis of public art in Vancouver found that public sculpture and other art facilitated conversation and orientation for people with dementia in a way similar to engagement with art creation observed in the hospital day room (Kelson, Phinney, & Lowry, 2017). In a qualitative study of “Singing for the Brain,” a group singing activity for PWD and their carers, Osman, Tischler, and Schneider (2016) found that social inclusion, support, and shared experiences were linked with positive impacts on memory and general affect.

Socialisation among the traditional groups was observed to be beneficial for wellbeing. Despite the development of doodle-directed conversation in one-to-one art programmes, the social element of group art programmes was not observed when using digital media. This echoes findings by Lim et al. (2012) who recommended that tablet activities are best suited to one-to-one engagement. In a contrasting report, Evans, Bray, and Evans (2015) reported that tablet use triggered social interaction in group environments. However, they reported that this increased interaction occurred when activities used the internet capabilities to access images, video, and music as conversation pieces.

Research has examined how the positive impacts of social inclusion might be applied to broader communities. By involving community arts practitioners, the social experience of hospital arts programmes might be made more inclusive. This potential has been realised in Japan, where programmes have been implemented for student artists to visit hospital art activities (Fondevilla & Iwata, 2016). The COOP programme has included collaborations with student volunteers as well, demonstrating feasible ways to approach social inclusion for hospital inpatients with dementia in London. Ultimately, these types of interactive programmes might include clinical care for an integrated person-centred care model.

**4.2.4.3 Implementation.** While engagement and wellbeing are key elements of the patient experience of dementia, further understanding of the hospital environment is critical to the successful ongoing implementation of arts in health programmes. Integrating clinical care with arts in health activities is also an important practice for ensuring that the arts in health programmes complement the work done by clinicians, ensuring a holistic experience of care in hospital. Understanding the clinical culture has important implications for the scheduling and implementation of arts in health programmes. Results from the present study echo feedback from other hospital art residencies. Lucy Byatt, an artist in residence at Strathmartine Hospital, Dundee, understood the importance of personal relationships with local staff (British Health Care Arts, 1997).

*“I began to feel that the best way of achieving successful working partnerships with both therapy and clinical staff was to encourage them to see that what I do, and the skills I have, could be relevant and even enliven areas of their work. The best way to do this was to start working with members of staff who were immediately enthusiastic about collaborating with me”.*

The COOP programme manager was responsible for all clinical staff relationships, and therefore functions as a bridge between clinical staff and commissioned artists. By connecting stakeholders, she gives the artists in residence room to work. This role was not taken for granted by Gwyneth Lamb (British Health Care Arts, 1997):

*“You cannot simply drop an artist onto a ward and expect them to get on with it..without good systems of communication, and “ground work” done in ensuring that all staff understand why the artist is there, friction can grow into resentment on both sides and the easiest, and perhaps the only, way the artist can resolve the situation is to close the studio door and leave the unwelcoming world of the hospital to its own devices. An artist needs adequate support. Many are expected to find their own way through bureaucratic and administrative structures”*

Once on the ward, COOP programme arts practitioners emphasised the need for open, positive energy and eye contact when first meeting patients. Anne Cattrell, an artist in residence at Thomas Clouston Clinic, Royal Edinburgh Hospital, had a similar experience in first meeting patient participants: “I have found meeting the clients in their environment helps to dispel anxiety and creates interest to motivate them to leave their ward and engage in a new activity” (British Health Care Arts, 1997).

Challenges to implementation were identified in the present study, especially in group-based interactions with a new interface. These findings echo a qualitative study performed by Upton et al. (2011), which identified “touchscreen technology as a challenge” as a key theme in the experience of using tablets for one-to-one and group interventions in care homes. Ergonomic considerations were reported, which aligns with the present study’s observation that complex screen manipulations were thought to be difficult to become accustomed to. Upton et al. also reported on the downstream social effects of this functional challenge, citing a care home staff member who worried that she might “spend too much time working out how to use it and putting off the person I am with.” However, Upton et al. believed the challenges were surmountable and did not present barriers to effective tablet use. The present study, in contrast, did not see tablet use for group artmaking as feasible, instead recommending that tablet-based art activities be used in one-to-one bedside interactions for hospital inpatients with dementia.

***The role of the arts in health programme leader.*** The present study highlights the many ways arts programme leaders interact with and support clinical staff in the care of wellbeing for hospital inpatients with dementia. The positive feedback received from therapy and medical staff indicates clinical support for the role of arts in health programme leader on the hospital ward. Cowdell (2010) used an ethnographic approach focused on the relationship between nurses and hospital inpatients with dementia. This study described reasons for difficulty providing optimal care, citing Bourdieu’s theory of practice (Bourdieu, 1977). Focused on the concept of “habitus,” Bourdieu believed that habitual practice is deeply ingrained and a reflection of cultural values. The present study found parallels, noting the potential for arts practitioners to fill the space presented by this “empathy gap.” Although a meta-analysis showed that people with severe mental illness can be helped through sustained relationships with professionals (Ljungberg, Denhov, & Topor, 2015), this is not feasible for hospital medical staff, who are often pulled in many directions at once. Arts in health programme leaders can potentially fill this void.

***Clinical culture in the care for dementia.*** Results from the present study reported universal support for the arts programmes among clinical and therapy staff, across levels of active involvement with recruiting and participating. While this is an encouraging finding for the ongoing implementation of the COOP programme, it contrasts with issues reported across acute care settings more generally. Furthermore, explicit support for the COOP programme reported in this study does not acknowledge the implicit values that might prioritise other

activities over arts in health activities. For instance, the present study reported difficulty scheduling certain activities due to healthcare assistant breaks.

While the main aim of the study was to understand the experience of arts in health interventions, it observed the value of broader organisational factors in the care for dementia and delirium in hospital. Reasons for lack of tailored care include the socio-cultural elements of ward culture and lack of communication among clinical professionals (Teodorczuk, Mukaetova-Ladinska, Corbett, & Welfare, 2015). This study pointed to the “overarching medical dominance” of the ward culture, recommending cultural historical activity theory as an approach for illuminating structural deficiencies in care for dementia. Adoption of technological innovations may aid in addressing these challenges. Symon, Long, and Ellis (1996) identified ways computer-supported cooperative work should be designed in order to incorporate elements of status, conflict, and motivation in hospital settings.

The opportunity for clinical and therapy staff to see patients in a new light represents the iteratively communicative nature of artistic expression. Stigmatised attitudes towards older patients with frailty or dementia have been documented by George, Long, and Vincent (2013) and Oliver (2008). No clinicians observed in the present study exhibited these attitudes, which may have been subject to selection bias. If clinicians with stigma towards older patients existed on the included wards, they may have been less likely to participate in the arts activities. Regardless, the increased empathy observed in attending clinicians through the art programmes shows the potential to decrease implicit stigma and explicit stigma in other acute care settings. This increased empathy is tied to person-centred and holistic care (Irving & Dickson, 2004), approaches that are recommended at local and national levels. Additionally, environmental interventions can serve to address the ward culture. By having patient art displayed in the ward, clinical staff might be given passive opportunity to consider the patient as an expressive person rather than a medical case to be solved. This was observed to be the case in Edgar Horne Ward, where the COOP programme installed shelves for the display of patient art on a rotating basis.

The interplay between interpersonal clinical care and the built environment in which it takes place affects the lived experience of dementia in hospital (Digby & Bloomer, 2014; Hung et al., 2017). Holden and Woods (1995) described the “psychological environment” which they defined as a space which “creates a feeling of worth or well-being.” This term might describe the intersection of activity and environment provided by group art in the day rooms. The physical environmental shift, coupled with the activity, promotes socialisation.

Each of these things individually seems to contribute to wellbeing, and their confluence is all the more powerful.

Additional benefits to clinical culture were observed in the co-creation of art between patient participants and physiotherapists who attended the activity with them. For these dyads, art served as a focus for communication. For tablet activities, Upton et al. (2011) highlighted “intergenerational parity” as a benefit. This was due to the ability of participants and children to interact using a shared medium. While the present study did not include intergenerational interactions, the interactional benefits derived let clinicians and patient participants share in co-creation in a way they would not have outside of an art programme. Findings in the present study echo Holden (1995) who stated, “if both the participants in the conversation have their attention on something specific...it is more likely that the patient will remain on the same topic as the staff member.” Lim et al. (2012) also recommended one-to-one tablet use in order to properly calibrate engagement with the tablet individually. Further to the group art activities, this concept is exemplified by the doodle-directed conversation reported in Section 4.2.3.

***Activity environment.*** Just as mind and body are intimately linked, so are activity and environment, and the state of one greatly depends on and interacts with the other. The present study emphasises the importance of the day room environment. Through a combination of travel, change of posture, meeting new people, and change of surroundings, patients were observed and professed to feel different and ready to engage. Gilmour (2006) argued that the intentional creation of a home-like space in a hospital environment “is an expression of core nursing values...and supports the maintenance of identity and personal expression.” Indeed, consideration of environment should not be cast aside when considering acute care considering that it is a “part of the therapeutic process” (Coser, 1962).

Results from the present study indicate that some potential participants may have refused participation due to the distance needed to travel to the day room. Similar challenges have been reported elsewhere. Phinney, Chaudhury, and O’Connor, (2007) identified a barrier to recruitment of hospital inpatients to activities in the day room, finding that “familiarity of the social and physical environment promotes involvement in activities.” Refusal to travel may have been influenced by the decline of spatial information processing and resulting disorientation in dementia (Booth et al., 2016). In cases when the day room activity space was unavailable, these patients were able to be reached at the bedside and were able to engage with the arts without the environment changing.

A qualitative study of hospice care environments in Sweden proves instructive for how the environmental design of hospital wards can be approached. Rasmussen and Edvardsson (2007) described how patients feel the “atmosphere or spirit of the place,” which has influence, whether positively or negatively. They went on to explore the environmental impact on wellbeing, including positive aspects of “home” environments and “cultures of slowness.” They referred to the ward environment as an “elusive phenomenon,” perhaps referring to the transient nature of patients and staff combined with the constant stream of medical equipment and processes. Their work focused on the subjective concept of “home.” No participant in the present study had been under the illusion that the hospital represents home. Indeed, most patients treated their environment as antithetical to home, evidenced by emphatic pleas to be able to go home that may have been related to BPSD. The other central concept was “atmosphere,” which they described as encompassing both physical and psychosocial aspects of the environment. This was less apparent in the present findings, where the day room was more a simple change of pace.

Environmental effects for other patient groups have been considered. Rowlands and Noble (2008) performed qualitative research on the environmental effects of hospital wards on cancer patients. They identified four themes: *staff behaviour*, *immediate environment*, *single vs multi-bedded rooms*, and *contact with outside environment*. While participants in the present study faced similar challenges, their experiences were best summarised by a consideration of the ways physical environment, social environment, and activity interacted. The day room was the setting in which this artistic and social exchange was best expressed. This was achieved by a physical separation from the bed bay – the domain of clinical care. For patient participants, the bed bay represented sleepless nights listening to the cries of an agitated neighbour. It represented a focus on their neighbour’s illness rather than their neighbour’s history, spontaneity, or whimsy. In the day room, patients sat upright and looked each other in the eye in an environment that let them engage socially as people rather than patients.

**4.2.4.4 Limitations and areas for future research.** As a qualitative method, ethnography has been criticised for its ability to only describe a single place and time. It does, however, have merit in asking questions not suited to quantitative inquiry (Leung, 2015). Presenting research using an ethnographic approach necessarily prioritises the researcher’s perspective and interpretation of events (Savage, 2000). In structuring the order of studies to be completed in this PhD, this ethnographic study was scheduled to both precede and

coincide with the controlled study in an effort to maximise the iterative process of thematic consolidation. This allowed for use of the knowledge, experience, and relationships developed through the experimental and cross-sectional studies to inform the observations made in the ethnographic study.

While the environmental and social impacts of group art programmes can be attributed to the impact of the day room, many potential participants were not able to be transported. Other times, art programmes had to be cancelled due to the day rooms being occupied. In these cases, bedside artistic engagement is recommended. Digital art and music are recommended for bedside activities while traditional media are better for group activities in the day room. There are a few advantages to digital media at the bedside. Firstly, they are self-contained to a single tablet, eliminating the need for setup and clean-up. By cutting out the setup and clean-up, these digital programmes can save on time and space, both of which are valuable resources for individual bedside activities on a hospital ward. Secondly, tablets functioned individually even during group sessions. Because patients were usually engrossed with learning the rules of a new device, they seldom looked up enough to notice the other members of the group. This effect could be put to better use in the hospital bed where patients would more likely want to be provided an escape from their environment. Furthermore, consideration should be given to the type of patient who would particularly enjoy digital art. According to this study's results, enthusiastic joiners enjoyed the novelty and were more engaged with digital tablets than hesitant joiners.

This fundamental difference in the way art is experienced across media should be further explored. Experimental studies could use the digital media sessions as a method of controlling for socialisation during group art activity. This way, differences in outcome measures could be explained in part to the socialisation present in traditional art groups and absent in digital art groups.

Results from the present study might contribute to the emerging “participatory arts methodology.” In an exploratory cross-cultural study, Raw (2014) identified similarities between arts practices in Northern England and Mexico City. This practice found similar approaches among practitioners and groups across different settings. This group of results resonates with the COOP programme arts practice.

Alongside future research in digital art engagement might come the development of applications for artmaking in dementia. Findings from the present study indicate the need for

simplicity in application design. Artmaking apps, for instance, currently rely on layered menus in order to access precise controls over colour, texture, and thickness. For patients with dementia, it would be preferable to have less precise controls that are more immediately accessible on the main screen of the application. Fluidity comes from intuition and readily-available onscreen tools. For example, the “undo” button and the “eraser” button were quickly understood and integrated into the process among study participants.

**4.2.4.5 Conclusion.** This focused ethnography aimed to investigate the experiences of engagement with digital and traditional media for hospital inpatients with dementia in a group setting. Its results will be triangulated with the results of a 3-arm controlled study to answer the main research questions of this thesis, including

- How does arts engagement affect the patient experience of hospital inpatients with dementia?
- How do traditional and digital versions of arts in health programmes compare in affecting anxiety in hospital inpatients with dementia?
- How do traditional and digital versions of arts in health programmes compare in affecting wellbeing in hospital inpatients with dementia?
- How do traditional and digital versions of arts in health programmes compare in engaging hospital inpatients with dementia?

To answer these questions, the present study used participant observation and semi- and un-structured interviews to explore the relationships and processes involved with the regular production of arts in health programmes in a hospital ward day room. It identified key clinical and organisational partners as well as different ways patients relate to the prospect of attending a group art programme. It then went on to explore the experience of hospital inpatients with dementia in group art programmes in general before comparing and contrasting experiences in music and visual art, using digital and traditional media. Broadly, traditional media were more effective for fostering a social, group atmosphere while digital media facilitated curiosity and exploration of novelty. Finally, it was suggested that future quantitative studies investigate the magnitude of these differences on psychological health and wellbeing. Further research presented in Chapter 5 explores the impact of this difference on positive and negative mental health through measures of wellbeing and anxiety.

## CHAPTER 5 THREE-ARM CONTROLLED STUDY

### 5.1 Introduction

The complex interactions between activity, environment, and socialisation described in Chapter 4 provided the basis for exploring quantitative measurements of the experience of digital and traditional programmes. The focused ethnography reported that factors such as availability of space, staff communication, and willingness of patients impacted on the feasibility of implementing the art programme. Along with setting the context for the implementation of the programme, Chapter 4 described qualitative findings regarding patient experience once engaged in the art programme. In doing so, it addressed the primary research questions of this thesis: *How does arts engagement affect the patient experience of hospital inpatients with dementia?*

Chapter 4 also considered the impact of engagement with digital media versus traditional media. In doing so, it addressed three of the secondary research questions, including

- How would traditional and digital versions of arts in health programmes compare in affecting anxiety in hospital inpatients with dementia?
- How would traditional and digital versions of arts in health programmes compare in affecting wellbeing in hospital inpatients with dementia?
- How would traditional and digital versions of arts in health programmes compare in engaging hospital inpatients with dementia?

While the focused ethnography identified and explicated themes of experience answering these questions, it was conceived as part of a mixed-methods study to be triangulated with a quantitative study measuring change in relevant outcomes. This chapter therefore reports on a quasi-experimental study that was designed and undertaken to measure engagement, wellbeing, and change in anxiety across groups engaged in traditional and digital artmaking as well as a control group.

### 5.2 Methodology

The present study is the last of three phases designed to answer the thesis research questions. First, a cross-sectional study measured current and previous cultural and artistic engagement and analysed associations with loneliness, depression, and quality of life. Second, a focused ethnographic study used embedded observation and interviews to identify themes of experience of engagement in group art activities among people with dementia.

Methodology for the broader mixed-methods study is presented in Chapter 2. The study reported here is a 3-arm controlled study including a control group and two intervention groups: traditional media and digital media. Among interventional research designs, randomised controlled trials (RCTs) are widely considered the most authoritative (Sibbald and Roland, 1998). RCTs are generally used to assess the causal links between an intervention and its intended outcomes in a generalised population. However, the aim of the present study was to investigate the effects of arts in health programmes as they exist in the hospital setting. Patient participants in the Care of Older People (COOP) programme elected to take part, and no patient was prescribed or coerced. The focused ethnography examined the programme in this naturalistic setting, and the quantitative portion took the same approach. Therefore, a non-randomised, quasi-experimental study that controlled for potential confounding factors was undertaken. All participants, regardless of study group, participated in a pre- and post-questionnaire. This questionnaire can be found in Appendix C.

The present study focused on visual art programming alone, in contrast to the range of media included in the focused ethnographic study. The decision to focus on one type of art engagement was made after consideration of many factors. First, limiting the type of engagement to visual art production allowed the present study to control for the type of engagement and its impact on outcome measures. Second, the number of art group leaders was controlled for by only including one type of art engagement. The level of control inherent in this methodology, contrasted with the focused ethnography, reflects the broader pragmatic epistemology of mixed methods in studying engagement with the arts through a scientific lens. Third, it filled a gap in the research field identified from the systematic literature review presented in Chapters 1 and 2. Only two of the nineteen studies reviewed were of visual art-based programmes. The study by Hazzan et al. (2016) was a qualitative descriptive study of eight participants with dementia. Their study categorised themes of engagement with the arts. Carer involvement was considered a key part of engagement, however the focused ethnography did not observe family carers in any programmes. Hattori et al. (2011) reported results from a controlled study with thirty-nine participants, finding reduced apathy after engagement in a colouring activity. These studies demonstrated the feasibility of a range of methodologies for studies focused on visual art activities, but they represented a small evidence base compared with the nine music-based studies reviewed. Finally, the difference in technical method was larger between digital and traditional visual arts media than music. Digital music engagement was found to be similar to

traditional media because it involved tapping on the screen. However, the digital visual art activities required patients to have a more nuanced ability to interact with the screen by navigating menus and using multiple gestures to create textured paint strokes. This was observed to effect a significantly different experience between digital and traditional visual art groups, which was then expected to yield more divergent impacts on experience when measured with validated scales in the controlled study.

### **5.2.1 Instruments**

This study used anxiety, wellbeing, and engagement as key outcome measures of interest. These were identified from existing literature and through conversations with local clinical staff as measures that are particular challenges for hospital inpatients with dementia and that might be addressed through an arts in health intervention. The choice to include one measure of wellbeing and one measure of mental ill health (anxiety) was chosen based on research indicating that they are not simply opposites of one another. Rather, Keyes (2005) found that mental wellbeing and illbeing existed on different continua, indicating a need to measure both in order to holistically evaluate the effects of a psychosocial intervention. Specific scales were chosen based on validation with the study population and ease of administration.

**Measuring Anxiety.** Anxiety was chosen as a measure of mental ill health due to its changeability compared with depression. Measurements of depression such as the Geriatric Depression Scale do not account for changes over a short time period (Sheikh & Yesavage, 1986). The full State-Trait Anxiety Inventory (STAI) is one of the most widely used scales for measuring anxiety across populations (Tluczek, Henriques, and Brown 2009) including people with dementia (Forstmeier, Maercker, Savaskan, & Roth, 2015; Narme et al., 2012; Taşdemir & Oz, 2011). However, the STAI includes 40 items and can take up to 20 minutes to administer, making it unsuitable for inclusion in two questionnaire batteries surrounding an hour-long intervention. In response to this limitation, multiple short forms have been developed specifically for use in fast-paced acute settings. (Chlan, Savik, and Weinert 2003; Marteau and Bekker 1992). Among them, the version developed by Marteau and Bekker has been identified as more suited to less immediate, anticipatory anxiety associated with dementia (Tluczek, Henriques, and Brown 2009). Furthermore, its brevity lends it to unobtrusive administration. In a direct precedent to the present study and it has been used to evaluate an arts in health intervention using a pre- post-design in a naturalistic setting (Sandmire, Gorham, Rankin, & Grimm, 2012). The 40 items of the original STAI are each

measured on a 4-point scale, with respondents agreeing on a scale from “not at all” to “very much” with statements such as “I feel calm” and “I am tense” (Marteau & Bekker, 1992). Scores from the 6-item short form are then multiplied by 3.33 in order to standardise it to the 20-item original STAI. Higher scores indicate higher levels of anxiety, and on a 20-80 point scale, 30 has been used as a cut-off point between low and moderate anxiety (Devier et al., 2009).

**Measuring wellbeing.** Subjective wellbeing has been measured using a variety of methods. The systematic review presented in Chapter 1 identified three measures of wellbeing used for hospital inpatients with dementia. Wu and Koo (2015) used the Herth Hope Index, Life Satisfaction Scale, and Spirituality Index of Wellbeing. However, these scales contain items focused on longer-term outlook. While this made them appropriate for the 6-week intervention studied by Wu and Koo, the present study focused on shorter-term impacts from a single intervention. Observational measures are also popular for use with people with dementia, including the Observed Emotion Rating Scale (Cheong et al., 2016) and the Greater Cincinnati Chapter Well-Being Observation Tool (Kinney & Rentz, 2005).

Outside of the hospital environment, Positive Affect Negative Affect Scales and Visual Analogue Scales (VAS) have been used in many studies of short term wellbeing effects of heritage-in-health interventions (Camic, Hulbert, & Kimmel, 2017; Chatterjee & Thomson, 2015; Johnson, Culverwell, Hulbert, Robertson, & Camic, 2015). VAS are often used to measure subjective experience and health-related quality of life. They have also been used with people with dementia, and research has found that VAS results for people with dementia track closely with the general population (Arons, Krabbe, van der Wilt, Olde Rikkert, & Adang 2013). Arts in health programmes, being targeted towards wellbeing and quality of life outcomes, are especially eligible interventions for the use of VAS. The Canterbury Wellbeing Scale (CWS) has been recently developed to measure the experience of people with dementia in museum object handling programmes (Johnson, Culverwell, Hulbert, Robertson, & Camic, 2015). The CWS has been used with people with mild-to-moderate dementia in museum groups (Camic, Hulbert, & Kimmel 2017) and is currently being validated for non-English language use.

However, this study made use of the UCL Museum Well-being Measures Toolkit. Involving specialists across 32 museums, 4 development phases, and partner feedback (Thomson & Chatterjee, 2015), the toolkit has been used in many pre- post- studies to measure short term changes in wellbeing (Chatterjee & Thomson, 2015; Thomson, Ander,

Menon, Lanceley, & Chatterjee, 2012). Additionally, it has been used with older adults in healthcare settings, including an acute hospital in London (Thomson & Chatterjee, 2016).

From the UCL Wellbeing Measures Toolkit, the present study used the Generic Wellbeing Questionnaire (GWQ) short version. As the name suggests, the toolkit was developed to measure wellbeing effects of museum interventions for older people, including those with dementia. However, the toolkit has been used for measuring wellbeing outside of museum settings. Paddon et al (2014) used elements of the toolkit as pre- and post-session scales to measure change in wellbeing. The toolkit includes scales developed for different types of interventions and populations, and it explicitly encourages a “pick and mix” approach (Thomson & Chatterjee, 2013). It includes long and short versions of the GWQ, and the short version was chosen in order to keep the questionnaire battery brief.

Because the GWQ asks wellbeing questions retrospectively, it was only used in the post-activity questionnaire battery. Questionnaire items include positive statements such as “I felt happy” and “I felt engaged,” and participants are asked to indicate the level of agreement they have with each item. The short version used for the present study includes 6 items, each measured on a 5-point scale from “none of the time” to “all of the time.” Total wellbeing scores were calculated as the sum of the 6 item responses for a final scale of 6 – 30. A higher score indicates a higher level of wellbeing, and post-activity scores were used to compare wellbeing benefits from each intervention group and the control group. While recall bias may be an issue among participants with severe dementia, this scale was developed for people with dementia who would be likely to recall their experiences over the past hour or two (Thomson & Chatterjee, 2014).

**Measuring engagement.** Different measurements of engagement in dementia exist on a spectrum between purely qualitative observations of relative engagement and quantified, atomised facets of engagement. The focused ethnography presented in Chapter 4 developed its own themes of engagement, but quantitative measures of engagement also exist. The Observational Measure of Engagement (OME) (Cohen-Mansfield, Dakheel-Ali, & Marx, 2009) utilises both qualitative and quantitative measures of engagement. Developed for use with care home residents with dementia, the OME is useful for its unobtrusive collecting methods and nuanced measurements of different dimensions of engagement. Importantly, it includes provision for recording notes for each 15-minute window. As no two observation periods are the same, this note-taking section is potentially useful for linking qualitative phenomena to trends in quantitative data collected by the OME.

Other measures of engagement were identified by this thesis's systematic review of arts in health activities for hospital inpatients with dementia. Rylatt (2012) used a researcher-developed measure in a bespoke service evaluation. Hazzan et al. (2016) also developed their own measure of engagement by modifying the Philadelphia Affect Rating Scale. Cheong et al. (2016) used the Menorah Park Engagement Scale (MPES) to measure engagement in individual and group creative music therapy. Inspired by the Montessori educational method, Cameron Camp developed a programme called Montessori Programming for Dementia (MPD) (Camp, 2010). In developing the MPD, Camp identified engagement as the most salient outcome and developed the MPES to measure engagement to MPD. While MPES has been used to evaluate engagement for other programmes (Volicer & van der Steen, 2014), it was tailored specifically for use with MPD. Involving 4 categories of engagement (constructive, passive, self-, and non-engagement), MPES records only the most desirable, "highest" form of engagement. In practice, this means a programme participant who may be absent-mindedly engaged in the activity would be marked as constructively engaged with no acknowledgement of distraction or observed apathy. This approach therefore tends to simplify the analysis and potential complexity of engagement during an arts in health programme.

The utility of the OME has been recognised by researchers working to develop a tool for measurements engagement in hospital activities. Morse and Chatterjee (2017) developed the Museum Engagement Observation Tool, which integrates elements from the OME and the Video-Coding-Incorporating Observed Emotion. Developed specifically for hospital inpatients with dementia, the Museum Engagement Observation Tool is a thorough intra-activity tool that elicits richer data than the OME alone. However, its depth could mean potential difficulty in applying to multiple patients within a single session. Additionally, the quick use of OME items lends itself more easily to analysis comparing simple engagement measures to changes in anxiety and wellbeing.

The development of the Museum Engagement Observation Tool points to the adaptability of the elements included in the OME. These elements include: *rate of refusal*, *duration of time engaged with stimulus*, *level of attention towards stimulus*, *attitude towards stimulus*, and *type of action towards stimulus* (Cohen-Mansfield, Dakheel-Ali, and Marx, 2009). The present study used three of these elements: *duration*, *level of attention*, and *attitude*. These elements were chosen based on relevance to the activities observed and the example set by Leone et al. (2012), who used these three elements of the OME in a study of

tailored stimuli for activities with people with dementia. Duration was measured in number of seconds engaged over a 15-minute period. Level of attention was measured on a 1 – 4 point scale, with 1 being *not attentive* and 4 being *very attentive*. Attitude towards the stimulus was measured on a 1 – 7 point scale, with 1 being *very negative attitude* and 7 being *very positive attitude*. Potential issues exist with the terminology of the term “attitude” for this element of the OME. “Attitude” might be seen as an internally-focused judgement of the emotional and mental state of the person with dementia. Given the complex personality (Rankin, Baldwin, Pace-Savitsky, Kramer, & Miller, 2005) and behavioural (Snowden et al., 2001) changes that occur in dementia, a measure of “attitude” could be skewed or unfairly harsh toward the participant. Rather, this element of the OME is observed externally on a scale from “very negative” to “very positive.” It therefore bears resemblance to and may be thought of as “affect” or “observed mood” as found in other scales for dementia such as Dementia Quality of Life Instrument (Chua et al., 2016) or the Philadelphia Geriatric Center Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996). The form for the OME tool used for the present study can be found in Appendix D.

### **5.2.3 Study procedure**

Patients aged 65 and over who selected to take part in the arts programme on any day during the period of study were approached at their bedside by the researcher about 30 minutes before the beginning of a scheduled art session. Those who did not decline to participate were provided information to consent. After informed consent was given, the Mini-Mental State Exam (MMSE) was administered. If the participant scored between 10 and 23 points, inclusive, the baseline questionnaire was administered. The baseline questionnaire included demographic questions and the STAI. After giving informed consent and completing the baseline questionnaire, participants were taken by ward staff to the day room to participate in the 60-minute art activity. Details of digital and traditional visual art programmes can be found in Section 4.1.4, and details of the study environment can be found in Section 2.4.3. During the activity, engagement was measured using the OME (Cohen-Mansfield, 2009). Within 30 minutes after each art activity ended, a follow-up semi-structured verbal questionnaire was administered. The follow-questionnaire included a follow-up STAI and the GWQ. On days when there was not an arts activity scheduled to take place, potentially-eligible patients were approached at their bedside and asked to take part in the study as controls. Their involvement consisted of completing the two questionnaires an hour apart, but without taking part in the arts activity in between. Engagement was not

measured in the control group because there was no activity undertaken as a part of normal care. Participant involvement for both groups ended when the follow-up questionnaire was completed. All questionnaires were designed to take as little time as possible. They were verbally administered to account for patients who may have had seeing impairment or were confused by filling out the questionnaire form. Participant involvement is further described by the flowchart in Figure 13.

#### **5.2.4 Study Participants**

Study participants were hospital inpatients at an NHS Trust with mild to moderate dementia. Inclusion criteria were willingness and ability to give informed consent for participation in the study, a score between 10 and 23 on the MMSE, age of at least 65 years, and status in a hospital ward as an inpatient. Exclusion criteria included a participant scoring below 10 on the MMSE, indicating severe dementia, severely impaired sight or hearing, or the existence of a language barrier, preventing the patient from understanding the questionnaire or providing informed consent.

#### **5.2.5 Statistical methods**

Data were analysed using IBM SPSS Statistics 23.0 software. Descriptive statistics were used to describe means and frequencies of variables measured. Multivariate analysis of covariance (MANCOVA) was used to test for significant differences between group means. The assumption of equality of covariance was checked using Box's Test of Equality of Covariance Matrices, and  $p$ -values greater than .05 were accepted. Error variances were measured using Levene's Test of Equality of Error Variances, and  $p$ -values greater than .05 were accepted. Change in anxiety between groups was measured by comparing post-activity measurements and using pre-activity measurements as covariates in the MANCOVA. Two-sample  $t$ -tests were carried out for dimensions of engagement as engagement was not measured in control group participants who did not participate in an arts activity.

Pearson correlations were used to analyse associations between engagement, anxiety, and wellbeing variables. For the MANCOVA, variance inflation factor and tolerance scores were used to confirm lack of multicollinearity. To suggest homoscedasticity, plots of standardised residuals vs standardised predicted values showed no clear funnelling. Cook's Distance values were calculated for regression models for variables predicting anxiety and wellbeing, and cases under 1 suggested no undue influence on the model. The Durbin Watson

Test was used to check for autocorrelation among predictor variables, and values between 1.5 and 2.5 were accepted.

### 5.3 Results

Ninety hospital inpatients with dementia were recruited to the study. Thirty participants were recruited to each of the three groups, and no participants dropped out over the course of the study. Recruitment reached the originally intended number, however it took longer than originally intended. Original study ethics for the present study and the focused ethnographic study were approved for data collection to take place between September and December 2017. However, data was collected for only the focused ethnographic study during this period. Therefore, ethical approval was obtained to extend the data collection period through July 2018. Recruitment for the present study ran from January – April 2018.

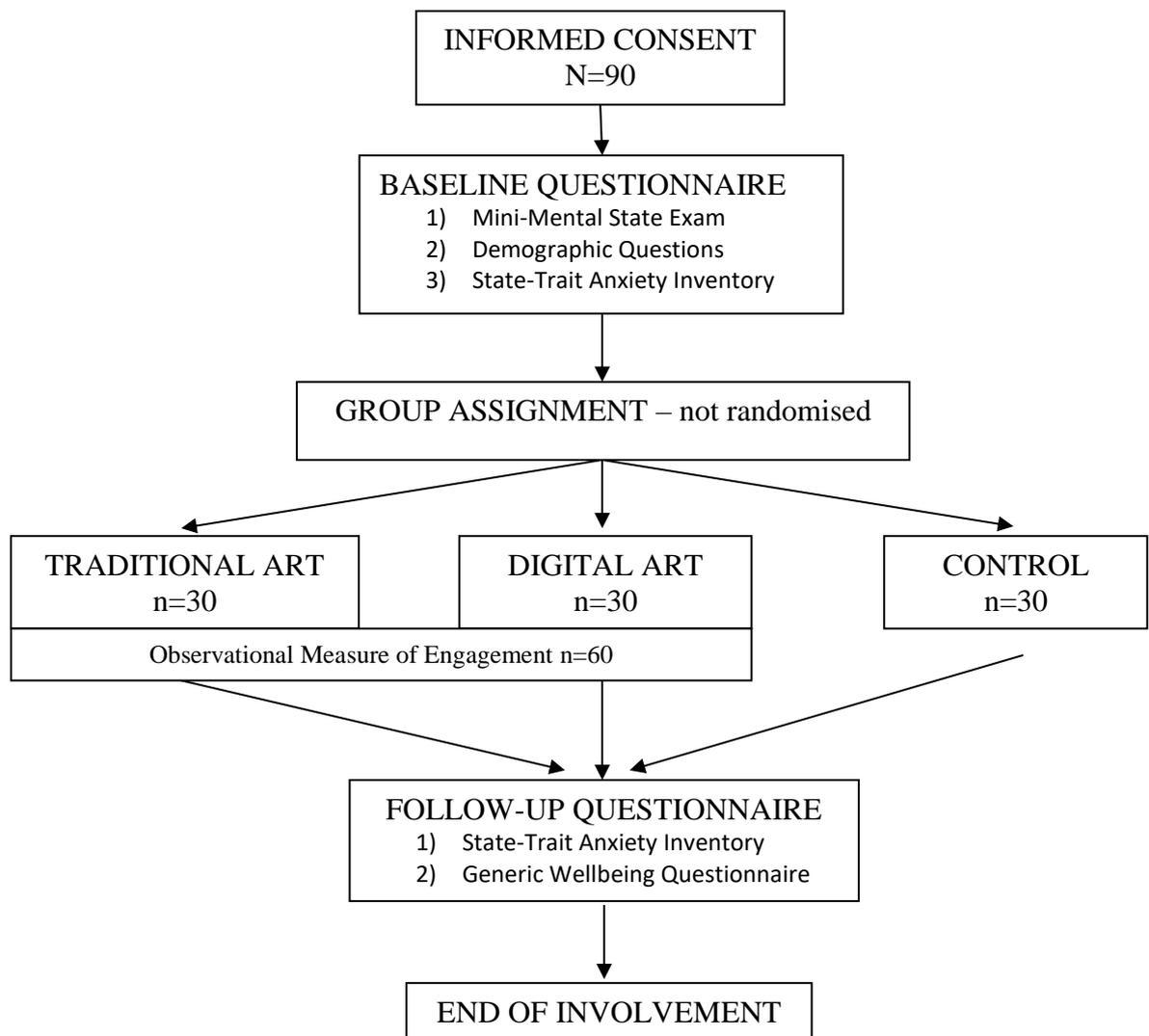


Figure 13. 3-arm controlled study participant recruitment diagram.

### 5.3.1 Demographic variables

Means of each variable by intervention group are displayed in tables below. Where non-parametric distributions of demographic variables were identified, they were transformed in order to be included in parametric analysis.

**Age.** Mean age was 80.68 years (SD = 6.5) with a skewness of -.154 and a kurtosis of -.674. A Kruskal-Wallis H test showed that there were no statistically significant differences in age among the three groups,  $\chi^2(2) = 5.80$ ,  $p=.06$ .

**MMSE.** Mean MMSE score was 17.66 (SD = 3.49) with a skewness of -.245 and kurtosis of -.692. A Kruskal-Wallis H test showed that there were no statistically significant difference in MMSE score among the three groups,  $\chi^2(2) = 3.46$ ,  $p=.18$ .

**Sex.** Study participants were 54.4% female (n=49) and 45.6% male (n=41). A Kruskal-Wallis H test showed that there were no statistically significant differences in sex ratio among the three groups,  $\chi^2(2) = 1.70$ ,  $p=.43$ .

Table 24

*Participant Sex by Study Group*

<b>Sex</b>	<b>Female (%)</b>	<b>Male (%)</b>
Traditional	19 (63)	11 (37)
Digital	16 (53)	14 (47)
Control	14 (47)	16 (53)

**Educational attainment.** Level of education was coded into four groups: leaving school before age 16 (31%), age 16 – 18 (37%), undergraduate education (22%), and postgraduate education (3%). A Kruskal-Wallis H test showed that there were no statistically significant differences in level of education among the three groups,  $\chi^2(2) = .23$ ,  $p=.89$ .

Table 25

*Educational Attainment by Study Group*

<b>Educational Attainment</b>	<b>&lt;16 years (%)</b>	<b>16-18 years (%)</b>	<b>Undergraduate (%)</b>	<b>Postgraduate (%)</b>
Traditional	8 (30)	11 (41)	7 (26)	1 (4)
Digital	9 (32)	12 (40)	7 (25)	0 (0)
Control	11 (37)	10 (33.3)	6 (20)	2 (6.7)

**Number of Cohabitants.** The mean number of cohabitants was .55 (SD = .93) with a skewness of 1.92 and a kurtosis of 3.17, indicating a strong positive skew. To act as a covariate for analyses of variance, number of cohabitants was binarised between no cohabitants and any number of cohabitants. After binarisation, skewness was .63, and kurtosis was -1.65, producing a normalised variable able to be included in an analysis of covariance. A Kruskal-Wallis H test showed that there were no statistically significant differences in number of cohabitants among the three groups,  $\chi^2(2) = 2.90$ ,  $p = .87$ .

**Length of Stay.** Mean length of stay was 17.81 days with a skewness of 2.40 and a kurtosis of 6.0, indicating a positive skew. To act as a covariate for analyses of variance, length of stay was categorised into five windows: 1 – 4 days, 5 – 7 days, 8 – 14 days, 15 – 30 days, and 31 – 150 days. Skewness of the binned data was .21 and kurtosis was -1.22, indicating an acceptably normal distribution able to be included in an analysis of covariance. A Kruskal-Wallis H test showed that there were no statistically significant differences in length of stay among the three groups,  $\chi^2(2) = 1.22$ ,  $p = .54$ .

Table 26

*Demographic Variable Means by Study Group*

<b>Demographic Measurement</b>		<b>n=</b>	<b>Total Mean</b>	<b>Traditional</b>	<b>Digital</b>	<b>Control</b>	<b>Test Statistic</b>	<b>p-value</b>
Sex	Female	90	49 (54.4%)	19 (63.3%)	16 (53.3%)	14 (46.7%)	$\chi^2(2) = 1.70$	.43
	Male		41 (45.6%)	11 (36.7%)	14 (46.7%)	16 (53.3%)		
MMSE Score		90	17.66 (3.49)	17.97 (3.87)	18.30 (3.10)	16.70 (3.37)	$\chi^2(2) = 3.46$	.18
Length of Stay	1-4 days	85	22 (24.4%)	11 (36.7%)	6 (20%)	5 (16.7%)	$\chi^2(2) = 1.22$	.54
	5-7 days		21 (23.3%)	5 (16.7%)	10 (33.3%)	6 (20%)		
	8-14 days		17 (18.9%)	4 (13.3%)	6 (20%)	7 (23.3%)		
	15-30 days		18 (20%)	7 (23.3%)	3 (10%)	8 (26.7%)		
	>30 days		12 (13.3%)	3 (10%)	5 (16.7%)	4 (13.3%)		
Age		90	80.68 (6.47)	80.27 (6.62)	76.97 (6.46)	82.80 (5.92)	$\chi^2(2) = 5.80$	.06
Number of cohabitants	0	85	55 (61.1%)	19 (63.3%)	18 (60%)	18 (60%)	$\chi^2(2) = 2.90$	.87
	1+		30 (33.3%)	9 (30%)	10 (33.3%)	11 (36.7%)		
Education	<16 years	84	28 (31.1%)	8 (26.7%)	9 (30%)	11 (36.7%)	$\chi^2(2) = .23$	.89
	16 – 18 years		33 (36.7%)	11 (36.7%)	12 (40%)	10 (33.3%)		
	Undergraduate		20 (22.2%)	7 (23.3%)	7 (23.3%)	6 (20.0%)		
	Postgraduate		3 (3.3%)	1 (3.3%)	0	2 (6.7%)		

Note. MMSE = Mini-Mental State Exam

Table 27

*Anxiety and Engagement Variable Means by Study Group*

<b>Outcome Measurement</b>	<b>n=</b>	<b>Total Mean</b>	<b>Traditional</b>	<b>Digital</b>	<b>Control</b>	<b>Test Statistic</b>	<b>p-value</b>
STAI Pre-Test	90	49.78 (17.10)	48.89 (15.37)	47.33 (18.93)	53.11 (16.86)	$\chi^2(2) = 1.62$	.45
STAI Post-Test	90	46.41 (17.12)	41.78 (16.06)	45.44 (17.16)	52 (17.06)	$\chi^2(2) = 5.38$	.07
Duration OME	60	589.50 (246.20)	545 (261.54)	634 (225.43)		$\chi^2(1) = 1.67$	.20
Attention OME	60	3.02 (.83)	2.90 (.85)	3.13 (.82)		$\chi^2(1) = 1.28$	.26
Attitude OME	60	4.27 (1.52)	5.20 (1.32)	3.33 (.78)		$\chi^2(1) = 22.83$	.000

Note. STAI = State-Trait Anxiety Inventory; OME = Observational Measure of Engagement

### 5.3.2 Outcome measures

This study measured three dependent variables for outcome measures in anxiety, wellbeing, and engagement. Anxiety was measured using the STAI before and after the intervention period. Observational measures of engagement include duration of engagement over a 15-minute period, attention paid towards the activity, and attitude taken towards the activity. Table 27 displays summary statistics for anxiety and engagement, divided by group. The GWQ was administered only after the intervention, and summary statistics for each item can be found in Table 28. This section will describe the dependent variables and the statistical procedures used to test assumptions in preparation for analyses of variance.

#### **Anxiety**

*Pre-test State-Trait Anxiety Inventory.* The mean anxiety score of the pre-test was 49.78 (SD = 17.1) with a skewness of -.128 and a kurtosis of -1.18. Mean baseline anxiety for the traditional group was 48.89 (SD = 15.4), for the digital group was 47.33 (SD = 18.9), and for the control group was 53.11 (SD = 16.9). A Kruskal-Wallis H test showed that there were no statistically significant differences in baseline anxiety among the three groups,  $\chi^2(2) = 1.62, p=.45$ .

*Post-test State-Trait Anxiety Inventory.* The mean anxiety score of the post-test was 46.41 (SD = 17.11) with a skewness of .139 and a kurtosis of -1.25. Mean post-test anxiety for the traditional groups was 41.78 (SD = 16.1), for the digital group was 45.44 (SD = 17.2), and for the control group was 52 (SD = 17.1). A Kruskal-Wallis H test showed that there were no statistically significant differences in post-test anxiety among the three groups,  $\chi^2(2) = 5.38, p=.07$ .

#### **Engagement**

*Duration - Observational Measure of Engagement.* Duration of engagement was measured in seconds engaged over a period of 15 minutes. Mean engagement across digital and traditional groups was 589.50 seconds (SD = 246.2) with a skewness of -.59 and a kurtosis of .73. Mean duration of engagement for the traditional group was 545 seconds (SD = 261.5) and for the traditional group was 634 seconds (225.4). A Kruskal-Wallis H test showed that there was no statistically significant difference in engagement duration between the digital and traditional media groups,  $\chi^2(1) = 1.67, p=.2$ .

*Attention – Observational Measure of Engagement.* Level of attention paid to the activity was measured on a scale of 1 – 4, from “not attentive” to “very attentive.” Mean attention across

digital and traditional groups was 3.02 (SD = .83) with a skewness of -.34 and a kurtosis of -.6. Mean attention for the traditional group was 2.90 (SD = .9) and for the digital group was 3.13 (SD = .8). A Kruskal-Wallis H test showed that there was no statistically significant difference in attention between the digital and traditional media groups,  $\chi^2(1) = 1.28, p=.3$ .

*Attitude – Observational Measure of Engagement.* Attitude towards the activity was measured on a scale of 1 – 7 from “very negative” to “very positive.” Mean attitude across digital and traditional groups was 4.27 (SD = 1.52) with a skewness of .10 and a kurtosis of -.95. Mean attitude for the traditional group was 5.20 (SD = 1.3) and for the digital group was 3.33 (SD = .8). A Kruskal-Wallis H test showed that there was a strongly statistically significant difference in attention between the two groups,  $\chi^2(1) = 22.83, p=.00$ , indicating a much more positive attitude observed among participants in traditional media groups compared with digital media groups.

### Wellbeing

*Generic Wellbeing Questionnaire.* Mean wellbeing scores across digital, traditional, and control groups was 20.47 (SD = 5.01) with a skewness of -.07 and a kurtosis of -.95. Scores for each item are summarised in Table 28.

Table 28

#### Mean Wellbeing Questionnaire Items

Variable(s)	Mean	SD
I felt happy		
Traditional	3.97	.89
Digital	3.50	.78
Control	2.87	1.04
I felt engaged		
Traditional	4.10	.96
Digital	4.13	.97
Control	1.67	.55
I felt comfortable		
Traditional	3.97	.96
Digital	3.73	8.28
Control	3.47	.68
I felt safe and secure		
Traditional	4.20	.71
Digital	4.07	.69
Control	4.13	.68

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I enjoyed the company of other people	Traditional	4.07	.87
	Digital	3.57	1.01
	Control	1.43	.63
I talked to other people	Traditional	3.87	.94
	Digital	3.23	.94
	Control	1.43	.63
Total GWQ Score	Traditional	24.17	3.5
	Digital	22.23	3.0
	Control	15.0	2.73

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### 5.3.3 Comparing among groups and measures

**Summary of analysis of variance among the three groups.** A multivariate analysis of covariance was conducted for the 3 participant groups for anxiety and wellbeing. This one-way MANCOVA analysed difference in post-activity anxiety and total wellbeing between groups, using pre-activity anxiety, length of stay, number of cohabitants, and age as covariates. There was a statistically significant difference between groups on the combined dependent variables after controlling for length of stay, number of cohabitants, and age  $F(4, 154) = 26.13, p < .001, \text{Wilks' } \Lambda = .355, \text{partial } \eta^2 = .404$ .

**Summary of analysis of variance of anxiety among the three groups.** This result was followed up with an individual ANCOVA test for anxiety to identify which groups differed. A one-way ANCOVA was conducted to determine a statistically significant difference between traditional, digital, and control groups on anxiety, controlling for pre-activity anxiety, length of stay, number of cohabitants, and age. There was a significant effect of group on post-activity anxiety,  $F(2, 74)=9.17, p<.001, \text{partial } \eta^2 = .20$ .

The traditional group exhibited the greatest decline in levels of anxiety. Pairwise comparisons show significant mean differences in anxiety between traditional and digital groups, with the traditional group showing lower mean anxiety following the workshop (5.28,  $p<.001$ ). Similarly, there was a significantly greater decline in anxiety in the traditional group compared with the control group (6.92,  $p<.001$ ). No significant difference in anxiety was found between digital and control groups.

**Summary of analysis of variance of wellbeing among the three groups.** As shown above, a MANCOVA found statistically significant differences between groups for outcome measures, including wellbeing, after controlling for demographic variables. Therefore, a one-way ANCOVA was conducted to determine a statistically significant difference between traditional, digital, and control groups on wellbeing, controlling for length of stay, number of cohabitants, and age. There was a significant effect of group on wellbeing,  $F(2, 75)=53.88$ ,  $p<.001$ , partial  $\eta^2 = .59$ .

Further analysis indicates that both traditional and digital groups experienced greater wellbeing than the control group. Pairwise comparisons show significant differences in wellbeing between control and traditional groups (8.97,  $p<.001$ ) and control and digital groups (7.11,  $p<.001$ ). No significant difference in wellbeing was found between traditional and digital groups.

**Summary of the differences in engagement across intervention groups.** Engagement was not measured for the control group. Therefore, a paired-samples t-test was conducted to compare the engagement duration, attention, and attitude in traditional and digital art groups. There was a significant difference in the scores for attitude for the traditional ( $M=5.20$ ,  $SD=1.32$ ) and digital ( $M=3.33$ ,  $SD=1.06$ ) groups;  $t(55.4) = 6.03$ ,  $p<.001$ , indicating that attitude towards the activity was observed to be significantly more positive in the traditional group. There was no significant difference in the scores for duration of engagement for the traditional ( $M=545$ ,  $SD=261.5$ ) and digital ( $M=634$ ,  $SD=225.4$ ) groups;  $t(56.8)=-1.41$ ,  $p=.16$ , indicating similar lengths of time spent engaged with the different media despite having different attitudes about the media. There was no significant difference in the scores for attention level of engagement between traditional ( $M=2.9$ ,  $SD=.85$ ) and digital ( $M=3.1$ ,  $SD=.82$ ) groups;  $t(57.9) = -1.09$ ,  $p = .28$ . This suggests that across both activities, participants engaged for similar amounts of time and with similar levels of attention, but there was a more positive attitude towards the traditional rather than the digital art activities.

**Summary of Pearson Product-Moment Correlations among Dependent Variables.** Correlations were run comparing results for engagement measures, anxiety, and wellbeing. A positive correlation was found between engagement duration and level of attention  $r(60) = .70$ ,  $p < .001$ , indicating that being engaged with the art activity for longer is associated with more focused attention. By some standards (Taylor, 1990), this would be regarded as a strong correlation, although this practice is debated (Kozak, 2009).

A moderately positive correlation was also found between attitude towards activity and wellbeing  $r(60) = .30$ ,  $p < .05$ , indicating that participants observed to have a more positive attitude

towards the activity also reported greater wellbeing after the programme. A moderately negative correlation was found between attitude towards activity and anxiety  $r(60) = -.46, p < .001$ , indicating that participants observed to have a more positive attitude towards the activity reported lower levels of anxiety.

**Regression Analysis for Engagement Variables Predicting Anxiety and Wellbeing.** A series of 3-stage hierarchical regression analyses were conducted with anxiety and wellbeing as dependent variables. All models controlled for age, gender effects, number of cohabitants, and length of stay. The regression for post-test anxiety controlled for pre-test anxiety in all models.

Engagement duration was not found to be significantly associated with post-test anxiety, suggesting that length of time engaged is not linked with change in anxiety. Its predictive value changed significantly with the addition of attitude towards activity to the model ( $\beta = -.264, t = -4.95, p < .001$ ), suggesting that observed attitude is more predictive of change in anxiety than duration or level of attention. Full regression results for variables predicting post-test anxiety can be found in Table 29.

*Multiple Regression Analysis of Study Group and Post-test Anxiety (N = 60)*

Table 29

Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1 Duration	.006	.004	.16	[-.002, .013]	.82	42.72 **
Model 2 Duration	.004	.005	.48	[-.007, .015]	.84	.20
Attention level	.738	1.64	.66	[-2.56, 4.04]		
Model 3 Duration	.004	.004	.35	[-.01, .013]	.90	24.50**
Attention level	1.38	1.35	.31	[-1.34, 4.10]		
Attitude	-2.64**	.53	.000	[-3.71, -1.57]		

Note. \*\*p < .01

Engagement duration was not found to be significantly associated with measured wellbeing, suggesting that length of time engaged is not linked with level of wellbeing. Its predictive value changed significantly with the addition of attitude towards activity to the model ( $\beta = .815, t = 2.69, p$

= .01), suggesting that observed attitude is more predictive of wellbeing than duration or level of attention. Full regression results for variables predicting wellbeing can be found in Table 30.

*Table 30 Multiple Regression Analysis of Study Group and Wellbeing (N = 60)*

Independent Variables	$\beta$	SE $\beta$	p	95% CI	R <sup>2</sup>	F Change
Model 1 Engagement duration	.002	.002	.40	[-.002, .005]	.07	.74
Model 2 Engagement duration	.001	.003	.76	[-.005, .006]	.07	.17
Attention level	.336	.812	.68	[-1.30, 1.97]		
Model 3 Engagement duration	.001	.003	.77	[-.004, .006]	.19	7.25*
Attention level	.136	.768	.86	[-1.41, 1.68]		
Attitude	.815*	.303	.01	[.21, 1.42]		

Note. \*p < .05

## 5.4 Discussion

This study's principle aims were to explore how anxiety, wellbeing, and engagement were affected by participation in digital and traditional media art groups by hospital inpatients with dementia. It utilised a controlled study design that included three groups: digital, traditional, and control. By measuring baseline and follow-up anxiety and follow-up wellbeing, the study was able to detect differences between groups. Intra-activity measurements of engagement duration, attention level, and attitude were also measured, and differences between intervention groups were measured. This study follows on from a growing body of literature finding that engagement with novel interventions is feasible for people with mild to moderate dementia (Fissler, Küster, Schlee, & Kolassa, 2013; Vahia et al., 2017).

### 5.4.1 Central findings.

This study found that engagement with the arts improved psychosocial outcomes for hospital inpatients with dementia compared with a control group. Both digital and traditional groups experienced higher levels of wellbeing than the control group. However, while the traditional group experienced significant decreases in anxiety, the digital and control groups showed no significant change in anxiety. This discrepancy between improvement in wellbeing and anxiety in the digital

group might be attributed to the differing qualities of engagement with digital and traditional arts media. Specifically, the duration of engagement or level of attention paid to the art sessions were not correlated with anxiety or wellbeing. However, attitude towards the art activity was correlated with improvements in both anxiety and wellbeing across digital and traditional media, suggesting the importance of patient personality and mood in group art programmes.

The present study is the largest quantitative study of visual art production as a psychosocial intervention among hospital inpatients with dementia. Hattori et al. (2011) performed the only other quantitative study of visual art production among hospital inpatients with dementia. This randomised controlled trial recruited 39 people with dementia and measured cognition, mood, vitality, quality of life, apathy, behavioural symptoms, and caregiver burden. Among outcome measures, the only significant change was a reduction in apathy. Comparisons with other types of psychosocial interventions found similar impacts on mood and wellbeing. Cheong et al. (2016) found improved mood, higher positive engagement, and lower negative engagement after participation in Creative Music Therapy. A six-week spiritual reminiscence programme was found to increase wellbeing in a Taiwan hospital (Wu & Koo, 2016). Further links with qualitative findings will be discussed in Chapter 6. Findings relating to each of the main outcome measures will now be discussed, with reference to the wider literature.

#### **5.4.2 Wellbeing**

Both digital and traditional group participants were found to have higher wellbeing levels than the control group following engagement in their activities. The present study demonstrated the feasibility of group art interventions for wellbeing improvement in hospital inpatients as a subset of broader psychosocial interventions for wellbeing (Gate et al., 2016). This indicates that, while the reported and observed experiences of digital and traditional activities may have been different, they shared a positive impact on wellbeing. Patients who attended art groups may have been more likely to socialise due to the change in physical and social environment, where patients who stayed in bed may have been less likely to socialise with their neighbours at any given hour.

The integration of social engagement and activities such as artistic engagement is central to general concepts of wellbeing. Seligman (2012) describes wellbeing as a construct with measurable elements, summarised by the PERMA model including elements of engagement, relationships, meaning, and accomplishment. A critical analysis of the literature on activity and wellbeing in older

people found the most evidence for association between informal social activity and wellbeing in later life (Adams, Leibbrandt, & Moon, 2011). Across digital and traditional media, art groups may provide this short-term informal social activity by integrating it with artistic expression.

It should be highlighted that wellbeing was measured only by the second questionnaire, whereas anxiety was measured both before and after the intervention period. This element of the study design was included because the GWQ includes retrospective questions focused on the experience of the period in question – the art programme for the intervention groups and the previous hour for the control group. While change in wellbeing was not measured, comparisons of perceived wellbeing over the past hour can be made between groups.

This study adds evidence to the literature around visual artmaking and wellbeing. Kinney and Rentz (2005) found improved elements of wellbeing including attention, pleasure, self-esteem, and normalcy after participation in the painting activity *Memories in the Making*. Additionally, this study contributes to work done pushing forward the use of technology in artmaking to optimise the improvement of wellbeing (Damianakis, Crete-Nishihata, Smith, Baecker, & Marziali, 2010; Mihailidis et al., 2010).

### **5.4.3 Anxiety**

Baseline anxiety scores were high, indicating the need to implementing strategies to lower anxiety in hospital inpatients with dementia. The overall mean baseline anxiety score for study participants was 49.78, well above the cut-off score that has been used to indicate moderate anxiety (Devier et al., 2009). This could be attributed to the cumulative effect of dementia, comorbidities, and unease living in a hospital environment. High rates of anxiety have been measured in hospital environments across patient groups (Bjelland, Dahl, Haug, & Neckelmann, 2002; Gullich, Ramos, Zan, Scherer, & Mendoza-Sassi, 2013), and anxiety is generally higher in people with dementia (Seignourel, Kunik, Snow, Wilson, & Stanley, 2008).

Participants in the traditional art group had significantly lower levels of anxiety at the end of the study than both digital art and control groups. There was no significant difference in anxiety change between the digital art group and the control group. This result might be attributed to the potentially stressful nature of engagement with a new device. Improvement in anxiety may be stronger for longer-term tablet interventions, as there is evidence to suggest that older people may be more enthusiastic towards tablet use after an orientation period (Holtum, 2016).

The lack of improvement in anxiety in the digital group may be linked to the type of art produced. In response to a novel medium, more patients took to abstract art to explore colour, texture, and the general tablet interface. However, in traditional art groups, more patients took to figurative drawings of natural features and historic objects. This result echoes findings from a business case for visual art in clinical settings. By addressing anxiety and agitation, it found that abstract art had greater potential for negative responses than figurative art (Nanda, Eisen, Zadeh, & Owen, 2011).

This study contributes to the literature base exploring treatments for anxiety in dementia, an area that has only recently received individual attention (Seignourel, Kunik, Snow, Wilson, & Stanley, 2008). Cognitive behavioural therapy (CBT) has shown promise in lowering anxiety (Kraus et al., 2008). However, the one-to-one nature of CBT may not be feasible in addressing anxiety across all hospital inpatients with dementia. By showing that group art engagement can lower anxiety, the present study presents a feasible, cost-effective alternative to CBT or pharmacological treatments (Qazi, Shankar, & Orrell, 2003).

#### **5.4.4 Engagement**

The present study is among the first to integrate intra-activity measures of engagement with pre- and post-outcome measures of interest. Several studies included in Chapter 1's systematic review considered engagement. However, none utilised a validated measure of engagement in the same way. Cheong et al. (2016) used the MPES to measure engagement with others before and after a music intervention. Hazzan et al. (2016) considered engagement in a similar way by asking carers to report the engagement of the participant after participating in an art course. Rylatt (2012) used a bespoke measure of engagement during a multi-media course, finding high levels of engagement among participants in a creative therapy programme.

Previous research making use of the OME has used engagement as a primary outcome measure. Leone et al. (2012) considered engagement as the antithesis of apathy and measured it in a randomised controlled trial with 40 participants. By categorising 25 types of stimuli, they found that "guidance" was the most powerful predictor of increased engagement. While the present study did not compare interventions with and without guidance from art programme leaders, it did report high levels across digital and traditional media that were guided by practitioners and volunteers.

#### 5.4.5 Limitations and areas for future research

The present study has several limitations. First, this study was not randomised, making generalisability less clear. However, participants were broadly equivalent on baseline measures. To account for small variations, this study included these demographic factors as covariates in the statistical models. Attitude during artistic engagement was found to be associated with wellbeing. Because the OME was not used with the control group, the attitude of control group participants is not known. It is possible that study participants were more likely to attend an art programme if their attitude was positive. Future studies might account for this by using the OME with the control group, using a neutral intervention that is more commonly part of acute care at the bedside.

A second limitation is that patients who were more open to new experiences may have been more likely to volunteer for the digital art group than the traditional art group. However, it is notable that this activity received weaker responses than traditional arts activities, so the potential direction of bias from more open-minded participants engaging in the digital activity was counteracted. Third, this study was not blinded, although analyses were verified by a second researcher. Finally, this study made no distinction between different types of dementia, which may have important implications for how anxiety is experienced and modified by engagement with the arts. In a cross-sectional study, Ballard et al. (2000) found that 72% of patients with vascular dementia were found to have symptoms of anxiety compared with 38% of those with Alzheimer's disease.

Practical considerations led the study design to include measurements of anxiety and wellbeing immediately following the arts programmes. While measurement of long-term impacts of engagement with the arts would be useful, short term improvements can help with important clinical outcomes such as orientation and communication. The pre-post design also allowed the study design to compare the arts in health interventions directly with normal care. Measures taken in the day or week following the intervention would need to consider care differences between participants, and the lack of randomisation would severely decrease the generalisability. Furthermore, Bruer et al. (2007) argued that short-term benefits from music interventions could be used for targeted boosts to mood and cognition during critical periods during a day or week in an acute care setting. Future studies could look at repeated engagement with the arts in a hospital setting, including outcome measures such as length of stay, readmission rates, and mortality. Further control of the type of art produced may also have produced different results. Abstract and figurative art production may

impact anxiety and wellbeing in different ways, but this study did not take into account the actual content of the art produced. Future studies might control for this in the study design phase or by including an evaluation measure of the art produced.

Future studies might also examine the global effect of tablet use, considering the broad uses including social media, video and music streaming, and web browsing. A growing popular and academic sentiment has warned against this aspect of the rise of portable touchscreen technologies. Critics have cited addiction (Kwon et al., 2013), loneliness (Bian & Leung, 2015), depression, and need for touch (Elhai, Levine, Dvorak, & Hall, 2016). However, these studies do not have standardised measurements for how the touchscreen technologies are used, and many studies focus on university students. By restricting engagement to just one painting app, this study avoided the complex considerations of social media and multitasking that accompany the technological capabilities of the tablet. Future studies might also critically evaluate the nature of the art produced rather than just the effects of general engagement with the arts. While the value of the measurement of art is debated (Gilmore, Glow, & Johanson, 2017), elements of colour use, abstraction and gesture might contribute to the understanding of how artistic production is associated with wellbeing outcomes. Finally, future studies might also consider comparisons between other digital and traditional analogues. Tablet apps exist for a variety of traditional activities including music production, pottery, and gardening.

#### **5.4.6 Conclusion**

This chapter presented methodology, results, and discussion for a 3-arm controlled study measuring the effect of engagement with digital and traditional arts in hospital inpatients with dementia. The aims of the study were to examine how engagement with the arts would affect anxiety and wellbeing among participants, including the differences in engagement between digital and traditional media. Traditional media were found to be the most beneficial, with significant improvements in anxiety and wellbeing measured compared with the control group. The digital group experienced better wellbeing than the control group, but no significant improvement in anxiety. Elements of engagement were compared between digital and traditional media, finding that attitude toward digital media was more negative than towards traditional media. Further implications of these findings and their relation to findings from Chapters 3 and 4 will be discussed in Chapter 6.

## CHAPTER 6 DISCUSSION

### 6.1 Introduction

This thesis presents the first studies comparing the processes and outcomes involved with artistic engagement with digital and traditional media for hospital inpatients with dementia. The main aims of the studies presented in Chapters 3, 4, and 5 were to investigate the previous and current experience of engagement with individual and group art activities. To do so, this thesis adopted a pragmatic perspective and answered particular questions regarding the lived experience of dementia in hospital, patterns of engagement with the arts, and effects of engagement with the arts. A mixed methods design was chosen based on existing literature in dementia care (Bunn et al., 2016; Sampson et al., 2008), hospital-based services research (Curry et al., 2013; Zapka et al., 2013), and arts in health research fields (Paddon, Thomson, Menon, Lanceley, & Chatterjee, 2014; Windle et al., 2016). The prior experience of myself and my academic supervisors also influenced the development of the thesis methodology. Chapter 3 presented a cross-sectional study which provided data from validated scales for cognition, loneliness, depression, and quality of life in addition to patterns of individual, voluntary, unprompted engagement with the arts. In contrast, the focused ethnography in Chapter 4 and controlled study in Chapter 5 examined the experience of artistic engagement in an organised group setting in ward day rooms separate from the clinical areas of the hospital ward. These studies, considered together, describe a broad spectrum of engagement with the arts, including variation in medium, environment, motivation, and group dynamic. While chapters dedicated to each study have discussed individual research findings, it is necessary to consider triangulated results in order to gain an overall view of the experience of arts engagement in hospital inpatients with dementia. In doing so, the cross-sectional study will be referred to as Study 1, the focused ethnographic study as Study 2, and the 3-arm controlled study as Study 3. To begin, central findings will be discussed, comparing results with extant literature.

### 6.2 Addressing the research questions

The primary question underpinning the research was *How does arts engagement affect the patient experience of hospital inpatients with dementia?* To answer this question, three studies investigated a variety of ways hospital inpatients with dementia engage with the arts, including unstructured individual engagement and planned group activities in the hospital ward. The central finding was that engagement with the arts can improve wellbeing and the overall experience of hospital stay among inpatients with dementia. This improvement was measured using multiple

methods and instruments, and it included many different forms of arts activities including digital and traditional versions of group art and music activities.

### **6.2.1 How are lifetime and current experiences of the arts linked to loneliness, depression, and quality of life for hospital inpatients with dementia?**

The findings from Study 1 showed that current artistic engagement is associated with significantly lower levels of loneliness. Specifically, passive engagement with artistic and cultural activities including reading, listening to music, listening to the radio, and watching television are associated with lower levels of loneliness. This finding suggests that the subjective feeling of loneliness is not solely related to lack of objective social engagement (as all hospital patients were staying in multi-bed wards and had regular interactions with staff). By considering individual, solitary engagement, Study 1 provides support to previous conceptual findings separating loneliness and objective social isolation. This has been studied in mental health research fields, with a recent systematic review proposing a five-domain model for social isolation (Wang et al., 2017). This model included distinctions such as separate domains for the size and quality of one's social network. This acknowledgement of the complexity of feelings associated with social engagement is echoed by this thesis and is particularly suited to pragmatic research.

Findings from Study 1 suggest that individual engagement with the arts may be able to increase the capacity to be alone through engagement with artistic stimuli. This can be particularly powerful given research showing that social isolation and loneliness are associated with decreased cognitive functioning (Shankar, Hamer, McMunn, & Steptoe, 2013). While loneliness is characterised by a negative subjective experience of being alone, it has been suggested that aloneness can be a positive subjective experience. Solitude has also been defined in a similar manner to social isolation, as an objective "state of being alone" (Galanaki, 2014), and Winnicott (1958) theorised that its relationship to loneliness is mediated by the capacity to be alone. Solitude, including an increased capacity to be alone, has been linked to increased freedom, creativity, and spirituality (Long & Averill, 2003), themes of subjective experience that might be highlighted and expressed through engagement with the arts.

The mechanisms behind the relationship between lower levels of loneliness and engagement with the arts have been considered (Cutler, 2012; Laing, 2016). In *Tackling Loneliness in Older Age – The Role of the Arts*, Cutler (2012) pointed to the empathetic power of storytelling that might

“allow a carer to see that person in a new light.” This point was highlighted explicitly in findings presented in Study 2, where clinical staff were reported to expand their conception of their patients through their newfound abilities after participation in the art programme. However, this does not account for the solitary passive activities associated with lower levels of loneliness found in Study 1. Causation has not been established, so it might be that participants less prone to loneliness are more likely to engage with passive activities measured by Study 1 such as reading, watching television, and listening to music or the radio. Another possible explanation is described by the social surrogacy hypothesis, developed through a series of studies showing that attachment to characters in a television show (Derrick, Gabriel, & Hugenberg, 2009) or broader narrative forms (Mar, Oatley, Djikic, & Mullin, 2011) can serve as subjectively functional alternatives to social engagement. These findings might be contrasted with a study by Queen et al. (2014) who found that older adults who were lonely engaged in similar activities as those who were not lonely. Additionally, Queen et al. found that loneliness was associated with engaging in more solitary activities. However, their study included participants without cognitive impairment, suggesting that engagement and loneliness patterns in dementia are more likely to fit the social surrogacy hypothesis.

Study 1 additionally found that life course arts engagement and past-year cultural engagement are not associated with outcome measures of loneliness, depression, or quality of life. This suggests that current experience is most important for the lived experience of hospital inpatients with mild-moderate dementia. Encouragingly, this implies that past experience with the arts might not serve as a barrier to benefits derived from current engagement. This could be related to the reduction in cognitive capacity and functional ability in people with dementia, leading to a new experience of engagement with the arts regardless of past history. Additionally, it could be related to the ability of artistic engagement to increase self-efficacy. This is supported by a key finding from Study 2 which reported that most participants in group visual art and music sessions experienced a transformation from believing they could not successfully engage with art to being proud of the artwork or music created.

Study 1 adds to the growing body of research studying the impact of cultural engagement in older people (Fancourt & Steptoe, 2018; Rajan & Rajan, 2017). While Study 1 did not report significant wellbeing effects on hospital inpatients with dementia, previous studies have measured longitudinal effects on other outcomes. An observational study of the English Longitudinal Study of Ageing reported that regular cultural engagement such as museum attendance and may have a

protective effect against dementia (Fancourt, Steptoe, & Cadar, 2018). However, it did not include data on the effect of cultural engagement after the development of dementia. While cultural engagement in older age might protect against the development of dementia, there is little evidence of the effect of life course cultural engagement on wellbeing after onset of dementia. Further longitudinal studies could consider the ways in which cultural engagement patterns change after dementia onset as well as the possible changes in its effect on wellbeing through the progression of dementia.

Study 1 reported low levels of engagement with active arts activities such as playing an instrument, singing, or dancing, and no association was found between these activities and outcome measures. The low level of engagement measured may have been due to practical challenges presented in older age. Once patients were given a structured opportunity to participate in group arts sessions, Studies 2 and 3 found that active arts engagement can have benefits for wellbeing. While Studies 2 and 3 considered the complex interplay of social engagement, environmental change, and artistic engagement in the improvement of wellbeing, the finding from Study 1 provides evidence that engagement with the arts on its own can have beneficial effects. Additionally, the relationship to the environment may play a role in depression among hospitalised inpatients with dementia. A survey of 120 people with dementia reported that quality of life and depression were linked with disorientation in people with dementia (González-Salvador et al., 2000), a finding that has implications for new and unfamiliar environments such as a hospital ward. It was further confirmed by results from Study 2 which reported the effect of the environment and environmental change on the wellbeing of hospital inpatients with dementia. It also reported on the ways in which the environment interacted with the experience of artistic and social engagement. This could apply to the experience of individual engagement in the hospital ward.

The broad considerations of arts engagement in Study 1 served as a baseline for the subsequent focused ethnographic and controlled studies of specific group arts programming in the hospital. Although Study 1 showed that individual engagement was not associated with depression or quality of life, it did not consider the effect of a group setting on the potential for art activities to impact such psychosocial outcomes. These issues were examined in Studies 2 and 3, and the triangulation among the three studies considers the ways in which individual artistic engagement compares with environmental and social change present in group arts in health programmes.

### **6.2.2 How would traditional and digital versions of arts in health programmes compare in affecting wellbeing in hospital inpatients with dementia?**

Group art programmes were found to share contributions to wellbeing, despite differences in social engagement between digital and traditional media groups. As outlined in Study 2, the improvement in wellbeing was driven by artistic engagement, social engagement, and environmental change. Artistic engagement yielded physical benefits, a sense of self-efficacy, and art-based social engagement. The benefit of environmental change was reported for both digital and traditional media groups. The simple act of moving to the day room led to a variety of benefits including physical exercise, opportunities to meet new people, and more home-like surroundings. Taken together, all elements of the PERMA model of wellbeing were fulfilled including positive emotion, engagement, relationships, meaning, and accomplishments (Seligman, 2012).

Study 3 showed that both digital and traditional art groups experienced higher levels of wellbeing compared with a control group. This adds to the growing body of evidence that people with dementia can improve wellbeing through engagement with the arts in a variety of settings (All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017). It also adds evidence to the literature of wellbeing in older age. A study of 2,548 participants in the English Longitudinal Study of Aging found lower negative affect and more life satisfaction among those engaged with education, art, or music class (Fancourt & Steptoe, 2018). Qualitative findings from Study 2 added context to the finding that participation in group arts activities encourages wellbeing. In both digital and traditional media groups, participants expressed pride in the work they created, despite differing experiences in the production process itself.

These differences were mainly exhibited in the domains of mood and social engagement. While both digital and traditional groups had opportunities for social engagement during the art programmes, digital group participants were observed to interact with the art programme leader more, with conversation focused on the mechanics of the digital interface. Mood, as reported by Study 2, was found to be more variable in digital group participants. This was due to factors throughout the process including confusion and frustration using a digital screen and disappointment by not having a tangible work to take with them. This was echoed by significantly more negative attitude in the digital group as measured by the Observational Measure of Engagement (OME) in Study 3. Despite these frustrations, digital group participants experienced satisfaction from having

learned new skills using a novel medium, as observed in Study 2. Group social engagement was also lower in digital group participants due to increased focus on the tablet screen. However, social engagement with the art group leader was high in the digital group due to the increased need to teach how to use the tablet. The Generic Wellbeing Questionnaire used in Study 3 could have potentially detected these differences in social engagement through the item “I enjoyed the company of other people.” However, results on this item were not significantly different between digital and traditional media groups.

### **6.2.3 How would traditional and digital versions of arts in health programmes compare in affecting anxiety in hospital inpatients with dementia?**

The findings from Study 3 showed that anxiety is significantly more reduced in those who participate in traditional art groups compared with digital art groups and the control group of participants who received normal care without leaving their hospital bed. This finding was, on the one hand, unexpected given that both traditional and digital groups experienced wellbeing benefits. Studies across settings and patient groups have consistently reported associations between higher anxiety and poor wellbeing (Ram et al., 2017; Smalbrugge et al., 2006; Steptoe, Mohabir, Mahon, & McKenna, 2000). However, at the same time, wellbeing has been shown to exist on a separate continuum from mental ill health (such as anxiety) (Keyes, 2005). This suggests that while traditional art can support both, digital art can only improve mental health without addressing symptoms of mental ill health. The divergence from previous research may stem from the differing study designs. Many of the studies associating high anxiety and poor wellbeing are cross-sectional and therefore do not measure the impact of an intervention.

By tracking change in anxiety and its relationship to wellbeing after an art programme, Study 3 considered the ways in which anxiety and wellbeing diverge during an intervention. Study 3 found no significant difference in anxiety change between digital and control groups, and Study 2 reported themes that outline a possible explanation for this difference. From Study 2, environmental change was identified as a key benefit for group art activities across digital and traditional groups. However, a key effect of environmental change was the accompanying social interaction. In the traditional art group, social interaction was as much a part of the activity as artistic engagement. This social interaction may have served to reduce anxiety in the traditional visual art group. While digital group participants appreciated the environmental change, they were engrossed by the digital tablet, often to

the exclusion of the outside world. This consumption of attention was consistent regardless of technical ability to manipulate the touchscreen.

Additionally, many participants faced potentially anxiety-inducing challenges learning how to engage with the digital art media compared with those who had no previous experience with traditional art media. Some participants seemed agitated and frustrated by recurring unintended screen manipulations. Despite this, many digital group participants reported feeling accomplished by learning a new skill. This increase in self-efficacy is not measured by the Generic Wellbeing Questionnaire, however it may have impacted the answer to the items “I enjoyed the company of other people” and “I talked to other people.”

Studies 2 and 3 provide further clarity on previous research on the experience of tablet use among people with dementia. Importantly, they were based upon the use of a single application per group, thereby limiting the scope of the tablet’s capabilities. This was done in order to control for the impact of using a screen to perform the same function as a traditional artistic medium. However, arts in health programmes might consider the impact of multiple application use among people with dementia. In a series of qualitative studies, Upton et al. (2011) found that tablets were especially useful for bringing back memories. This was a finding relating to the use of the internet capabilities of the tablet, suggesting that the strength of tablet use is in its connectedness - throughout the course of the intervention, applications were used to access pictures and engage with social media. Other studies have considered more focused outcomes. Vahia et al (2017) found that the use of simple apps was helpful for agitation, a behavioural symptom that has been linked with anxiety in a variety of studies of dementia (Cooke, Moyle, Shum, Harrison, & Murfield, 2010; Haupt, Karger, & Jänner, 2000; Sung, Lee, Li, & Watson, 2012). While Vahia et al. (2017) aimed to control for broad digital capabilities of tablets, there is a scope for use of current apps and app development for wellbeing in ageing populations (Wildevuur, 2013).

Lower levels of anxiety through arts engagement may be linked to patient personality and initial mood. This builds on research finding that engagement with the arts can lower stress and anxiety in students (Chang, 2005; Sandmire, Gorham, Rankin, & Grimm, 2012) and adults (Visnola, Sprūdža, Baže, & Piķe, 2010). Study 2 found that patient personality and mood had great power to impact on likelihood of participation in art group in addition to experience of the art group. A mix of patient personalities was found to be ideal, with “enthusiastic joiners” providing social momentum

and lifting the spirits of “hesitant joiners.” Study 2 observed that hesitant joiners experienced a more transformative emotional improvement from art group participation while enthusiastic joiners experienced relief from boredom on the hospital ward. This finding suggests that experience of arts engagement is connected to patient attitude more than cognitive impairment in dementia despite functional challenges observed with more severe progression of dementia. This finding is in line with conclusions made by Twelftree (2001): “It does not appear that ill-being is a necessary consequence of dementia...variations in well-being between individuals with dementia do not appear to be related to levels of cognitive impairment.”

#### **6.2.4 How would traditional and digital versions of arts in health programmes compare in engaging hospital inpatients with dementia?**

Studies 2 and 3 reported that engagement with digital and traditional arts differed in substance rather than duration. While digital and control groups were engaged for similar lengths of time, the type of engagement observed was vastly different. Attitude and attention, as measured in Study 3 by the OME, diverged between digital and traditional groups. Attitude toward the activity was measured to be much more negative in the digital group. Study 2 explained this by documenting the frustration participants experienced engaging with an unfamiliar interface. The comparatively positive attitude reported for the traditional group might be explained by the social interaction and general familiarity with the medium. Level of attention paid to the art activity was found to be higher in the digital group in Study 3. This may be explained by findings from Study 2 which report focus on the unfamiliar interface to the exclusion of interaction with the outside environment. While attitude toward an activity might be affected differently for different types of dementias, this study effectively randomised type of dementia by not considering specific diagnoses. Because refusal rates were very low, it is unlikely that patients with different types of dementia gravitated towards either digital or traditional activities.

The attention paid to a novel activity is augmented by the inherent visual attention demanded by touchscreens, even for those familiar with them. This challenge has been acknowledged by research groups developing methods that do not require full visual attention for activities such as text entry (MacKenzie & Castellucci, 2013) and driving (Large, Crundall, Burnett, & Skrypchuk, 2015). Contrastingly, participants in the traditional art group were commonly engaged in conversation, even while engaged in artistic production. While this resulted in lowered scores on the “attention” item of

the OME, the combination of artistic and social engagement may contribute to the improvement in anxiety observed in the traditional group but not observed in the digital group.

Study 2 identified reminiscence as a potentially useful tool for initially engaging with people with dementia in arts in health activities. It was a key strategy for arts programme leaders to first ask about past experiences because it allowed them to tailor the subject of the art activity to the individual. While no negative experiences of reminiscing were observed during the study period, the practising principle was to help transition patients from reminiscence into in-the-moment expression. This was observed to be effective for engagement and wellbeing. However, time perception in dementia is complex, and it is unclear how perception of time changes with the onset and progression of dementia. Evidence exists that time awareness declines as dementia progresses (Grewal, 1995), including when compared with people with amnesia (Nichelli, Venneri, Molinari, Tavani, & Grafman, 1993). Cognitive and neurological research has begun investigating this, producing models such as the Scalar Expectancy Theory in which memory affected by dementia is a separate process, and therefore changes separately, from other physiological time senses such as the internal clock (Caselli, Iaboli, & Nichelli, 2009). A systematic review of time distortion in Alzheimer's disease found that compromised episodic memory is tied to the "ability to mentally project oneself in time" (Haj & Kapogiannis, 2016). Engagement with the arts might effectively address the disorientation associated with compromised time perception by offering an ever-flexible balance of novelty and familiarity.

Engagement with digital media was found to be beneficial for wellbeing, and this may be due to the self-efficacy derived from learning a new skill rather than an inherent benefit to touchscreen usage. However, the use of new digital technologies has been investigated for its harmful effects on students (Samaha & Hawi, 2016) and other younger populations (Young & Rogers, 1998). Issues include information overload with exposure to social media and constant news reporting (Holton & Chyi, 2012). Additionally, the ubiquitous presence of screens in daily life has been investigated for its ability to cause and exacerbate stress (Kneidinger-Müller, 2017). While attention manipulation and information overload on touchscreens might be considered a problem for the general population, they might be leveraged for use in dementia care. Attention deficit has been cited as a challenge in dementia (Kolanowski et al., 2012), and devices that command attention could be used to increase engagement with desirable activities such as the arts, carer communication, and reminiscence. This, coupled with the versatility of the tablet as an "accessible and flexible resource" (Evans, Bray, &

Evans, 2015), indicates the potential for future use and research centred on tablets despite the challenges reported in Study 2.

### **6.2.5 Additional findings**

Both Studies 2 and 3 collected intra-activity data in addition to post-activity impacts, but the initial research questions did not ask how engagement and outcome measures might be connected. Study 3 found that duration of engagement was not related to outcome measures, but attitude and level of attention were. As discussed in Section 5.2.2, “attitude” might be thought of as “affect” or “observed mood” as these terms might better describe the external nature of the researcher’s observation. This finding echoes the finding in Study 2 that patient mood and personality in relation to the physical environment, the social environment, and the activity influences the outcome of the arts activity. By classifying activity participants into “enthusiastic joiners” and “hesitant joiners,” Study 2 considered the unexpected ways in which participants would have divergent experiences in a group art programme. Enthusiastic joiners were more socially engaged, and they did not experience a vastly improved mood due to their initial positive mood. Rather, enthusiastic joiners benefitted from high levels of positive social engagement, which was reported explicitly and characterised as relief from boredom in Study 2. Additionally, high levels of social satisfaction were measured by the Generic Wellbeing Questionnaire in Study 3. Hesitant joiners, on the other hand, had to be convinced to attend the group art programme and began the programmes in a more negative mood. This gave considerable scope for their mood to be improved. This mood improvement was the results of a combination of environmental, social, and artistic factors.

Further, the initial research questions did not consider how the fluid process of collaboration in group arts engagement might be best optimised to produce positive effects. However, Study 2 considered this at length, outlining the balance between novelty and familiarity that was considered by arts programme leaders. At the outset of a programme, the novelty of a new environment, new social opportunities, and new artistic activity tend to be intimidating for participants. While this may be true of other patient groups, including older adults without cognitive impairment, people with dementia tend to be more withdrawn and difficult to engage (Honda, Meguro, Meguro, & Akanuma, 2013). Art programme leaders therefore began by emphasising the familiar, including prompting reminiscent conversation. As the programme progressed, and participants became more familiar with

the environment, social dynamic, and artistic engagement, art programme leaders began to emphasise the novel possibilities of the art form, pushing participants to express more freely.

A major apparent difference between digital and traditional art activities lies in the novelty of digital tablets among the study population. The equivalence in engagement duration scores between traditional and digital art groups suggests that hospital inpatients with dementia might feasibly learn this new skill, despite studies of skill-acquisition over the life course, which show that skill-learning slows down dramatically around age 60 (Janacek, Fiser, & Nemeth, 2012). This supplements literature in the field of skill learning in dementia. A review of literature on learning methods for people with dementia included 23 experimental studies (Tilborg, Scherder, & Hulstijn, 2007), finding that implicit motor-learning capacities remained largely intact in people with Alzheimer's Disease. Case studies have also demonstrated that people with AD can learn new music, despite poor performance on anterograde memory tests (Cowles et al., 2003). A study of depressed people with and without Alzheimer's disease found that people with Alzheimer's disease had preserved procedural learning, while declarative learning deteriorated. This finding bolsters the case that people with dementia can learn how to use new technologies, especially when the user interface minimises functions that require declarative learning.

Study 2 detailed the ways in which the art programme leaders, clinical staff, and volunteers were instrumental in facilitating artistic engagement and skill learning. Previous research has shown that people with mild progression of dementia could be taught new tasks by both modelled behaviour and verbal instruction (van Tilborg, Kessels, & Hulstijn, 2011). However, different leadership styles impact on the experience by art group participants. A pilot RCT examined effectiveness of learning styles in people with dementia, finding that "errorless learning" was more effective than trial-and-error learning (Kessels & Hensken, 2009). Often used in classrooms, errorless learning may be an effective approach for learning new media because only the effective process is learned and practiced.

### **6.3 Statement of key findings**

The key finding of this thesis is that engagement with the arts can improve wellbeing for hospital inpatients with dementia. The studies presented also identified the types of engagement that may contribute to this improved wellbeing. While engagement with the arts was the central focus, other domains factored into the patient experience. Social engagement emerged as a complement to

artistic engagement during the group art programmes, and the balance between the two was found to impact the perceived experience of the programme. Surrounding these domains was the environmental experience in the hospital, including the effect of environmental change for art activities in the ward day rooms. Additionally, the studies presented in this thesis found high rates of illbeing in hospital patients with dementia in addition to their reason for hospitalisation. High rates of loneliness, depression, and anxiety were measured. Lower levels of loneliness were found in participants who were currently engaging with the arts in their daily lives, an effect that was not influenced by previous life experience with the arts or other cultural engagement. Anxiety was found to be lowered by engagement with traditional art media in a group setting, a finding which has implications for agitation in hospital, ultimately impacting recovery time and length of stay. These key findings were drawn from a triangulation of three studies using mixed methods, and a methodological discussion of this triangulation is presented in the next section.

#### **6.4 Trust and validity of the findings: Triangulation**

Triangulation is the defining technique used to integrate mixed methods research. As a concept introduced as “multiple operationalism” in 1959 by Campbell and Fiske, it can improve methodological validity by using qualitative and quantitative results to compensate for each other’s weaknesses. Denzin (1978) defined it as “the combination of methodologies in the study of the same phenomenon.” As triangulation has gained popularity, its uses and definitions have expanded. Hales (2010) described four types of triangulation which might be implemented separately or in concert. First, data triangulation is the use of different sources of data, which this thesis does by including data from patient participants, arts programme leaders, and clinical staff. Second, methods triangulation is the use of different study designs. This is a mixed-methods thesis whose quantitative and qualitative designs were conceived in order to triangulate their methods. Third, investigator triangulation is the use of multiple investigators in order to control for biases in data collection or analysis. I was unable to include investigator triangulation as my PhD studies were to be the sole work of myself. Additionally, by using a single researcher perspective, this research controlled for variation in the way data was collected and interpreted. Finally, Hales (2010) identified theoretical triangulation, in which multiple theories and perspectives are used to examine a phenomenon. This thesis uses theoretical triangulation by considering constructivist and positivist perspectives in the evaluation of hospital art programmes.

In considering the integrational analysis of studies performed for this thesis, I chose triangulation as opposed to meta-analysis. Triangulation differs from meta-analysis as an approach to research synthesis. Meta-analysis uses a statistical approach to synthesise findings from methodologically similar studies. Its main aim is to calculate the robustness of an association or effect, making it ideal for answering specific research questions with greater validity. For meta-analysis to be most effective, the included studies should be as methodologically similar as possible. This limits meta-analyses to include only quantitative studies (Wolf, 1986). Triangulation, on the other hand, uses methodological diversity as its strength, integrating findings from qualitative and quantitative approaches to the same phenomena. I considered this preferable to meta-analysis because triangulation is more effective for the broad, holistic study of a phenomenon. When considering the impact of hospital arts programmes for dementia, triangulation represented a more pragmatic approach than a meta-analytical approach that might have resulted in a single robust finding.

Triangulation was considered in the evaluation of studies previously performed in this area. This thesis's systematic review of non-pharmacological interventions for dementia included a mixed-methods study by Daykin et al. (2017). This study centred on a qualitative evaluation of an arts in health programme, using passively collected discharge data as the quantitative component. However, the qualitative component did not account for care differences outside of the arts activities. This presented a difficulty in triangulation because the weaknesses of the quantitative study were not fully explained by the qualitative study. This thesis represents a more triangulated mixed methods study by actively collecting data across Studies 2 and 3. By using focused ethnographic data to shape the design and interpret results of the 3-arm controlled study, this thesis pragmatically explored arts engagement in inpatients with dementia. This pragmatic epistemology incorporates the positivist emphasis on measurable phenomena while allowing for the individualist, experience-based constructivist epistemology to provide deeper understanding (Morgan, 2014). Although the qualitative methods began with an open framework, domain analysis was used to identify themes of experience that were then quantitatively measured in the 3-arm controlled study design. Findings from the 3-arm controlled study were then reassessed using the same qualitative methods as the two studies ran concurrently. This process strengthened each study by addressing limitations while maintaining individual strength. The breadth of the ethnography's "thick description" provides

context and postulates mechanisms for the narrow, focused effects measured by the 3-arm controlled study.

This thesis consists of three studies, with results from Studies 2 and 3 being more fully integrated and focused to shared research questions than Study 1. This raises the question of whether Study 1 could be considered a part of a mixed methods study. However, considering the setting where patients are continually admitted and discharged, the long timeframe between Study 1 and Studies 2 and 3 is not as consequential as it might be in a community or care home setting. Further, there were no material changes in the layout or running of the hospital wards involved in this study, leading to a relative consistency in study environment.

As mentioned above, data comparisons between Study 1 and Study 3 should be interpreted with caution. While the demographic data was collected in the same fashion, other aspects of the studies were substantially different. Study 1 collected data on loneliness, depression, and quality of life, while Study 3 collected data on anxiety and wellbeing. This difference in outcome measure was influenced by a structural difference in study design. Because Study 1 adopted a cross-sectional design looking at life course and past-year cultural engagement in addition to current engagement, more stable measures were chosen. In particular, the Geriatric Depression Scale asks about how the participant has felt in the past week, an instruction that precludes the use of this scale for measurement of short-term experimental change such as the State-Trait Anxiety Inventory 6-Item Scale. Further, Study 1 measured the effects of life course arts engagement, past-year cultural engagement, and current engagement with the arts and was therefore subject to participant report of engagement frequency. In comparison, Study 3 experimentally manipulated that engagement, therefore it was based on researcher observation rather than depending on patient memory.

### **6.5 Situating the findings in the wider field of research**

Findings presented in this thesis sit within larger research fields including arts in health and dementia care. The systematic literature review of nonpharmacological interventions for dementia in a hospital setting (see Chapters 1 and 2) found a small, growing base of evidence for the effectiveness of arts interventions. It identified mostly small scale and pilot studies, and there was a dearth of mixed methods studies. There was also a lack of literature on the practical concerns of implementation of arts programmes in a hospital setting. Interactions between researchers, art programme leaders, clinicians, and therapists were not described by the studies included, leading to a

lack of understanding of the context in which the reported effects were taking place. Even qualitative studies included in the review focused on case studies of patients during the arts engagement rather than how the experience was particular to the hospital setting. Given the poorer outcomes experienced by hospital inpatients with dementia compared with inpatients without cognitive impairment (Goldberg et al., 2012; Sampson, Blanchard, Jones, Tookman, & King, 2009), further research was deemed necessary to identify ways experience of hospital inpatients with dementia might be improved through new types of care.

Studies identified in the literature review did not consider individual, unstructured engagement with the arts in hospital. In addition to overlooking the potential impact of engagement, this omission leaves no place for the consideration of previous experience and competency in the art groups conducted. By measuring current, past-year, and life course engagement with the arts, Study 1 considered the artistic history of hospital inpatients with dementia, pointing out that art activities in hospital settings do not exist in a vacuum of artistic engagement. Rather, arts activities can serve as exhibition opportunities for those who are proud of their art, as playgrounds for those who prefer to experiment, and as challenging classrooms for those who have no prior experience of art.

The literature review found the most compelling evidence for the effectiveness of music activities to improve the wellbeing of hospital inpatients with dementia. Nine studies of music engagement were reviewed compared with only two of visual art. From the visual art-based studies, Hattori et al. (2011) reported reduced apathy in participants while Hazzan et al. (2016) reported qualitative findings of increased engagement and communication with carers. This thesis adds to the field of visual art research by reporting both qualitative and quantitative impacts of visual art production across media.

Studies included in the systematic review presented in Chapter 1 focused on the impact of engagement with the arts on psychosocial outcome measures. However, none of the literature reviewed considered the mechanisms by which these impacts were effected. These studies generally lacked detail in describing the individual ways people feel about, engage with, and are affected by the arts in a hospital setting. This thesis considers the individual experience of engagement with the arts as a core tenet of its power. By exploring the interplay between familiarity and novelty of arts media and reminiscence and expression in arts engagement, this thesis aims to further understanding

of the complex phenomena related to arts engagement and how it might impact people living with dementia.

## CHAPTER 7 CONCLUSION

### **7.1 Introduction**

Chapter 6 triangulated findings from the three studies performed, illustrating the variety of activities and types of arts engagement that were implemented at an acute care centre in London. Effects of these activities were also explored, finding that engagement with the arts is beneficial for the wellbeing of hospital inpatients with dementia. The present chapter will detail implications of these findings for practice, suggest directions for future research, and contextualise their contribution within broader research and policy.

### **7.2 Implications for practice.**

Considering the power of engagement with the arts to improve wellbeing, this thesis recommends implementing arts in health programmes for hospital inpatients with dementia. The present section will discuss detailed implications addressing arts practitioners, clinical staff, hospital administrators and commissioners, and policymakers. It will conclude by outlining three key messages for practice.

Studies 1, 2, and 3 add evidence to the case that engagement with the arts can be beneficial to the experience of hospital inpatients with dementia. Although the NHS prioritises person-centred care, many barriers to effective implementation have been identified (King, Taylor, Williams, & Vanson, 2013; Moore et al., 2017). Arts in health activities might effectively fill this space by providing low cost, person-centred activities. Benefits of these activities include the potential for patients to be relieved from the boredom of the hospital ward and to socialise with other patients in the day room outside of an acute care environment.

By considering the implementation of arts in health programmes, this study has highlighted the need for arts in health programmes in the acute care context. The busy, complex, hierarchical aspects of the hospital ward leave little room for clinical staff to attend to patients beyond immediate needs. Clinical and therapy teams often experience shifting priorities as patients are discharged, admitted, and experience changing health states. Clinical and therapy staff are also moved between wards, creating a shifting work environment for themselves and the new teams they join. This leads to difficulty providing space and time to provide truly person-centred care. This thesis provides evidence of the potential of arts engagement to fill this space. By allowing for creative activity, socialisation, and a change of environment, arts programming can potentially fill a professional void,

allowing ward staff to prioritise focused clinical and therapeutic outcomes required for discharge. Additionally, artistic production gives clinical carers an opportunity to become acquainted with their patients outside of an acute care context.

Study 1 found that passive activities such as reading, watching television, listening to music, and listening to the radio were associated with lower levels of loneliness in hospital inpatients with dementia. These are all inexpensive, mostly solitary activities that might be easily encouraged and made available on older people wards. Therefore, passive solitary activities could be recommended for patients who are bedbound or on wards without a regularly scheduled participatory arts programme. The mental engagement of these activities should be considered, as research for fully passive activities such as watching television has been linked with lower mental wellbeing and vitality (Dempsey, Howard, Lynch, Owen, & Dunstan, 2014).

### **7.2.1 Implications for arts in health practitioners**

The planning and implementation of arts in health programmes can present a variety of challenges. Study 2 outlined experiences of facilitators leading group activities in music and visual arts and strategies undertaken to mitigate obstacles and facilitate positive experiences among participants. The present section identifies key implications of this thesis's findings for the practice of arts in health practitioners including *balance of novelty and familiarity, reminiscence and expression, roles of environment and social engagement, optimising tablet use, and consideration of patient type*.

**Balance of novelty and familiarity.** Study 2 considered the balance of novelty and familiarity, including its role in reminiscence and expression, how it is expressed through social and artistic engagement, and its role in creativity. Environment, activity, and socialisation all exist on a spectrum between discomfortingly novel and comfortably familiar. Depending on the participant's preferences and competencies, any arts activity could represent boring or comfortable familiarity, exciting or intimidating novelty. Furthermore, the art programme leader has considerable power in making a novel activity feel familiar or in making a familiar activity seem exciting. Considering this balance is critical to the effective planning and implementation of arts in health activities in the hospital day room.

**Reminiscence and expression through engagement with the arts.** Reminiscence plays a large role in care for dementia, and it has been extensively researched as a tool for life satisfaction

(Willemse, Depla, & Bohlmeijer, 2009), apathy (Politis et al., 2004), and death preparation (El Haj & Antoine, 2016). Its role in dementia care is variable, and it can include activities as informal as conversations about family events, former activities, and favourite music. Excluded from the concept of reminiscence is nostalgia (Dempsey et al., 2014), which is distinguished by a bittersweet yearning for irreproducible events. Engagement with the arts presents an alternative to nostalgic reminiscence because it is a present activity through which reminiscence can be re-expressed rather than wistfully reimagined. While nostalgia can be beneficial due to its emphasis on positive memories (Sedikides, Wildschut, Arndt, & Routledge, 2008), engagement with the arts is valuable for its present-focus. Findings from Study 2 support this review's conclusions. While there is a danger for painful memories to resurface, potential resulting distress was easily avoided at the first sign in our art groups, and no major incidents of distress or recall anxiety were observed. The arts in health intervention structure facilitates this avoidance. The creative potential of the arts gives a focus for distraction or recontextualisation for a painful memory.

**Roles of environment and social engagement in a hospital setting.** Many participants reported enjoying the company of new people, including art leaders, volunteers, and other patients who are not their immediate bed neighbours. The day room is a semi-public space available for patients to socialise. The chairs in the day room present opportunities for patients to sit upright, contributing to a feeling of normalcy and a transformation from the role of hospital inpatient. The power of this effect is highlighted in Study 2, and it represents a simple way to encourage physical activity and social engagement for hospital inpatients with dementia.

**Optimising tablet use.** Study 2 found that one-to-one tablet use was more accepted and beneficial than tablet use in groups. There may therefore be great potential for individual tablet use while confined to a hospital bed. Study 2 of this thesis found that one-to-one engagement with digital media can be employed successfully as a facilitator of "doodle-directed conversation." This could be a useful activity for bedside arts engagement, while traditional media are potentially more useful for day room art groups. Further, bedside arts activities may provide an effective middle ground between day room art groups and individual, solitary arts engagement. This can add to the broad range of bedside arts activities including creative writing, music, and dance (Newman, 2006).

This thesis presents research and strategy for a specific, arts-based intervention using digital tablets. This builds on a qualitative study performed by Upton et al. (2011) which explored broader

use of tablet applications for day-to-day activities in care home settings. Upton et al. reported on a variety of tablet uses including resident group use and one-to-one use with carers, family, or other residents. Tablet internet capabilities were used, including music, video, and photo searching for “history-based activities as part of a group reminiscence activity.” Upton et al. found that tablet sessions were beneficial for “increasing interpersonal interactions,” a finding that contrasts with the finding in Study 2 that participants were too focused on the application to engage socially with others in the group. This difference might be explained by the contrasting activities between the two studies. While tablet-based art creation might be more beneficial for individual activity, tablets might be useful as multimedia devices for group reminiscence sessions.

**Consideration of patient type.** Study 2 of this thesis identified 2 types of hospital inpatients with dementia who attended participatory art programmes – enthusiastic joiners and hesitant joiners. Enthusiastic joiners were characterised by their bright attitude throughout the programme, while hesitant joiners often needed convincing to attend and therefore had more scope to experience improved mood. Patient type was identified as being related to both patient personality and mood. Study 2 described interactions between enthusiastic joiners and hesitant joiners, finding that social engagement was mutually beneficial. This thesis therefore recommends that hospital arts programmes consider the patient types in attendance, aiming for a mix of enthusiastic and hesitant joiners.

### **7.2.2 Key messages for practice**

Following the implications for clinicians and arts in health practitioners outlined above, this thesis identified three key messages for practice:

- Considering the link between passive activities and lowered levels of loneliness, this thesis recommends making reading materials, radio, and television more readily available to hospital inpatients with dementia. The finding that people with dementia may derive wellbeing benefits from engaging with new technologies suggests that access to the internet through a digital screen could be additionally beneficial.
- Participatory group art sessions could provide a dedicated element of person-centred care and increase wellbeing through their combination of social engagement, artistic engagement, environmental change, and physical stimulation. By regularly programming and prioritising

group art sessions, clinical staff may augment the provision of person-centred care for patients with dementia.

- The use of digital tablets for patient activities has the potential to increase self-efficacy for those with dementia. By learning simple new tasks for creating art or accessing media on a tablet, hospital inpatients with dementia might be more alert and open to communication with clinicians. This would be especially useful for activities performed at the bedside. Digital tablets present an opportunity to engage with the arts that does not involve excessive preparation or clean-up. Despite challenges with some patients in learning how to manipulate a digital interface, tablets can be ideal for the one-to-one engagement that was observed to be most effective in Study 2.

### **7.3 Limitations and areas of interest for future research**

In designing and carrying out research to answer this thesis's research questions, a number of limitations have been identified. Likewise, this thesis has identified emergent areas for future investigation. Limitations and recommendations for future research have been presented in individual study chapters and are summarised here.

#### **7.3.1 Limitations**

**Overarching.** None of the studies included in this thesis made distinctions between different types of dementia. While specific dementias have been studied for their varying effects on outcomes such as memory, creativity, and psychological wellbeing, hospitals do not always diagnose specific dementias. Future research into the effect of arts engagement on specific types of dementia would aid in understanding how to target approaches to non-pharmacological interventions.

All studies performed for this thesis collected data on the day of meeting participants. This was done as a consequence of the acute care setting where patients are moved between beds, between wards, and are discharged with little notice. Additionally, ethical considerations led to complete anonymisation of participant data, including name and contact information. Therefore, the study designs did not include follow-up measures. However, targeted short-term benefits from arts engagement are important for improving the experience of dementia in hospital (Bruer, Spitznagel, & Cloninger, 2007) and have the potential to improve downstream effects such as improved nutrition (McDaniel, Hunt, Hackes, & Pope, 2001) and improved relationships with clinical staff, as reported in Study 2.

**Study 1.** The major limitation identified for Study 1 was its reliance on participant memory in reporting past year and life course engagement with the arts. Cognitive impairment is the primary symptom of dementia, and recall may have been compromised inconsistently across participants. An additional limitation was that the interviews took place at the bedside, within ward bays consisting of six beds. This was done in order to facilitate participation and include patients who may be unable to walk to a private area. However, participants may have been less forthcoming with other patients and clinical staff within earshot. Studies 2 and 3 aimed to recruit participants who would naturally participate in an arts in health programme. However, Study 1 aimed to describe the average hospital inpatient with dementia. Therefore, selection bias was a concern. Many potential participants I approached to take part in the questionnaire battery declined. Because of the social nature of participating in an interview, Study 1 participants may have been more extroverted than the average hospital inpatient with dementia.

**Study 2.** Ethnographic studies may be difficult to generalise to other settings or populations. However, it is useful for providing a rich description of the setting, describing nuances of relationships and processes through case studies, interviews, and observations over an extended period of time. The time dedicated to only ethnographic observation was two months before simultaneous data collection with the controlled study. This was done for time considerations, but a longer period of ethnographic-only data collection would have provided a more solid foundation for domain analysis and subsequent controlled study data collection. It would have provided enough data for Study 2 to function as a standalone study. However, for the purposes of this thesis, it is robust enough to be considered through its triangulation with Studies 1 and 3. The perspective of the researcher is of tantamount importance when considering the output of an ethnographic study. Readers should be aware of my background and relationships with the hospital, art programme leaders, and funding charity, as described in the thesis Introduction and Chapter 4.

**Study 3.** Randomised controlled studies are often seen as the gold standard for attributing causation. Study 3 was not randomised, however its gains credibility through its use of naturalistic recruiting. The aim of Studies 2 and 3 was to understand the effect of engagement with the arts as it exists in a hospital setting. Therefore, designing a heavily controlled experiment with randomisation was not desirable. Because I served as the only researcher for this thesis, it was impossible for the study to be blinded. Study 3 captured immediate quantitative effects of participation in group art programmes. Longitudinal effects would be desirable for tracking wellbeing throughout the hospital

stay and determining effects on outcomes such as length of stay and rates of discharge to social housing. Despite this, the short-term effects measured by Study 3 are useful for understanding how engagement with the arts can be integrated with hospital care in a way that enhances clinical care and provides holistic activities for the improvement of wellbeing.

### **7.3.2 Areas of interest for future research**

**Novelty and familiarity.** Further research is needed considering novelty and familiarity in organised programming for dementia care. Study 2 identified the balance of novelty and familiarity as a key consideration for the design and implementation of arts in health programmes. These domains are important because they describe individual considerations of environment, social engagement, and artistic engagement as well as the ways in which these considerations interact with each other. Past research has investigated this balance. In a study of participants without cognitive impairment, Förster (2009) found that novel stimuli were more likely to provoke general holistic perceptions while familiar stimuli provoked more attention to detail. This finding has implications for design for people with dementia, with familiar-feeling interfaces being prioritised for detailed art production activities. Future research considering the potential flow state balance between novelty and familiarity in dementia would be very beneficial for the design and implementation of future programmes. This research could potentially build on flow states, which are described as “complete absorption in what one does” (Nakamura & Csikszentmihalyi, 2014). Alongside this research might be an investigation of the use of arts engagement for reminiscence versus in-the-moment expression. Data comparing the two approaches would be illuminating, as would research experimenting with the blend between the two.

**Organisational research.** Study 2 identified organisational challenges in the effective, efficient, and regular implementation of arts activities in the hospital ward. For the provision of mental health services to older people, liaison service models, characterised by visiting psychiatrists to acute settings, have been recommended (Lievesley, 2009; Mujic, Hanlon, Sullivan, Waters, & Prince, 2004). This structure reflects the organisation of arts in health activities for hospital inpatients for dementia. By commissioning “liaison arts practitioners” to run their programmes on the wards, more patients might be reached for whom activities would be appropriate. The implementation and evaluation of this effort would involve challenges as wide as NHS protocols and priorities and as narrow as the relationships among clinical and therapy staff on an individual ward.

Therefore, there is scope to examine organisational cultures across healthcare settings for the standardisation of person-centred care through the implementation of arts programming.

**Researching related interventions.** There is a large scope for the study of other non-pharmacological interventions for hospital inpatients with dementia. Study 3 reported benefits to wellbeing in participants in group art programmes compared with controls. Study 2 described this benefit as being influenced by a complex interplay between social, environmental, and artistic factors. While the holistic impact of these factors may be appreciated, they could be better understood through focused research. Future research investigating the discrete impacts of socialisation, environmental change, and art production would inform the optimisation of future intervention designs.

The range of uses for tablets might also benefit from further exploration. Studies 2 and 3 focused on comparing experiences between traditional and digital media in artistic engagement. While Study 2 gathered qualitative data on a range of activities, Study 3 narrowed its focus to visual art production. Future studies could investigate other unique features of digital and connected technologies, such as the impact of social media use among older people, hospital inpatients, and people with dementia. This could add to the evidence base from qualitative case studies showing the feasibility of using internet capabilities to facilitate social engagement among people with dementia in care homes (Evans, Bray, & Evans, 2015).

Finally, future studies might consider the holistic use of tablets and their potential integration into the daily lives of people with dementia in acute care and other settings. This research might consider the use of tablets for commanding attention. While use of smartphones and other connected devices have been linked to decreased wellbeing in student populations (Demirci, Akgönül, & Akpınar, 2015), their use in dementia has potential cognitive, psychological, and wellbeing impacts.

**Engagement and wellbeing.** With the variation in intervention described above should come further consideration of the types of engagement facilitated in different interventions. This can inform researchers about the mechanisms involved in the improvement and maintenance of wellbeing. Study 1 found that solitary engagement with passive activities such as watching television, reading, and listening to music was associated with lower levels of loneliness. This finding was difficult to triangulate with Studies 2 and 3 due to their focus on group activities. However, Study 1 explored the possibility of this effect being due to the social surrogacy hypothesis

(Derrick, Gabriel, & Hugenberg, 2009). This would benefit from focused exploration with the aim of revealing strategies for individual activities that address loneliness in older people. Loneliness research especially timely given the high rates of loneliness reported among older people in Britain and the instatement of the country's first Minister for Loneliness (Prime Minister's Office, 2018).

Although explicit connections between wellbeing and engagement are not made in the study designs for Studies 2 and 3, feelings of self-efficacy or agency were identified as part of the experience of beginning and maintaining artistic engagement. Agency has been connected directly with wellbeing in daily activities (Chung, Ellis-Hill, & Coleman, 2017), and triangulation presented in Chapter 6 does consider the ways in which different types of engagement impact outcomes. Engagement duration and type might serve as proxies for wellbeing in future studies. Volicer et al. (1999) conceptualised wellbeing in patients with advanced dementia, identifying three dimensions of psychological wellbeing: "engagement-apathy, happy-sad mood, and calm-agitation." These three dimensions seem to correlate with the measurement items of the OME "duration, attitude, and attention." Future conceptual studies might be able to draw further links between intra-activity engagement and broader measures and conceptions of wellbeing.

**Other study populations.** All studies performed for this thesis included participants with mild to moderate progression of dementia. This reflected the research base identified in the systematic literature review presented in Chapters 1 and 2 of this thesis. However, the increased cost of care associated with severe dementia (Wolstenholme et al., 2018) calls for future research to investigate the impact of engagement with the arts, both passive and active, on psychosocial outcomes for patients with severe dementia.

Study 1 considered the differences between past experience of hospital inpatients with dementia and how these differences might affect the current experience of individual artistic engagement. However, Studies 2 and 3 did not. Study 2 reported many participants experiencing a transformation from feeling that they were not an artist to believing they could produce art. This feeling of self-efficacy contributed to wellbeing. Past experience with artistic and cultural engagement was not found to impact on the experience of individual engagement, but its effects on group engagement are not known. Future studies could gain insight into the effect of past experience with the arts on social engagement in group art programmes.

Because the differing experience of enthusiastic joiners and hesitant joiners was not anticipated by this research, Study 3 did not consider the relationship between patient type and outcomes in anxiety and wellbeing. Future research could investigate further using measures of personality type and intensity, with the goal of identifying interventions and interpersonal styles that might be recommended for specific patient personalities and moods. This research would be especially interesting due to the complex interactions observed in groups with different mixes of hesitant and enthusiastic joiners.

**Anxiety.** Study 3 measured anxiety immediately before and after the digital and traditional arts programmes. However, the impact of digital arts engagement on anxiety might benefit from longitudinal studies measuring impact over the course of several sessions. Anxiety has been characterised as a situational and predispositional construct, focused on the reaction to an experience (Heimberg, Turk, & Mennin, 2004; Levitt, 1968). If familiarity with tablet engagement persists between art sessions, anxiety may decline over longer timeframes. This would have implications for arts programming, considering that “anxiety detrimentally affects such cognitive processes as problem-solving, incidental learning, ability to communicate and performance on standard intelligence tests” (Levitt, 1968). Future research could shed light on how environment and socialisation compare with skill-learning of arts-based activities over longer interventions for patients with dementia, and whether such longer programmes differentially impact on anxiety and wellbeing.

**Study design.** Methodological innovation would give future studies advantages over the limitations discussed for the studies presented in this thesis. A major limitation identified in Study 1 was that it relied on biographical information recalled by participants with dementia. Considering that memory impairment is a primary symptom of dementia, this could have had a substantial impact on results. Rather than depending on recall using a cross-sectional design, future research might consider using a nested case-control design for hospitalised patients. This could work within an ongoing cohort study such as the English Longitudinal Study of Ageing, which has been used to investigate links between cultural engagement and dementia (Fancourt & Steptoe, 2018; Fancourt, Steptoe, & Cadar, 2018). Studies 2 and 3 evaluated the wellbeing effects of a single participatory art session. While the wellbeing benefits derived from a single art session can powerfully impact the hospital experience for a patient with dementia, the mid- to long-term effects are not known. Future longitudinal studies might study the impact of repeated engagement in group art activities and could

examine its relationship with recovery times and discharge rates, measures especially salient to hospital administration and policymakers.

Individual and integrated results from this thesis can inform future mixed methods research designs. Study 1, as a cross-sectional study, did not include consideration of the scheduled art group activities in the hospital. This was useful for gaining a picture of the baseline characteristics of hospital inpatients with dementia and for surveying patients who might not choose to attend hospital art activities. However, this study was conducted a full year before Studies 2 and 3 so involved an entirely different set of participants. No qualitative data regarding previous participant experience with the arts were collected. This would have been easily-elicited data and would be useful to include in future studies. Study 1 reported that questionnaire batteries took between 15 and 45 minutes to administer. This wide range was due, in large part, to the gregarious disposition of some participants. Although I kept focused on getting through the items on the questionnaire battery, many participants treated the interview like a conversation, telling me anecdotes of life events such as their singing lessons growing up or a memorable visit to the theatre with their grandchildren. None of this data was recorded, but future research might consider triangulating data by combining a cross-sectional survey with a qualitative study. While this would make participant recruitment a slower process, it might be possible to extend the ethnographic observation period much longer. If ethnographic data collection began with Study 1, it would have constituted a 1.5 year period of data collection, which conforms to a recommended fieldwork period over one year (Wolcott, 2005).

## **7.4 Contribution**

### **7.4.1 Empirical contributions**

This thesis explored different aspects of engagement with the arts among hospital inpatients with dementia. The main finding was that current engagement with the arts has a positive effect on psychosocial health and wellbeing. This finding was triangulated across three studies and represents the most in-depth mixed methods research for arts engagement in this population. In doing so, it added evidence to the growing body of research identified by a systematic review of non-pharmacological interventions for hospital inpatients with dementia performed for this thesis. Individual engagement with passive activities such as reading, watching television, and listening to music and the radio was associated with lower levels of loneliness. This is an important finding considering the high levels of loneliness found in people with dementia, regardless of setting.

Engagement with the arts in group settings was found to improve wellbeing. Drivers of this improvement were identified, with domains including environmental, physical, social, and emotional. This finding demonstrates the complexity of the experience of engaging with the arts, showing need for further exploration into the elements of cultural and artistic engagement. This thesis lays the groundwork for future research to isolate or modify elements of the experience of arts participation.

The findings detailing the domains of experience of the arts in health programme are significant because they contextualise the production of art itself within a network of experiences. For instance, engaging with art was found to facilitate social engagement among participants, at times to the exclusion of the art. Another example lies in the cross-sectional finding that current engagement is associated with lower levels of loneliness. However, these activities were passive activities including watching television and listening to the radio.

This thesis has contributed original knowledge to the areas of dementia care and arts in health research. This knowledge includes

- The level of current and past experience with artistic and cultural engagement of hospital inpatients with dementia, their psychosocial outcomes, and links between the two.
- The identification and examination of key partners, strategies, and perspectives in the implementation of structured group arts programme in an acute hospital ward.
- The identification and explication of elements affecting the experience of an arts in health programme for hospital inpatients with dementia.
- A comparison of process and experience interacting with digital and traditional media with recommendations for how best to utilise each for their strengths in addressing psychosocial outcomes for hospital inpatients with dementia.

#### **7.4.2 Methodological contributions**

By approaching this thesis from a pragmatic perspective, the mixed-methods design captured the complexity of psychosocial experience, engagement with the arts, and environmental concerns of hospital inpatients. It demonstrated the variety of ways the arts can be used to facilitate reminiscence, creativity, and social connection among hospital patients and staff members. By collecting a wide range of data using multiple methods, this thesis was able to provide a broad picture of the experience of dementia in hospital, raising issues for further exploration.

This thesis represents the largest mixed methods study of the impact of arts engagement on the experience of hospital inpatients with dementia to date. By recruiting 256 participants across 3 studies, it examined a large sample of hospital inpatients with dementia across two hospitals in London. Among the 19 studies included in the systematic review presented in Chapters 1 and 2, only Amieva et al. (2015) recruited more participants, with 655 participants over two years in a randomised controlled trial. Of the two mixed methods studies included in the systematic review, this thesis more closely resembles the study performed by O'Rourke et al. (2011). Both studies included validated scales and researcher-developed questionnaires triangulated with qualitative data gathered from semi-structured interviews. The intervention evaluated by O'Rourke et al. (2011) was a talk and reminiscence activity based around video clips pulled from YouTube, a novel screen-based technology used for dementia care. O'Rourke et al. included 6 participants in a study that represents a methodological pilot for the present larger-scale thesis.

This thesis builds on the positivist perspectives common in the research field. In a wide-ranging systematic review of the use of art therapy in dementia care, Beard (2011) pointed out the trend of biomedical outcomes, indicating a positivist approach to arts in health research. Additionally, of the 19 studies presented in the systematic review in Chapters 1 and 2, only 5 studies included a qualitative element. This thesis recognises the utility of relating biomedical outcomes in a clinical setting, but it further argues that the arts can be used to enhance the lived experience of dementia in an acute care setting where biomedical outcomes already serve as the priority. The mixed methods employed by this thesis aimed to investigate how the lived experience of dementia in an acute care setting relates to these biomedical and psychosocial outcomes by using a range of validated scales and triangulating results with qualitative data collected from participant observation and semi- and un-structured interviews. This design reflects a pragmatic approach that is suited to addressing challenges set forth by local, national, and international agencies regarding the global rise of dementia and the challenges presented by its care.

This thesis investigated a range of art activities among hospital inpatients with dementia. Each study narrowed the definition and type of art activity examined. Study 1 began the most broadly, reporting amount of individual engagement with the arts and culture across the life course, in the past year, and currently. Study 2 included qualitative consideration of the range of arts in health programmes offered across two hospitals by the CW+ Care of Older People Programme. The focus was on the regularly scheduled weekly visual art and music programmes. Finally, Study 3

focused on visual art production solely in a quasi-experimental, 3-arm controlled study. This funnelled progression of studies was designed with a purpose. By beginning with the overall cultural experience of hospital inpatients with dementia, Study 1 served as an exploratory survey of baseline experience with the arts and culture. Findings from Study 3 might then be more easily viewed in the context of general engagement with the arts rather than visual art production alone. Additional considerations prompted the choice to only include visual art engagement in Study 3. First, only 2 of 19 studies included in Chapter 1's systematic review of the literature were of visual art-based programmes, while 9 of the studies included were of music-based programmes. Study 3 therefore fills a gap in the research landscape. Second, the restriction of intervention type makes results from Study 3 more generalisable to other study settings. Third, the comparison of visual art and music groups in Study 2 provides a basis for relating visual art production to a larger, more thoroughly-researched intervention for hospital inpatients with dementia. Finally, digital visual arts programmes included only digital media rather than a mix of traditional and digital media within one group. Digital music programmes included this mix and were therefore deemed unsuitable for a controlled study design.

### **7.5 Concluding Statement**

This thesis represents one piece of a worldwide effort to address dementia and its impacts. Dementia is a growing global issue that affects millions of lives. Large entities such as the World Health Organization, the European Union, and the UK National Health Service have led efforts in surveillance, services, and research to track, prevent, and treat dementia. In order for these efforts to effectively address the challenges of dementia, they rely on innovation, research, and rigorously considered evidence.

This thesis contributes to the body of evidence aimed at improving the wellbeing of hospital inpatients with dementia, recognising that the vulnerability imposed by dementia is compounded by the vulnerability imposed by admission to hospital. The evidence presented indicates that engagement with the arts is an effective tool for improving the lived experience of dementia in hospital. At the same time, it is acknowledged that the lived experience of dementia must be as unique as the individuals affected by dementia. Engagement with the arts represents a holistic yet individualised intervention that can be difficult to study systematically. Using mixed methods, this thesis used strengths from qualitative and quantitative methods to describe a complex picture of the enriching experience of artistic engagement in hospital inpatients with dementia.



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## APPENDIX A: CROSS-SECTIONAL STUDY QUESTIONNAIRE BATTERY

**Mini-Mental State Exam**

<b>Maximum Score</b>	<b>Patient's Score</b>	<b>Questions</b>
5		What is the year? Season? Date? Day? Month?
5		Where are we now? Country? City? Area of the city? Hospital? Floor?
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		“I would like you to count backward from 100 by sevens.” (93, 86, 79...) Alternative: Spell “world” backwards. (D-L-R-O-W)
3		“Earlier, I told you the names of three things. Can you tell me what those were?”
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		“Repeat the phrase: ‘No ifs, ands, or buts.’”
3		“Take the paper in your right hand, fold it in half, and put it on the floor.” (The examiner gives the patient a piece of blank paper.)
1		“Please read this and do what it says.” (Written instruction is “Close your eyes.”)
1		“Make up and write a sentence about anything.” (This sentence must contain a noun and a verb.)
1		“Please copy this picture.” (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)
30		TOTAL

**DEMOGRAPHIC SECTION**

Age in Years

---

Sex

M

F

---

Reason for hospitalisation

*Are you happy to tell me why you are here?*

---

Number of days in hospital

*How long have you been in hospital?*

---

Level of education

*What is your highest level of education?*

School - age 16

School - age 18

Undergraduate

Post-graduate

---

Marital status/Household composition

*Who do you live with?*

---

Main adult occupation (ask patient)

*Did you have a main occupation before retirement? What was it?*

---

**CURRENT MUSICAL EXPERIENCE**

Do you currently:

	Never	From time to time	Several times a week	Every day <30 mins	Every day >30 mins
Sing					
Play a musical instrument					
Draw, craft, or paint					
Listen to music					
Dance					
Read					
Listen to the radio					
Watch television					

How many time in the past year did you go to:

	Number
A concert	
An art gallery or museum	
The theatre or dance performance	
The cinema	

**PREVIOUS MUSICAL EXPERIENCE**

For how many years in your life did you regularly:

	Number
Sing	
Play a musical instrument	
Dance	
Act	
Draw, craft, or paint	

How important in your life are the following activities:

Going to a concert	1	2	3	4	5	6	7	8	9	10
Attending an art gallery or museum	1	2	3	4	5	6	7	8	9	10
Attending a theatre or dance performance	1	2	3	4	5	6	7	8	9	10
Attending a sporting event	1	2	3	4	5	6	7	8	9	10
Going to the cinema	1	2	3	4	5	6	7	8	9	10
Singing	1	2	3	4	5	6	7	8	9	10
Playing a musical instrument	1	2	3	4	5	6	7	8	9	10
Drawing, crafting, or painting	1	2	3	4	5	6	7	8	9	10
Listening to music	1	2	3	4	5	6	7	8	9	10
Dancing	1	2	3	4	5	6	7	8	9	10
Reading	1	2	3	4	5	6	7	8	9	10
Listening to the radio	1	2	3	4	5	6	7	8	9	10
Watching television	1	2	3	4	5	6	7	8	9	10

### De Jong Loneliness Scale

*We would like to ask you a few questions. You can choose to answer all or none of the questions, and choosing not to answer will not affect your access to any of our services in any way. When answering the questions, you could take account of the following:*

- *There are no right or wrong answers*
- *We would like you to be completely honest*
- *In answering the questions it is best to think of your life as it generally is now (we all have some good or bad days)*

#### **1. I experience a general sense of emptiness**

Yes	More or Less	No
1	1	0

#### **2. There are plenty of people I can rely on when I have problems**

Yes	More or Less	No
0	1	1

#### **3. There are many people I can trust completely**

Yes	More or Less	No
0	1	1

#### **4. I miss having people around me**

Yes	More or Less	No
1	1	0

#### **5. There are enough people I feel close to**

Yes	More or Less	No
0	1	1

#### **6. I often feel rejected**

Yes	More or Less	No
1	1	0

### Geriatric Depression Scale (Short Form)

*Choose the best answer for how you felt over the past week.*

Number	Question		
1	Are you basically satisfied with your life?	<b>YES/NO</b>	
2	Have you dropped many of your activities and interests?	<b>YES/NO</b>	
3	Do you feel that your life is empty?	<b>YES/NO</b>	
4	Do you often get bored?	<b>YES/NO</b>	
5	Are you in good spirits most of the time?	<b>YES/NO</b>	
6	Are you afraid that something bad is going to happen to you?	<b>YES/NO</b>	
7	Do you feel happy most of the time?	<b>YES/NO</b>	
8	Do you often feel helpless?	<b>YES/NO</b>	
9	Do you prefer to stay at home, rather than going out and doing new things?	<b>YES/NO</b>	
10	Do you feel you have more problems with memory than most people?	<b>YES/NO</b>	
11	Do you think it is wonderful to be alive?	<b>YES/NO</b>	
12	Do you feel pretty worthless the way you are now?	<b>YES/NO</b>	
13	Do you feel full of energy?	<b>YES/NO</b>	
14	Do you feel that your situation is hopeless?	<b>YES/NO</b>	
15	Do you think that most people are better off than you are?	<b>YES/NO</b>	

### Quality of Life – Alzheimer’s Disease

(Interview Version for the person with dementia)

Interviewer administer according to standard instructions. Circle responses.

1	Physical health	Poor	Fair	Good	Excellent
2	Energy	Poor	Fair	Good	Excellent
3	Mood	Poor	Fair	Good	Excellent
4	Living situation	Poor	Fair	Good	Excellent
5	Memory	Poor	Fair	Good	Excellent
6	Family	Poor	Fair	Good	Excellent
7	Marriage	Poor	Fair	Good	Excellent
8	Friends	Poor	Fair	Good	Excellent
9	Self as a whole	Poor	Fair	Good	Excellent
10	Ability to do chores around the house	Poor	Fair	Good	Excellent
11	Ability to do things for fun	Poor	Fair	Good	Excellent
12	Money	Poor	Fair	Good	Excellent
13	Life as a whole	Poor	Fair	Good	Excellent

APPENDIX B. FOCUSED ETHNOGRAPHIC STUDY SEMI-STRUCTURED INTERVIEW  
OUTLINE

**INTRODUCTION AND RECAP OF CONSENT**

I will reintroduce myself as the researcher who has been observing the art programme. I will also reiterate the terms outlined in the PIS, especially that participation in the semi-structured interview is completely voluntary, and the participant may choose to end involvement at any time. The participant will also be reassured that they may pass on any question where they do not have a clear memory of the answer.

**ESTABLISHING STATE OF MIND**

*How are you feeling?*

**Probe:** Let the interviewee answer unfold

**EXPERIENCE OF THE ART PROGRAMME**

*Tell me about your experience participating in this [medium] programme.*

**Probe:** Ask them to relate their overall experience during the past hour.

**Prompt:** How did you feel [at the beginning eg. looking at the blank canvas]?

**Prompt:** How did you feel [at the end eg. having made music for an hour]?

**Prompt:** How did you feel while you [general activity]?

**SPECIFIC QUESTIONS**

*What are some thoughts that went through your mind during the activity?*

**Probe:** Ask them to pinpoint specific thoughts and feelings during the activity.

**Prompt:** Why did you make the choice to [insert choice made during activity]?

**Prompt:** What were you feeling when you [insert action performed during activity]?

**PRIOR EXPERIENCE OF ART**

*What does [medium] mean to you?*

**Probe:** Let interviewee answer unfold

**END OF INTERVIEW**

*Would you recommend this activity to other patients? Why or why not?*

*Thank you for your time. Do you have any questions that you would like to ask me?*

APPENDIX C. THREE-ARM CONTROLLED STUDY PRE-POST QUESTIONNAIRE  
BATTERY

**State-Trait Anxiety Inventory  
six-question short-form**

*A number of statements which people have used to describe themselves are given below. Read each statement and then circle the most appropriate number to the right of the statement to indicate how you feel right now, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.*

**Pretest**

	<b>I feel calm</b>	Not at all	Somewhat	Moderately	Very much
	<b>I am tense</b>	Not at all	Somewhat	Moderately	Very much
	<b>I feel upset</b>	Not at all	Somewhat	Moderately	Very much
	<b>I am relaxed</b>	Not at all	Somewhat	Moderately	Very much
	<b>I feel content</b>	Not at all	Somewhat	Moderately	Very much
	<b>I am worried</b>	Not at all	Somewhat	Moderately	Very much

**Posttest**

	<b>I feel calm</b>	Not at all	Somewhat	Moderately	Very much
	<b>I am tense</b>	Not at all	Somewhat	Moderately	Very much
	<b>I feel upset</b>	Not at all	Somewhat	Moderately	Very much
	<b>I am relaxed</b>	Not at all	Somewhat	Moderately	Very much
	<b>I feel content</b>	Not at all	Somewhat	Moderately	Very much
	<b>I am worried</b>	Not at all	Somewhat	Moderately	Very much

Please make sure that you have answered *all* the questions.

## Generic Wellbeing Questionnaire

Short 6-item version

Please circle a number for each statement to indicate how much you agree with it.

1) I felt happy

<b>None of the time</b>	<b>Not very often</b>	<b>Some of the time</b>	<b>Very often</b>	<b>All of the time</b>
1	2	3	4	5

2) I felt engaged

<b>None of the time</b>	<b>Not very often</b>	<b>Some of the time</b>	<b>Very often</b>	<b>All of the time</b>
1	2	3	4	5

3) I felt comfortable

<b>None of the time</b>	<b>Not very often</b>	<b>Some of the time</b>	<b>Very often</b>	<b>All of the time</b>
1	2	3	4	5

4) I felt safe and

secure

<b>None of the time</b>	<b>Not very often</b>	<b>Some of the time</b>	<b>Very often</b>	<b>All of the time</b>
1	2	3	4	5

5) I enjoyed the

company of other people

<b>None of the time</b>	<b>Not very often</b>	<b>Some of the time</b>	<b>Very often</b>	<b>All of the time</b>
1	2	3	4	5

6) I talked to

other people

<b>None of the time</b>	<b>Not very often</b>	<b>Some of the time</b>	<b>Very often</b>	<b>All of the time</b>
1	2	3	4	5

### APPENDIX D. OBSERVATIONAL MEASURE OF ENGAGEMENT

1)

Duration of patient involvement with stimulus (out of 15 minutes)

---

2)

Level of attention paid to stimulus

**Not attentive****Somewhat attentive****Attentive****Very attentive**

3)

Attitude towards stimulus

**Very negative****Negative****Somewhat negative****Neutral****Somewhat positive****Positive****Very Positive**

## APPENDIX E. LETTER OF APPROVAL FOR STUDY 1

Chelsea and Westminster Hospital   
NHS Foundation Trust

Department of Research and Development  
Research Delivery Team Office  
Unit G3, Harbour Yard  
Chelsea Harbour  
London  
SW10 0XD

26<sup>th</sup> July 2016

Greg Windle  
Arts in Health Researcher  
Royal College of Music  
Prince Consort Road  
SW7 2BS

Dear Greg

**Letter of Access for Research**

**Version: University researchers who do not require an honorary research contract**

This letter should be presented to your nominated manager at each participating site within this organisation before you commence your research at Chelsea and Westminster Hospital NHS Foundation Trust.

In accepting this letter, Chelsea and Westminster Hospital NHS Foundation Trust confirms your right of access to conduct research through this organisation for the purpose and on the terms and conditions set out below. This right of access commences on 26<sup>th</sup> July 2016 and ends on 31<sup>st</sup> December 2016 unless terminated earlier in accordance with the clauses below.

This letter of access is for research activities in relation to the following **only**:

**Study title: A cross-sectional profile of arts involvement and wellbeing in hospital inpatients with dementia**

**IRAS reference: 207483**

**REC reference: 16/EE/0262**

**Local reference: C&W16/053**

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from Chelsea and Westminster Hospital NHS Foundation Trust. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from the department of research and development giving confirmation of their agreement to conduct the research.

The information supplied about your role in research at this organisation has been reviewed and you do not require an honorary research contract with this organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out. Evidence of checks should be available on request to this organisation.

You are considered to be a legal visitor to the organisation premises. You are not entitled to any form of payment or access to other benefits provided by Chelsea and Westminster Hospital NHS Foundation Trust to employees and this letter does not give rise to any other relationship between you and this organisation, in particular that of an employee.

While undertaking research through this organisation you will remain accountable to your substantive employer but you are required to follow the reasonable instructions of this organisation or those instructions given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with this organisation's policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with this organisation in discharging its duties under the Health and Safety at Work Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on the organisations premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and Chelsea and Westminster Hospital NHS Foundation Trust prior to commencing your research role.

You are required to ensure that all information regarding patients or staff remains secure and **strictly confidential** at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on this organisations premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this organisation does not accept responsibility for damage to or loss of personal property.

This organisation may revoke this letter and terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **must stop** undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

No organisation will indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager, Madushree Miseer, in this organisation and the department of research and development in this organisation.

Yours sincerely,



**Damon Foster**  
Research Delivery Operations Manager  
Chelsea and Westminster Hospital NHS Foundation Trust

cc: Jennifer Allison, HR Advisor, [Jennifer.allison@rcm.ac.uk](mailto:Jennifer.allison@rcm.ac.uk)  
Daisy Fancourt, Academic Supervisor, [daisy.fancourt@rcm.ac.uk](mailto:daisy.fancourt@rcm.ac.uk)

## APPENDIX F. LETTER OF APPROVALS FOR STUDIES 2 AND 3



Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Mr Gregory Windle



23 August 2017

Dear Mr Windle

**Letter of HRA Approval**

**Study title:** Examining the effects of traditional and digital arts interventions on engagement, anxiety, and wellbeing in hospital inpatients with mild to moderate dementia

**IRAS project ID:** 218091

**REC reference:** 17/LO/0821

**Sponsor:** Royal College of Music

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

IRAS project ID	218091
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**HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **218091**. Please quote this on all correspondence.

Yours sincerely

Michael Higgs  
Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Prof Aaron Williamon, Royal College of Music [Academic supervisor]  
Ms Emma Hewett, Royal College of Music [Sponsor]  
Mr Damon Foster, Chelsea and Westminster Hospital NHS Foundation Trust [Lead  
NHS R&D]*

## Appendix A – List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		25 April 2017
IRAS Application Form [IRAS_Form_18072017]		18 July 2017
Non-validated questionnaire [Ethnography questionnaire]	1	20 April 2017
Other [Schedule of Events]	1	23 August 2017
Other [Statement of Activities]	2	23 August 2017
Other [Response to request for further information]		13 July 2017
Participant consent form	1	20 April 2017
Participant information sheet (PIS)	1.2	13 July 2017
Referee's report or other scientific critique report		18 April 2017
Research protocol or project proposal	2.3	13 July 2017
Summary CV for Chief Investigator (CI) [Greg Windle]		
Summary CV for supervisor (student research) [Daisy Fancourt]		
Summary CV for supervisor (student research) [Aaron Williamon]		
Validated questionnaire [3-arm baseline and follow-up questionnaire form]		

## Appendix B – Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.***

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Greg Windle  
 Email: [gregory.windle@rcm.ac.uk](mailto:gregory.windle@rcm.ac.uk)

### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/ consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities and Schedule of Events have been provided for use with participating NHS organisations in England. Exchange of the Statement of Activities will act as confirmation of an organisation's capacity and capability to host the research.
4.2	Insurance/ indemnity arrangements assessed	Yes	Insurance for the management and design of the study will be provided by the sponsor, and indemnity for the conduct by the NHS.  The insurance certificate supplied with the application expired on 31 July 2017. HRA Approval standards

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			<p>expect that the expiry date should be at least one month after the date the application for HRA Approval is submitted, which was 27 April 2017 for this study. It is not expected that NHS organisations request renewals of insurance certificates. The sponsor is reminded of their responsibility to maintain insurance as set out to the Research Ethics Committee.</p> <p>Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study</p>
4.3	Financial arrangements assessed	Yes	No application for external funding has been made and funding is not available to participating NHS organisations.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	The study has a favourable ethical opinion from the London – Chelsea Research Ethics Committee.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

### Participating NHS Organisations in England

*This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.*

There is a single participating NHS organisation at which research activities as described in the protocol and IRAS form will be conducted.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at [hra\\_approval@nhs.net](mailto:hra_approval@nhs.net). The HRA will work with these organisations to achieve a consistent approach to information provision.

### Confirmation of Capacity and Capability

*This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.*

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

### Principal Investigator Suitability

*This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

A Local Collaborator should be in place at the participating NHS organisation and a suitable individual has already been identified.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

**HR Good Practice Resource Pack Expectations**

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken*

The student researcher will require a Letter of Access on the basis of a standard DBS check and occupational health clearance.

**Other Information to Aid Study Set-up**

*This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.*

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.